

THE GENETIC INFORMATION  
NONDISCRIMINATION ACT AS AN  
ANTIDISCRIMINATION LAW

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*This Article provides the first in-depth reading of the Genetic Information Nondiscrimination Act (GINA) as an antidiscrimination statute. GINA, touted as the first major civil rights legislation of the new century, passed in May 2008. Thus, both to understand GINA's potential impact, as well as to improve its efficacy, the statute must be analyzed as an antidiscrimination law. When read as an antidiscrimination statute, GINA takes a clear position on one of the most contested issues in that area of law: antisubordination versus anticlassification. This debate queries whether antidiscrimination law should seek to elevate the social status of certain subordinated groups or should prevent all consideration of particular forbidden characteristics. GINA as currently drafted plainly favors anticlassification; it protects individuals from any intentional differential treatment by health insurers or employers based on genetic information. In contrast, an antisubordination approach to protecting genetic information would focus not on outlawing all forms of intentional, differential treatment, but on preventing a genetic underclass from forming. In particular, an antisubordination framework would allow employers to consider genetic information for accommodation purposes and victims of discrimination to challenge facially neutral policies that produce discriminatory results. This Article*

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*proposes that amending GINA to include more antisubordination protections would better safeguard genetic information.*

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INTRODUCTION

Genetic-information discrimination captures the imagination. It conjures images of gloomy dystopias in which the content of our genes determines the outcome of our lives. In this troubling vision of the future, our education, careers, incomes, relationships, and myriad other social, economic, and personal goods depend solely on our genetic material. Yet while this world might appear largely hypothetical, the possibility of genetic-information discrimination exists outside Orwellian fantasy. The fear that potential discriminators might use heredity in making decisions about our lives also feels uncomfortably familiar, reminiscent of a time when the State could sterilize a person against her will in the name of the public good. Failing to protect genetic information at once portends a bleak future and recalls an unfortunate past.

Congress debated the issues surrounding the Genetic Information Nondiscrimination Act (GINA)<sup>1</sup> for close to thirteen years before passing the statute in a near-unanimous vote in May 2008.<sup>2</sup> Ultimately, it drafted GINA as civil rights legislation, intended to outlaw a burgeoning form of discrimination.<sup>3</sup> Specifically, GINA prohibits discrimination on the basis of genetic information in health insurance and employment. Title I prohibits health insurers from using genetic information for determining eligibility or premiums and from requiring genetic testing.<sup>4</sup> Title II proscribes employers from hiring, firing, classifying, or otherwise disadvantaging employees on the basis of genetic information.<sup>5</sup>

Congress's choice to draft GINA as civil rights legislation shapes both how we must analyze and apply GINA. This Article argues that antidiscrimination law provides the proper theoretical framework for understanding and critiquing GINA. Reading GINA using traditional antidiscrimination theory reveals the statute's weaknesses, as well as possibilities for remedying those shortcomings.

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1 Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, 122 Stat. 881 (codified in scattered sections of 26, 29, and 42 U.S.C.).

2 The Senate passed GINA 95-0 on April 24, 2008. *See* 154 CONG. REC. S3374 (daily ed. Apr. 24, 2008). The House then approved the measure 414-1 with Congressman Ron Paul as the lone dissenter on May 1, 2008. *See* 154 CONG. REC. H2979-80 (daily ed. May 1, 2008). On May 21, 2008, President George W. Bush signed GINA into law. *See* Remarks on Signing the Genetic Information Nondiscrimination Act of 2008, 44 WEEKLY COMP. PRES. DOC. 736 (May 21, 2008). The Senate had also unanimously passed the bill in 2005. *See* 151 CONG. REC. S1595 (daily ed. Feb. 17, 2005). GINA has a complicated legislative history; advocates of genetic-information legislation began proposing bills in the early nineties with a new bill introduced in each subsequent Congress until GINA finally passed in 2008. *See* Mark A. Rothstein, *Is GINA Worth the Wait?*, 36 J.L. MED. & ETHICS 174 (2008). *See generally* Jessica L. Roberts, *Preempting Discrimination: Lessons from the Genetic Information Nondiscrimination Act*, 63 VAND. L. REV. 439, 442-51 (2010) (discussing GINA's legislative and political history).

3 *See* Genetic Information Nondiscrimination Act of 2008, § 2.

4 *See id.* §§ 101-106.

5 Section 202 makes it unlawful for an employer

(1) to fail or refuse to hire, or to discharge, any employee, or otherwise to discriminate against any employee with respect to the compensation, terms, conditions, or privileges of employment of the employee, because of genetic information with respect to the employee; or

(2) to limit, segregate, or classify the employees of the employer in any way that would deprive or tend to deprive any employee of employment opportunities or otherwise adversely affect the status of the employee as an employee, because of genetic information with respect to the employee.

*Id.* § 202.

Since its passage, GINA has failed to attract much attention from antidiscrimination scholars.<sup>6</sup> This lack of scholarly attention is perhaps because GINA differs from all previous antidiscrimination statutes. First and foremost, genetic information is fundamentally unlike other antidiscrimination categories. It does not, at present, form the basis of a widely recognized social group, nor does it currently have an associated identity.<sup>7</sup> Moreover, genetic-information discrimination is not yet occurring on a large scale.<sup>8</sup> Thus, instead of reacting to existing discrimination in the past and present, GINA anticipates discrimination in the future, making it the first predominantly forward-looking antidiscrimination statute.<sup>9</sup>

Although genetic information differs substantially from traditional antidiscrimination categories like race, sex, or disability, antidiscrimination theory provides a useful lens for examining its protection.

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6 Of the over one hundred law review and legal journal articles mentioning GINA since the statute passed in May 2008, only a handful have come from employment discrimination scholars, analyzing the law from an antidiscrimination perspective. See, e.g., Teneille R. Brown, *Double Helix, Double Standards: Private Matters and Public People*, 11 J. HEALTH CARE L. & POL'Y 295 (2008); Sharon Hoffman, *The Importance of Immutability*, 52 WM. & MARY L. REV. (forthcoming 2011); Pauline T. Kim, *Regulating the Use of Genetic Information: Perspectives from the U.S. Experience*, 31 COMP. LAB. L. & POL'Y J. 693 (2010); Roberts, *supra* note 2; Rothstein, *supra* note 2, at 177; Mark A. Rothstein, *GINA, the ADA, and Genetic Discrimination in Employment*, 36 J.L. MED. & ETHICS 837 (2008). However, GINA has been the subject of several student notes and comments. See, e.g., Patricia Alten, Note, *GINA: A Genetic Information Nondiscrimination Solution in Search of a Problem*, 61 FLA. L. REV. 379 (2009); Joanne Barken, Note, *Judging GINA: Does the Genetic Information Nondiscrimination Act of 2008 Offer Adequate Protection?*, 75 BROOK. L. REV. 545 (2009); Rhonda B. Evans, Recent Development, "Striking Out": *The Genetic Information Nondiscrimination Act of 2008 and Title II's Impact on Professional Sports Employers*, 11 N.C. J.L. & TECH. 205 (2009); Joan E. Flaherty, Comment, *Toxicogenomics and Workers' Compensation: A Reworking of the "Bargain"?*, 12 J. HEALTH CARE L. & POL'Y 267 (2009); Amy Foster, Comment, *Critical Dilemmas in Genetic Testing: Why Regulations to Protect the Confidentiality of Genetic Information Should Be Expanded*, 62 BAYLOR L. REV. 537 (2010); Erin Murphy Hillstrom, Comment, *May An Employer Require Employees to Wear "Genes" in the Workplace? An Exploration of Title II of the Genetic Information Nondiscrimination Act of 2008*, 26 J. MARSHALL J. COMPUTER & INFO. L. 501 (2009); Jennifer J. Lee, Note, *The First Civil Rights Act of the 21st Century: Genetic Information Nondiscrimination Act of 2008*, 4 ISJLP 779 (2008); Jeffrey S. Morrow, Note, *Insuring Fairness: The Popular Creation of Genetic Antidiscrimination*, 98 GEO. L.J. 215, 245 (2009); Recent Legislation, 122 HARV. L. REV. 1038 (2009).

7 See *infra* notes 105–108 and accompanying text; see also Kim, *supra* note 6, at 698 ("[I]ndividuals with genetic predispositions to disease do not even constitute an identifiable social group."). But see *infra* note 112. It appears that kinds of genetic identity groups may be starting to form; however, "genetic identity" as a concept is not yet on par with racial, ethnic, gender, or disability identity.

8 See *infra* notes 11–17 and accompanying text.

9 See Roberts, *supra* note 2, at 441.

In the 1960s and 1970s, following *Brown v. Board of Education*,<sup>10</sup> antidiscrimination scholars began pondering what should be at the heart of the American antidiscrimination project: (1) elevating the social status of subordinated groups or (2) preventing any decisions—positive or negative—based on certain forbidden traits. These two differing iterations of the antidiscrimination principle became known as antisubordination and anticlassification, respectively.

In seeking to improve the social status of subjugated groups, the antisubordination principle advocates positive differential treatment and claims for both intentional and unintentional discrimination. For example, an antisubordination approach to racial discrimination would allow positive differential treatment, such as affirmative action and diversity initiatives while outlawing both outright discrimination and policies that unwittingly produce racial disparities. Because no socially recognized group of genetically disadvantaged people exists at present, an antisubordination approach to protecting genetic information would seek to prevent the formation of a genetic underclass. Conversely, the anticlassification principle supports prohibiting all intentional differentiation on the basis of a protected trait. In the context of race, an anticlassification approach would forbid any explicit consideration of race—positive or negative—including affirmative action and diversity initiatives and would allow facially neutral policies that inadvertently produce racially disparate results. Likewise, anticlassification protection for genetic information would prohibit entities from ever considering genetic information for any reason.

As written, GINA favors anticlassification: it bans all consideration of genetic information and does not allow disparate impact actions. This Article argues that GINA could benefit from incorporating more antisubordination protections. In particular, the antisubordination principle supports amending GINA to allow positive differential treatment for accommodation purposes and challenges to facially neutral policies with discriminatory results. Moreover, by targeting the formation of a genetic underclass, antisubordination would lead to more consistent, comprehensive protection for genetic information.

This Article proceeds in three Parts. Part I explores the reasons behind protecting genetic information. Part II analyzes how Congress used antidiscrimination law to protect genetic information and examines the statute's current protections. Part III reads GINA using the traditional antidiscrimination principles of anticlassification and antisubordination, concluding that GINA could benefit from incorporating more antisubordination protections.

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10 347 U.S. 483 (1954).

## I. UNDERSTANDING GENETIC INFORMATION

Before parsing GINA, it is useful to take a step back and examine why genetic information warrants protection. Genetic-information discrimination—at least as conceived by GINA<sup>11</sup>—is not yet occurring on a widespread basis.<sup>12</sup> Only three federal cases dealt with genetic-information discrimination prior to GINA.<sup>13</sup> Furthermore, despite the numerous state statutes in force for decades,<sup>14</sup> no genetic-information employment discrimination cases had been filed when GINA passed in 2008.<sup>15</sup> Critics of GINA argued that discriminating on the

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11 As later discussed, GINA protects against discrimination on the basis of an individual's genetic information, but not against discrimination on the basis of a manifested genetic condition. Thus, many historical examples of genetic-information discrimination—such as the forced sterilization of people with disabilities—would in fact not fall under GINA's definition. Instead, they would be considered discrimination on the basis of genetically based disabilities.

12 I have argued elsewhere that genetic-information discrimination is not currently happening at rates comparable to the discrimination that prompted the passing of other employment discrimination statutes, such as Title VII, the Age Discrimination in Education Act (ADEA), and the Americans with Disabilities Act (ADA), making GINA the first preemptive antidiscrimination statute in American history. See Roberts, *supra* note 2, at 441; see also Gaia Bernstein, *The Paradoxes of Technological Diffusion: Genetic Discrimination and Internet Privacy*, 39 CONN. L. REV. 241, 245 (2006) (“Genetic discrimination is rare and apparently on the decline.”). The “opt-in” nature of genetic information could, in part, explain the low levels of current discrimination. See *infra* note 120 and accompanying text.

13 See Roberts, *supra* note 2, at 464–66 (discussing *Norman-Bloodsaw v. Lawrence Berkeley Lab.*, 135 F.3d 1260 (9th Cir. 1998), *EEOC v. Burlington N. & Santa Fe Ry. Co.*, 2002 WL 32155386 (E.D. Wis. May 8, 2002), and Terri Sergeant's ADA claim with the EEOC).

14 See *Genetic Employment Laws*, NAT'L CONF. STATE LEGISLATURES, <http://www.ncsl.org/default.aspx?tabid=14280> (last updated Jan. 2008).

15 See Nat'l Human Genome Research Inst., *The Role of the National Human Genome Research Institute (NHGRI) in the Federal Legislative Process*, GENOME.GOV, <http://www.genome.gov/12513974> (last visited Apr. 21, 2011); see also *The Genetic Information Nondiscrimination Act: Hearing Before the Subcomm. on Health of the Comm. on Energy and Commerce on H.R. 493*, 110th Cong. 37 (2007) [hereinafter *Hearing on H.R. 493*] (statement of Burton J. Fishman, Fortney & Scott, LLC) (noting that no genetic discrimination cases had been filed in over thirty states with such laws). Since GINA's employment provisions became effective in November 2009, only one claim that deals explicitly with discrimination has garnered significant media attention. See BARRY R. FURROW ET AL., HEALTH LAW 189 (6th ed. 2010) (“In the first five months after it became effective, about 80 claims of genetic discrimination in the workplace had been filed with the EEOC. While most of these cases involved allegations of an employer inappropriately obtaining or releasing genetic information, at least one high profile case in 2010 involved a claim by a woman who alleged that she was fired by her employer after she had a double mastectomy.”); see also Steven Greenhouse, *Ex-Worker Says Her Firing Was Based on Genetic Test*, N.Y. TIMES, May 1, 2010, at A12

basis of genetic information was a practical impossibility: we simply do not know enough about genetic science to use it to discriminate.<sup>16</sup> This limited history of discrimination raises an interesting question: if entities were not using genetic information to discriminate (at least not to a significant degree), why would Congress pass a federal statute protecting genetic information? This Part provides some of the practical and normative justifications behind safeguarding genetic information absent large-scale, current discrimination.

### A. *Fear of Genetic-Information Discrimination*

Although Congress likely had multiple motivations for enacting GINA,<sup>17</sup> alleviating fear was one of the statute's major objectives.<sup>18</sup> Despite the limited examples of genetic-information discrimination, more than ninety percent of Americans expressed concern regarding the misuse of their genetic information.<sup>19</sup> They feared that, if given access, potential discriminators would use genetic information to make decisions. For example, a health insurer could use an insured's genetic information in the underwriting or rating process. Thus, if a person is at an increased genetic risk for developing cancer, a health insurer might increase her premium or even deny coverage based on that risk. Similarly, an employer could use an employee's genetic information in making an employment-related decision. For instance, an employer may choose not to hire an individual with a heightened proclivity for developing cancer because that person could have an

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(discussing Pamela Fink's allegation that her employer improperly fired her following her preventive double mastectomy).

16 See Colin S. Diver & Jane Maslow Cohen, *Genophobia: What Is Wrong with Genetic Discrimination?*, 149 U. PA. L. REV. 1439, 1476–77 (2001).

17 In a previous article, I proposed that Congress had two primary motivations in passing GINA: a research justification—geared toward alleviating fear surrounding genetic testing—and an antidiscrimination justification. See Roberts, *supra* note 2, at 471–80.

18 See Robert Klitzman, *Views of Discrimination Among Individuals Confronting Genetic Disease*, 19 J. GENETIC COUNS. 68, 69 (2010); Roberts, *supra* note 2, at 471–74; see also Bernstein, *supra* note 12, at 288 (“[T]he failure of the current patchwork of state and federal laws in affecting individuals’ public fears points to the need for a comprehensive federal statute.”); Kim, *supra* note 6, at 699 (“GINA, then, is more about addressing the perception or fear of genetic discrimination than reversing any present reality of such discrimination.”).

19 See *Hearing on H.R. 493*, *supra* note 15, at 44 (statement of Kathy Hudson, Director, Genetics and Public Policy Center); see also Karen H. Rothenberg & Sharon F. Terry, *Before It's Too Late—Addressing Fear of Genetic Information*, 297 SCIENCE 196, 196 (2002) (citing studies documenting the fear surrounding genetic testing); Daniel Schlein, *New Frontiers for Genetic Privacy Law: The Genetic Information Nondiscrimination Act of 2008*, 19 GEO. MASON U. C.R. L.J. 311, 315–16 (2009) (same).

adverse effect on the cost of employer-provided health insurance. Alternatively, an employer might choose not to promote that individual because she could become sick at some point in the future and eventually need to be replaced. Not surprisingly, survey respondents expressed the desire to keep their genetic information private from their employers, their health insurers, researchers, law enforcement, and even their doctors and spouses.<sup>20</sup> This anxiety led people to avoid genetic testing because they feared that it could harm them<sup>21</sup> or their loved ones.<sup>22</sup> (Whether the fear surrounding genetic testing is legitimate is completely irrelevant so long as that fear results in real-world consequences.<sup>23</sup>)

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20 See GENETICS & PUB. POL'Y CTR., U.S. PUBLIC OPINION ON USES OF GENETIC INFORMATION AND GENETIC DISCRIMINATION 1-3 (2007) [hereinafter U.S. PUBLIC OPINION], [http://www.dnapolicy.org/resources/GINAPublic\\_Opinion\\_Genetic\\_Information\\_Discrimination.pdf](http://www.dnapolicy.org/resources/GINAPublic_Opinion_Genetic_Information_Discrimination.pdf) (surveying 1199 adults eighteen and over regarding their fears surrounding access to their genetic test results).

21 See Standards for Privacy of Individually Identifiable Health Information, 65 Fed. Reg. 82,462, 82,466 (Dec. 28, 2000) (to be codified at 45 C.F.R. pts. 160, 164) (quoting Sen. Patrick Leahy) (explaining that one-third of women offered a genetic test for breast cancer declined out of fear of discrimination); Email from John Quillin, Genetic Counselor, to Amanda Sarata (Sept. 9, 2004, 10:59 AM), reproduced in SEC'Y'S ADVISORY COMM. ON GENETICS, HEALTH, & SOC'Y, U.S. DEP'T OF HEALTH & HUMAN SERVS., PUBLIC PERSPECTIVES ON GENETIC DISCRIMINATION 93 (2004) [hereinafter PUBLIC PERSPECTIVES] ("[F]ear of discrimination is a prevalent and influential concern among actual or would-be genetic counseling patients."); Bernstein, *supra* note 12, at 261 ("[R]esearch has shown that fear of genetic discrimination by insurers and employers is the primary barrier against testing."); Klitzman, *supra* note 18, at 77-78 (describing the effect of fear of discrimination on genetic testing and treatment decisions).

22 See Carolyn Park, *Genetics Offers Tool in Combat of Cancer*, ARK. DEMOCRAT-GAZETTE, Aug. 24, 2008, at 1 (quoting Dr. Kent McKelvey) (noting that genetic tests are "fundamentally different from traditional medical tests" because of their immediate impact on family members); see also PUBLIC PERSPECTIVES, *supra* note 21, 20-21 (testimony of Carolina Hinestrosa, a breast cancer survivor and Executive Vice President of National Breast Cancer Coalition) (explaining that she avoided genetic testing out of fear that it might negatively impact her daughter); Olympia J. Snowe, *Genetic Non-Discrimination—Time to Act to Protect Our Privacy*, OLYMPIA J. SNOWE: U.S. SENATOR FOR ME. (July 16, 2004), <http://snowe.senate.gov/ws07-16-04.htm> (describing a constituent's letter in which a mother declined genetic testing out of concern for her daughter).

23 See Bernstein, *supra* note 12, at 288 (noting that in the context of AIDS testing "reducing the actual level of risk would not necessarily reduce the perceived risk"). Even if the underlying fear is irrational, addressing it could still have positive effects if eliminating that fear would lead to better health services and advances in scientific research. See also MICHELE SCHOONMAKER & ERIN WILLIAMS, CONG. RESEARCH SERV., GENETIC TESTING: SCIENTIFIC BACKGROUND AND NONDISCRIMINATION LEGISLATION 2 (2004) ("[N]ew legislation is needed to allay the fears of individuals about the poten-

The resulting underuse of genetic technology has negative repercussions for researchers and individuals alike.<sup>24</sup> Scientific studies require subjects. The lack of interest in genetic testing, therefore, raised concerns for scientists who feared that public anxieties were impeding their research. If people are not using genetic technology, researchers lack test subjects. Without test subjects, researchers cannot design and run studies, and—consequently—genetic technology cannot advance.<sup>25</sup> Additionally, failing to use genetic technology could negatively impact personal health. Avoiding genetic testing deprives patients of the health benefits of genetic science. In addition to assessing risk or confirming a proposed diagnosis, genetic technology can improve overall care. Science is moving toward an era of

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tial for discriminatory practices so that they can seek beneficial health services, participate in much-needed clinical research, and otherwise reap the benefits of the publically funded Human Genome Project (HGP).”).

24 See PUBLIC PERSPECTIVES, *supra* note 21, at 20–21 (testimony of Carolina Hines-trosa); Paul Steven Miller, *Is There a Pink Slip in My Genes? Genetic Discrimination in the Workplace*, 3 J. HEALTH CARE L. & POL’Y 225, 234 (2000) (“Refusal to submit to genetic tests due to fear of discrimination results in negative consequences both for the individuals who do not get tested and for the advancement of scientific research in this area.”); Rivka Jungreis, Note, *Fearing Fear Itself: The Proposed Genetic Information Nondiscrimination Act of 2005 and Public Fears About Genetic Information*, 15 J.L. & POL’Y 211, 244 (2007) (observing that assuaging public fear of genetic testing will benefit society “in two spheres—that of the advancement of scientific research, and that of the individual’s pursuit of optimal healthcare”); *Senate Passes Bill Barring Genetic Discrimination*, ISSUES SCI. & TECH., Winter 2003, at 24, 24 (quoting Sen. Bill Frist); see also Perry W. Payne, Jr., *Genetic Information Nondiscrimination Act of 2008: The Federal Answer for Genetic Discrimination*, 5 J. HEALTH & BIOMEDICAL L. 33, 38 (2009) (noting that genetic research is slowed by the fear of misuse of genetic information).

25 See *Protecting Workers from Genetic Discrimination: Hearing Before the Subcomm. on Health, Emp’t, Labor and Pensions of the H. Comm. on Educ. and Labor*, 110th Cong. 31 (2007) [hereinafter *Protecting Workers from Genetic Discrimination*] (statement of Karen Rothenberg, Dean, University of Maryland School of Law); see also *Hearing on H.R. 493*, *supra* note 15, at 40 (statement of Karen Pollitz, Research Professor, Georgetown University Health Policy Institute) (describing adverse actions insurance companies take in response to knowledge of clients’ genetic test results); Regulations Under the Genetic Information Nondiscrimination Act of 2008, 75 Fed. Reg. 68,912, 68,912 (Nov. 9, 2010) (to be codified at 29 C.F.R. pt. 1635) (“Scientific advances require significant cooperation and participation from members of the general public.”); U.S. PUBLIC OPINION, *supra* note 20, at 1 (noting genetic research and clinical practice are impeded when people opt out of genetic testing); Letter from Michael O. Leavitt, U.S. Sec’y of Health & Human Servs., to Reed V. Tuckson, Chair, Sec’y’s Advisory Comm. on Genetics, Health, & Soc’y (Nov. 8, 2005), available at [http://oba.nih.gov/oba/sacghs/reports/Secretary\\_Response\\_to\\_SACGHS\\_11\\_08\\_05.pdf](http://oba.nih.gov/oba/sacghs/reports/Secretary_Response_to_SACGHS_11_08_05.pdf) (“[T]he public is concerned about the potential for genetic discrimination in health insurance and employment and . . . their fears have the potential to affect their health care decisions and their willingness to participate in genetics research.”).

“personalized medicine” in which health care professionals can use an individual’s genetic profile to tailor her medical treatment.<sup>26</sup> Thus, by failing to use genetic technology, a patient may not receive the best care possible.

GINA’s proponents cited fear of genetic-information discrimination and its negative impact on research and personal health when arguing for the statute.<sup>27</sup> Moreover, Congress explained in its findings that GINA “is necessary to fully protect the public from discrimination and *allay their concerns about the potential for discrimination*, thereby allowing individuals to take advantage of genetic testing, technologies, research, and new therapies.”<sup>28</sup> Congress, therefore, designed GINA at least in part to alleviate the anxieties surrounding genetic testing and the misuse of genetic information.<sup>29</sup>

Specifically, people expressed the fear that they would be judged based on their genetic material, a concept that could be called “social genetic determinism.” Social genetic determinism expresses the anxiety that our genes will somehow determine—for better or worse—the trajectory of our lives.<sup>30</sup> In popular culture, the film *Gattaca*<sup>31</sup>—which

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26 See Meredith Simons, *Need Medical Treatment? Get It Your Way: Houston Researchers Lead the Way in Tailoring Therapy to Patients’ DNA*, CHRON.COM (Nov. 14, 2009), <http://www.chron.com/disp/story.mpl/health/6721058.html>.

27 See Zach Wamp, *A Look into Your Future Health?*, WASH. TIMES, Jan. 5, 2004, at A15 (“We must not allow the fear of discrimination on the basis of genetic information to impede this groundbreaking medical progress.”); *Sen. Gregg Pushes for Protection of Patients from Genetic Discrimination*, U.S. FED. NEWS, July 22, 2004; see also NANCY LEE JONES & AMANDA K. SARATA, CONG. RESEARCH SERV., THE GENETIC INFORMATION NON-DISCRIMINATION ACT OF 2008 (GINA), at ii (2008) (stating that Congress enacted GINA to address fears of genetic-information discrimination, which have “an adverse effect on those seeking genetic testing, as well as on participation in genetic research”). The National Human Genome Research Institute, an organization that lobbied in favor of GINA, identified the fear of genetic discrimination as a major hurdle to genetic science and to enjoying the benefits of the Human Genome Project. See, Nat’l Hum. Genome Research Inst., *Genetic Discrimination*, GENOME.GOV, <http://www.genome.gov/10002077> (last updated Nov. 26, 2010).

28 Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, § 2(5), 122 Stat. 881 (emphasis added); see also Regulations Under the Genetic Information Nondiscrimination Act of 2008, 75 Fed. Reg. 68,912, 68,912 (Nov. 9, 2010) (explaining that Congress intended GINA to “prohibit[ ] discrimination based on genetic information and [to] restrict[ ] acquisition and disclosure of such information, so that the general public would not fear adverse employment- or health coverage-related consequences for having a genetic test or participating in research studies that examine genetic information”).

29 I discuss possible problems with basing legislation on fear in another article. See Roberts, *supra* note 2, at 480–83.

30 Typically, “genetic determinism” stands for the proposition that genes unilaterally determine physical and behavioral traits, called phenotypes. See Richard

commentators reference *ad nauseam* when discussing advances in genetic science<sup>32</sup>—represents a genetically deterministic world; the perceived quality of people’s DNA determines their social status, their careers, and ultimately the courses of their lives. A genetically deterministic society, therefore, results when genetic information limits individual choice or freedom. The anxieties surrounding genetic-information discrimination represent at once fears about our present and future, as well as concerns rooted in our past.

### 1. Social Genetic Determinism in the Past

The fear of a genetically deterministic society is not merely based in science fiction. It most likely stems, to some degree, from the United States’s regrettable history with eugenics-based laws and policies. Eugenics—defined in 1883 by English scientist Sir Francis Galton as “improving the quality of the stock”<sup>33</sup>—purported that certain socially undesirable characteristics, such as criminality, poverty, and “feble-mindedness,”<sup>34</sup> had a genetic basis and advocated the elimination of those so-called genetic defects.<sup>35</sup> Starting near the

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Strohman, *Maneuvering in the Complex Path from Genotype to Phenotype*, 296 *SCIENCE* 701 (2002); see also Karen H. Rothenberg, *Breast Cancer, the Genetic “Quick Fix,” and the Jewish Community: Ethical, Legal, and Social Challenges*, 7 *HEALTH MATRIX* 97, 103 (1997) (“[G]enetic determinism results when an individual believes her future is defined and predicted by genetic makeup and cannot be changed.”). Societies can likewise be genetically deterministic, using genetic information to limit people’s choices or their freedom. (Thank you to Jessica Clarke for her use of the word “determinism” in describing this sentiment as it pertains to antidiscrimination law.) Thus, under one scenario, genes are biologically deterministic; under the other, they are socially deterministic. This Article deals exclusively with the latter, which I call “social genetic determinism.”

31 GATTACA (Columbia Pictures 1997).

32 See, e.g., Michael Tomasson, *Legal, Ethical, and Conceptual Bottlenecks to the Development of Useful Genomic Tests*, 18 *ANNALS HEALTH L.* 231, 239–40 (2009); Jeffery Lawrence Weeden, *Genetic Liberty, Genetic Property: Protecting Genetic Information*, 4 *AVE MARIA L. REV.* 611, 662–63 (2006); Jeremy A. Colby, Note, *An Analysis of Genetic Discrimination Legislation Proposed by the 105th Congress*, 24 *AM. J.L. & MED.* 443, 444 n.5 (1998); Marisa Anne Pagnatarro, Note, *Genetic Discrimination and the Workplace: Employee’s Right to Privacy v. Employer’s Need to Know*, 39 *AM. BUS. L.J.* 139, 184–85 (2001).

33 See JACQUELINE VAUGHN SWITZER, *DISABLED RIGHTS* 36 (2003).

34 See *id.* at 34–38.

35 See *id.* Eugenics and social genetic determinism are not identical concepts. Eugenics as an ideology has two key elements: (1) linking certain unfavorable (or favorable) characteristics to genetics and (2) seeking to eliminate those negative genes (or alternatively to promote those positive ones), making it arguably one of the earliest iterations of genetic engineering. See WILLIAM F. ROWE & SANDRA SAVAGE, *SEXUALITY AND THE DEVELOPMENTALLY HANDICAPPED* 6–8 (1987). Conversely, a geneti-

beginning of the twentieth century and continuing for decades,<sup>36</sup> states adopted laws founded in eugenics.

Many states sanctioned forced sterilization to eliminate “unfavorable” traits.<sup>37</sup> Perhaps the most famous state-ordered sterilization was that of Carrie Buck. Buck was eighteen years old when a court ordered the Virginia State Colony for Epileptics and Feeble Minded, where Buck had been institutionalized, to sterilize her without her consent.<sup>38</sup> Holding that states could involuntarily sterilize individuals based on their undesirable genetics, the Supreme Court explained: “[S]ociety can prevent those who are manifestly unfit from continuing their kind. . . . Three generations of imbeciles are enough.”<sup>39</sup> And Carrie Buck was far from alone. In the years between 1921 and 1964, states sterilized over sixty thousand people in the United States without their consent.<sup>40</sup> While Virginia eventually repealed its sterilization statute<sup>41</sup> and offered a formal—albeit posthumous—apology to Carrie Buck,<sup>42</sup> the Supreme Court has never officially overturned the decision.<sup>43</sup>

## 2. Social Genetic Determinism in the Present and Future

As tempting as it may be to dismiss *Buck v. Bell*<sup>44</sup> as an unfortunate relic of a less enlightened time, the idea that genetics correspond to socially undesirable attributes is currently having a renaissance. For

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cally deterministic society need only implicate the first half of the definition: society may shunt people with particular genetic traits into various organizations, institutions, occupations, or social classes based on the perceived favorability of those characteristics but would not necessarily advocate the eradication of unfavorable genes (“negative eugenics”) or the promotion of favorable genes (“positive eugenics”). See LORI B. ANDREWS ET AL., *GENETICS* 81 (2d ed. 2006) (distinguishing between positive and negative eugenics). Thus, all examples of eugenics involve some element of social genetic determinism, yet all examples of social genetic determinism may not rise to the level of eugenics.

36 See SWITZER, *supra* note 33, at 48–51.

37 See *id.* at 36.

38 See *Buck v. Bell*, 274 U.S. 200, 205 (1927).

39 *Id.* at 207.

40 See SWITZER, *supra* note 33, at 38.

41 Virginia’s sterilization law was repealed in 1968. See *id.*

42 See Michael G. Silver, Note, *Eugenics and Compulsory Sterilization Laws: Providing Redress for the Victims of a Shameful Era in United States History*, 72 GEO. WASH. L. REV. 862, 886–87, 887 nn.221–22 (2004) (citing Press Release, Governor Mark R. Warner, Statement on the 75th Anniversary of the *Buck v. Bell* Decision (May 2, 2002)).

43 Although the Court did not overturn *Buck*, fifteen years later it held that involuntarily sterilizing individuals convicted of certain kinds of felonies violates equal protection. See *Skinner v. Oklahoma*, 316 U.S. 535, 538 (1942).

44 274 U.S. 200 (1927).

example, research has examined the genetic components of aberrant behaviors such as aggression<sup>45</sup> and substance abuse.<sup>46</sup> More recently, a study at Florida State University (FSU) made headlines by alleging a correlation between genes and gang membership.<sup>47</sup> Scientific research (however tenuous) regarding the link between genetics and certain behaviors—criminality in particular—harkens back to many of the ideas expressed in *Buck*.

Although genetically based social policies are not currently in effect, the United States's history with eugenics, as well as developing research and technology, made concerns regarding the possibility of social genetic determinism strong enough for Americans to avoid genetic testing. For example, one individual stated: "My sisters are so afraid that if their company finds out, they might get fired. . . . They don't want to be tested because of that."<sup>48</sup> Another person expressed concern that his employer might treat him differently as a result of his genetic information:

I just was worried about being viewed differently. . . . I don't know if discrimination is the right word—but it's probably the best word. . . . An analogy is: women who are young and probably going to have kids. Although they aren't discriminated against, everybody knows: if you hire this person, you might be stuck with a huge maternity leave bill. That influences people, even good people, *indirectly*. They have reservations, want a back-up plan, and may not give these employees all the work: "I won't give you all these

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45 See Alan R. Felthous & Ernest S. Bartatt, *Impulsive Aggression*, in AGGRESSION 123, 127 (Emil F. Coccaro ed., 2003).

46 See generally Boris Tabakoff & Paula L. Hoffman, *Genetics and Biological Markers of Risk for Alcoholism*, 103 PUB. HEALTH REP. 690 (1988) (discussing evidence that some individuals are genetically predisposed to alcoholism).

47 See Kathleen Kingsbury, *Which Kids Join Gangs? A Genetic Explanation*, TIME (June 10, 2009), <http://www.time.com/time/health/article/0,8599,1903703,00.html>. A genetic variation that may code for the lower production of a particular enzyme responsible for breaking down a variety of neurotransmitters could be responsible for increased aggression. See *id.* This particular trait has been called the "warrior gene" and created controversy in New Zealand when offered as an explanation for the perceived heightened violence in the Maori community. See Peter Crampton & Chris Parkin, *Warrior Genes and Risk-Taking Science*, 120 N.Z. MED J., Mar. 2, 2007, at 63, 63–65, <http://www.nzma.org.nz/journal/120-1250/2439> (summarizing ethical concerns associated with the supposed "warrior gene" as an explanation for Maori violence in New Zealand). In a similar logical move, the FSU study proposes that lowered production of that same enzyme in young men may be linked to a greater likelihood of joining gangs and using weapons. See Kingsbury, *supra*. According to the study, young men with the low-active variant were twice as likely to join a gang as men with the high-active variant. See *id.*

48 Klitzman, *supra* note 18, at 77 (alteration in original).

projects.” It would be illegal. But I’m sure a little bit of that goes on.<sup>49</sup>

Thus, people—even those who know they are at risk—may forgo genetic testing, not for health reasons, but to prevent differential treatment in other areas of their lives, such as employment. They fear becoming the victims of a genetically deterministic society.

### B. Norms Behind Protecting Genetic Information

From a practical perspective, Congress passed GINA in an attempt to alleviate the public fears surrounding genetic testing. However, strong normative values also underpin the desire to protect genetic information. Exploring these values goes beyond the practical goal of GINA—encouraging people to use genetic technology—by providing a theoretical foundation for protecting genetic information.

All kinds of decisionmakers could find genetic information potentially appealing. Take, for example, a genetic variant linked to aggression.<sup>50</sup> Even if that variant indicates only a slight proclivity for aggressive behavior, one can imagine a scenario in which the most exclusive daycare facilities or preschools would request genetic information as part of their application process to screen out potentially aggressive children. This practice appears both logical and efficient; if there is a way to prescreen children for a propensity for aggression—no matter how slight—it could reduce the chances of violence at a school even before any sort of actual incident occurs.<sup>51</sup> One could likewise imagine requests for genetic information dealing with aggression or impulsivity when applying for drivers’ licenses or loans. (In fact, scientists have already identified a genetic variant allegedly

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49 *Id.* at 72–73 (alterations in original).

50 Research regarding a gene linked to aggression, as well as other potentially negative behaviors, does in fact exist. *See supra* notes 45–47 and accompanying text.

51 Some scholars articulated the potential benefits of using genetic information to differentiate between children in the classroom. *See* Dorothy Nelkin & Laurence Tancredi, *Classify and Control: Genetic Information in the Schools*, 17 *AM. J.L. & MED.* 51, 69 (1991) (“Schools have long differentiated and classified students through diagnostic and evaluative tests. Detailed and sensitive information about individual children—their genetic makeup, predisposition to violence and mental illness, brain structure and susceptibility to disease—serves well-recognized educational needs. It also serves administrative needs, enhancing efficiency and economy in the management of education. Technologies that assess genetic capabilities and reveal biochemical states that ‘cause’ behavior enable educators to predict which children will be slow learners, disruptive, handicapped or difficult in the classroom.” ((footnote omitted)).

linked to “bad driving.”<sup>52</sup>) Even without an exact correlation, such screening could potentially lower the risk of car accidents or loan defaults, even if only to a very small degree. Thus, genetic information could provide a convenient, albeit crude, proxy for all kinds of other physical and even behavioral traits. We already limit who enters certain schools, drives, or borrows money; our genetic profiles could just provide one more criterion to consider.

Yet while genetic information as a category is not inherently dangerous, the concern is that people might value genetic traits beyond other potentially more useful information. With enough decisions based on genetic information, we may eventually find ourselves in a genetically deterministic world. For example, if preschools screen children in the hope of creating a safer playground, it is not such a far leap to screen job applicants according to their genetic profiles. If given the choice, would we want to use genes to screen potential surgeons for impulsivity or potential police officers for aggression?

Once we start limiting people’s educational or career options, that practice would affect a variety of other things, including their opportunities and their income levels. This slippery slope gets at what lies at the core of the fears surrounding a genetically deterministic society: creating a genetic underclass, a group of people who occupy a subjugated social status on the basis of their genetic information alone.<sup>53</sup>

At least four overlapping norms undergird the fear of a genetic underclass: (1) humanity (the belief in the intrinsic value of human life); (2) democracy (the belief in rewarding achievement and providing equal opportunity); (3) immutability (the belief a person should not be penalized for something outside her control); and (4) privacy (the belief that a person should be able to keep certain kinds of intimate information private).

## 1. Humanity

Decisions based solely or even predominantly on genetic information hold the potential to obscure our humanity. Specifically, a genet-

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<sup>52</sup> See *Blame Genetics for Bad Driving, Study Finds*, CNN (Oct. 29, 2009), <http://www.cnn.com/2009/TECH/science/10/29/bad.driver.gene/index.html?iref=allsearch>.

<sup>53</sup> Some have argued that what frightens us is not creating a genetically determined underclass but rather explicitly recognizing that an implicit genetic underclass already exists. See, e.g., Robert H. Bork, *The Challenges of Biology for Law*, 4 TEX. REV. L. & POL. 1, 3 (1999).

ically deterministic society could objectify its members by reducing them to mere clusters of genetic traits.<sup>54</sup>

Both law and legal philosophy express a belief in the inherent value of human life and the importance of respecting that value.<sup>55</sup> Objectification, a dignitary harm, results when a human being is treated *less* than human as the result of a social process.<sup>56</sup> Social genetic determinism objectifies individuals by reducing them to their genetic profiles. Allocating jobs, educations, or other social goods and privileges based on genetic traits fails to acknowledge that, while genetic information might reveal some aspects of a person's identity—such as elements of her appearance, her health risks, or even her talents and tendencies—it is incapable of capturing the essence of that person in her entirety. A genetically deterministic society would, therefore, treat individuals as clusters of genetic traits instead of as full human beings.

## 2. Democracy

Democracy is another norm that undergirds the protection of genetic information. Used here, democracy stands for “a social state in which all have equal rights, without hereditary or arbitrary differences of rank or privilege.”<sup>57</sup> Americans have a longstanding belief in the value of merit, defined in terms of personal achievement.<sup>58</sup> Merit includes the notion that one should not be rewarded merely for her inherent talents or her potential, but for the tangible fruits of her

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54 See MICHAEL H. SHAPIRO ET AL., *BIOETHICS AND LAW* 741 (2d ed. 2003) (“[T]he risks of reducing persons to objects consisting of particular characteristics that have become salient precisely because we can exercise some control over them.”).

55 See NGAIRE NAFFINE, *LAW'S MEANING OF LIFE* 99 (2009) (“Legal doctrine and legal philosophy are replete with assertions about the intrinsic value of human life and the need to respect it.”).

56 See SHAPIRO, *supra* note 54, at 10; see also Andrea Dworkin, *Against the Male Flood: Censorship, Pornography, and Equality*, 8 HARV. WOMEN'S L.J. 1, 15 (1985) (discussing objectification in the context of gender discrimination, and stating, “Objectification occurs when a human being, through social means, is made less than human, turned into a thing or commodity, bought and sold”).

57 4 OXFORD ENGLISH DICTIONARY 443 (2d ed. 1989) (providing the modern use of the term “democracy”).

58 See Devon W. Carbado & Cheryl I. Harris, *The New Racial Preferences*, 96 CALIF. L. REV. 1139, 1141 (2008) (describing meritocracy as a “core American value”).

efforts.<sup>59</sup> Thus, a true meritocracy requires equality of opportunity, so that all individuals might prove themselves deserving of social goods.<sup>60</sup>

A genetically deterministic society with the resulting genetic underclass would create the very kind of arbitrary class distinctions that democracy, as a norm, seeks to avoid. Our genes might speak to some of our innate abilities, but they do not determine our actual accomplishments.<sup>61</sup> Thus, basing decisions on genetic information runs counter to the central concepts behind democracy: the value of merit and the importance of equal opportunity.

### 3. Immutability

Similar to the democratic belief that individuals should be rewarded for their personal achievements is the inverse notion that individuals should not be penalized for traits they did not choose and cannot change.<sup>62</sup> Although possibly not true as the science of genet-

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59 The *Oxford English Dictionary* defines “meritocracy” as “government or holding of power by people chosen on the basis of merit (as opposed to wealth, social class, etc).” 9 OXFORD ENGLISH DICTIONARY, *supra* note 57, at 635; see Norman Daniels, *Merit and Meritocracy*, 7 PHIL. & PUB. AFF. 206, 207–08 (1978) (defining “meritocracy” as: “a society whose basic institutions are governed by a partial theory of distributive justice consisting of principles of the following types: (1) A principle of job placement that awards jobs to individuals on the basis of merit; (2) A principle specifying the conditions of opportunity under which the job placement principle is applied; (3) A principle specifying reward schedules for jobs.”). The concept of a meritocracy does not, however, completely discount innate ability. Daniels notes that “most meritocrats believe it is obvious that people differ in levels of skill and it is at least probable that they differ in the capacity to acquire levels of skills.” *Id.* at 208.

60 See Daniels, *supra* note 59, at 207 (describing a meritocracy as an environment where “[a]ll social barriers . . . —social class, family background (but not the family), race, and religion—are prevented from influencing decisions on education or career”); *id.* at 217 (“Fair equality of opportunity requires not only that negative legal or quasilegal constraints on equality of opportunity be eliminated, but also that positive steps must be taken to provide equality of access—and the means to achieve such equality of access—to those with inferior initial competitive positions resulting from family background or other biological or social accidents.”).

61 See Bork, *supra* note 53, at 3 (noting we might also fear “the inability of genetic testing to predict accurately what the individual might prove capable of accomplishing”).

62 Immutability as a concept in antidiscrimination law relies on the notion that fairness is a matter of free will, dependent on freedom of choice and taking responsibility for those choices. See Roberts, *supra* note 2, at 476 & n.187 (discussing the immutability norm’s basis in the concept of free will). In fact, protecting race, sex, national origin and—even at times—age and disability has been linked to those traits’ perceived immutability. See *id.* at 477 & nn.189–93 and accompanying text. Religion is the most prominent exception to the immutability norm. See *id.* at 477 n.194 and accompanying text.

ics continues to develop,<sup>63</sup> genes are for the most part determined before birth and subsequently remain more or less outside of our immediate control.<sup>64</sup>

Because of the currently immutable nature of genes, people can do very little to avoid being treated differently on that basis.<sup>65</sup> For

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63 See Ilise L. Feitshans, *Spider Silk Jeans or Spider Silk Genes?: The Future of Genetic Testing in the Workplace* 20 (2000) (unpublished manuscript), [http://ssrn.com/paper.taf?abstract\\_id=248671](http://ssrn.com/paper.taf?abstract_id=248671) (“In the next years, humanity will have the information to change many . . . aspects of genetic destiny. Genes linked to color blindness, colon cancer, Huntington’s disease, Down[ ] Syndrome, or other conditions that are considered to be a ‘defect’ today may be altered or deleted through new treatments or cures. For others, genes bring special gifts, such as physical strength, great intelligence, artistic ability or musical talent.”). By 2020, Dr. Francis S. Collins, former director of the National Human Genome Research Institute, speculates that “gene-based designer drugs” will be capable of treating numerous conditions such as Alzheimer’s, diabetes, and high blood pressure. See *Genetic Information in the Workplace: Hearing on S.1332 Before the S. Comm. on Health, Educ., Labor, & Pensions*, 106th Cong. 1 (2000) (testimony of Dr. Francis S. Collins, National Human Genome Research Institute).

64 Although some gene therapy is currently available, most is somatic; doctors insert therapeutic genes into a patient’s body cells, in the hope that those cells will then reproduce. See Kristine Barlow-Stewart, *Gene Therapy*, CENTRE FOR GENETICS EDUC. (June 2007), <http://www.genetics.com.au/pdf/factsheets/fs27.pdf>.

65 Advocates of genetic information legislation have cited the immutable nature of genes to justify the need to protect them. See *Hearing on H.R. 493*, *supra* note 15, at 106 (statement of Frank S. Swain) (“[W]e are born with our 46 chromosomes and 30,000 genes. We cannot control or change them.” (quoting Rep. Louise Slaughter)); Roberts, *supra* note 2, at 478 (“No American should have to worry that their genes—which they did not choose, and over which they have no control—will be used against them.”). Individuals who felt they had suffered discrimination on the basis of their genes have likewise cited the immutability of genetic information as evidence of the unfairness of their treatment. See, e.g., Letter from Michelle Thompson to Whom It May Concern (Sept. 24, 2004), reproduced in PUBLIC PERSPECTIVES, *supra* note 21, at 65 (“I learned that not only was I a carrier for Hemophilia (which was not my fault or choice), but that I had a 50% chance of inheriting Huntington’s Disease as well (not my fault or choice).”). Scholarly accounts also echoed this sentiment. See, e.g., Jennifer S. Geetter, *Coding for Change: The Power of the Human Genome to Transform the American Health Insurance System*, 28 AM. J.L. & MED. 1, 3 (2002) (“Genetic discrimination is unfair because it penalizes people (by limiting their coverage options) not because of their actions or choices, but because of their immutable genotype.”); Eric Mills Holmes, *Solving the Insurance/Genetic Fair/Unfair Discrimination Dilemma in Light of the Human Genome Project*, 85 K.V. L.J. 503, 563 (1997) (“Since one cannot choose one’s genetic make-up, arguably there should be no duty to pay more for insurance because of a poor genetic make-up.”); see also Colby, *supra* note 32, at 457 (“Genetic discrimination unfairly discriminates because of the involuntary and presently immutable nature of our genetic endowment.”). But see Sonia M. Suter, *The Allure and Peril of Genetics Exceptionalism: Do We Need Special Genetics Legislation?*, 79 WASH. U. L.Q. 669, 712 (2001) (arguing against using immutability to justify protecting genetic informa-

example, research like the FSU study has the potential to label people as violent or criminal on the basis of their genetics instead of their behavior. Thus, linking behaviors to genetics may justify treating people with the “violent” variant differently than those with the “nonviolent” variant regardless of actual conduct.<sup>66</sup> Additionally, an individual may feel “locked in” to certain behaviors or life choices if she discovers a supposed genetic proclivity for them, no matter how small the actual correlation between the genetic variant and the behavior might be.<sup>67</sup>

In addition to its effect on individuals, basing decisions on immutable traits could also negatively impact social accountability. For instance, while the FSU study does note that nurture plays an important role,<sup>68</sup> attributing an issue such as gang membership—which is also tied to a number of social, economic, and other factors—to genetics might obscure the role of society in both creating and remedying the problem. Politically, it may allow society to avoid accountability by blaming individual physiology for what are in fact social problems.<sup>69</sup>

#### 4. Privacy

Lastly, privacy supports protecting genetic information. Violating genetic privacy produces both “instrumental” and “intrinsic” harms.<sup>70</sup> On one level, the desire for genetic privacy relates to the fear of a genetically deterministic society: if employers, health insurers, and other potential discriminators can never access our genetic informa-

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tion because “[a]lthough we cannot control the genes we inherit, we cannot control a great many other risk factors, such as in utero exposures, environmental conditions, or drunk drivers, which may have profound effects on our future health”).

66 For instance, one scientist involved in the FSU study noted that “[a]t the very least this [research] suggests a genetic risk factor that can help us identify those youth most at risk . . . We can then intervene earlier to prevent it.” Kingsbury, *supra* note 47.

67 See Laura F. Rothstein, *Genetic Information in Schools*, in *GENETIC SECRETS* 317, 322 (Mark A. Rothstein ed., 1997) (acknowledging the potential problem of labeling and self-fulfilling prophecy that could be associated with the use of genetic information in academics).

68 See Kingsbury, *supra* note 47 (noting the correlation between child abuse and violent tendencies).

69 See Robert G. Resta, *The Twisted Helix: An Essay on Genetic Counselors, Eugenics, and Social Responsibility*, 1 J. *GENETIC COUNS.* 227 (1992); see also SHAPIRO, *supra* note 54, at 883, 885–86.

70 See SHAPIRO, *supra* note 54, at 403–04 (distinguishing between instrumental and intrinsic value of privacy).

tion, they cannot use it to disadvantage us.<sup>71</sup> However, a privacy violation also constitutes its own inherent wrong, regardless of how that information is used (or not used).

Violating privacy as a wrong unto itself relates to norms of autonomy and self-definition. Keeping certain information secret allows individuals to control their interactions with their communities by choosing which information to share and which information to conceal.<sup>72</sup> In short, privacy guards our ability to define our public identities.<sup>73</sup> Moreover, controlling intimate information helps us avoid potential embarrassment by keeping that information private.<sup>74</sup>

Our genetic profiles are just the kind of intimate information that privacy norms seek to protect.<sup>75</sup> Genetic information may reveal all kinds of personal things: our proclivity for developing certain medical conditions,<sup>76</sup> our need for sleep,<sup>77</sup> or even our musical ability.<sup>78</sup>

71 See Mary R. Anderlik & Mark A. Rothstein, *Privacy and Confidentiality of Genetic Information: What Rules for the New Science?*, 2 ANN. REV. GENOMICS HUM. GENETICS 401, 405 (2001). For more on the “opt-in” nature of genetic information, see *infra* notes 118–120. Individuals have expressed instrumental privacy concerns. For example, one person who had undergone genetic testing explained why others avoid testing:

People are afraid of it getting on the record, so they don’t get tested. The people I know who tested were already very sick. The son of a guy in our group is beginning to be symptomatic. The father tells him to get tested, but he just refuses. “I don’t want to know, and don’t want it on my record.” And you have to reach a certain level before doctors consider [medication].

Klitzman, *supra* note 18, at 77. Similarly, a 2007 study indicates that while individuals might trust their doctors and their spouses with the results of their genetic tests, they had far less confidence when asked about sharing that information with law enforcement, health insurers, or employers. U.S. PUBLIC OPINION, *supra* note 20, at 2.

72 SISSELA BOK, *SECRETS* 20 (1983).

73 ELLEN ALDERMAN & CAROLINE KENNEDY, *THE RIGHT TO PRIVACY*, at xiii (1995) (“Privacy . . . encompasses our right to self-determination and to define who we are. Although we live in a world of noisy self-confession, privacy allows us to keep certain facts to ourselves if we so choose.”).

74 See David Orentlicher, *Genetic Privacy in the Patient-Physician Relationship*, in *GENETIC SECRETS*, *supra* note 67, at 77, 78.

75 See MORROW, *supra* note 6, at 237–39 (noting the privacy concerns behind protecting genetic information).

76 Huntington’s disease is a popular example in the literature dealing with genetic-information discrimination because if a person has the associated genetic trait, she has a one hundred percent chance of developing the disease (assuming she lives long enough to reach the onset age). See Henry T. Greely, *The Revolution in Human Genetics: Implications for Human Societies*, 52 S.C. L. REV. 377, 382 (2001) (“[Huntington’s disease] is what geneticists call one hundred percent penetrant—one hundred percent of the people with the genotype get the disease.”).

77 See Laurent Seugnet et al., *Identifier of a Biomarker for Sleep Drive in Flies and Humans*, 103 PNAS 19,913, 19,913–18 (2006).

Failing to protect the privacy of our genetic information could, therefore, expose personal details related to our innermost identities.<sup>79</sup> Furthermore, unlike other kinds of private information, genetic information not only divulges intimate facts about an individual person but also about that person's entire family.<sup>80</sup> As a result, the intrinsic harms associated with revealing genetic information extend beyond the person whose privacy is initially violated.

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GINA prohibits health insurers and employers from discriminating on the basis of genetic information. From a purely pragmatic standpoint, protecting genetic information could alleviate the fears that prevent people from taking genetic tests. Yet behind those fears lie several normative justifications for safeguarding genetic information. Exploring these practical and theoretical reasons for protecting genetic information helps explain why Congress drafted GINA, even absent widespread existing genetic-information discrimination.

After examining why Congress chose to protect genetic information in the current Part, the following Part examines how Congress protected genetic information, specifically its decision to draft GINA as an antidiscrimination law.

## II. PROTECTING GENETIC INFORMATION

Congress could have protected genetic information in a number of different ways. For example, it could have drafted GINA as a privacy law that allows individuals to decide when to disclose their genetic information<sup>81</sup> or as a property law that confers an economic

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78 See Siamak Baharloo et al., *Absolute Pitch: An Approach for Identification of Genetic and Nongenetic Components*, 62 AM. J. HUM. GENETICS 224, 229 (1998).

79 See Anderlik & Rothstein, *supra* note 71, at 404 (asserting that there is an intrinsic value to keeping genetic information private).

80 See Orentlicher, *supra* note 74, at 81 (noting that privacy is particularly important to genetic information because it reveals intimate information about one's family members).

81 Genetic privacy laws function by requiring consent from the relevant party to access her genetic information. In 2008, when GINA passed, several states already protected genetic information using privacy legislation. See *Genetic Privacy Laws*, NAT'L CONF. OF STATE LEGISLATURES, <http://www.ncsl.org/default.aspx?tabid=14287> (last updated Jan. 2008).

Congress also considered privacy-based protections. In fact, early iterations of GINA directly referenced genetic privacy, such as several proposed bills called the "Genetic Privacy and Nondiscrimination Act" and others. *E.g.*, H.R. 3636, 108th Cong. (2003); H.R. 2555, 106th Cong. (1999); H.R. 3299, 105th Cong. (1998); H.R. 341, 105th Cong. (1997); S. 422, 105th Cong. (1997); S. 1898, 104th Cong. (1996); S.

right in one's genetic information.<sup>82</sup> Instead, Congress opted to pass

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1416, 104th Cong. (1995). For example, the Human Genome Privacy Act of 1991, H.R. 2045, 102d Cong. (1991), gave individuals the right to inspect and correct any of their genetic information maintained by government agencies and outlined the process for disclosing private genetic information. Likewise, certain versions of the "Genetic Privacy and Nondiscrimination Act" also provided requirements for disclosing genetic information. See H.R. 341 § 4; S. 1416 § 4.

While several proposed bills included sections on disclosure, GINA contains no such provision. Perhaps Congress ultimately rejected a privacy framework because it would not provide adequate protection. Although people would be able to control access to their genetic information, genetic-information consent forms could become a standard component of applications for jobs or insurance. See Klitzman, *supra* note 18, at 75. Thus, people may feel compelled to disclose their genetic information as a routine part of the application process. Alternatively, if an individual chooses not to disclose her genetic information, potential discriminators may assume that an individual has negative genetic traits and behave accordingly.

82 Congress could also have protected genetic information using property law. At the time of GINA's passing, five states defined genetic information as personal property, with one extending that right to DNA samples. See *Genetic Privacy Laws*, *supra* note 81. Thus, in protecting genetic information, Congress could have established specific property interests in genetic material under certain circumstances. A number of scholars have suggested this approach. See, e.g., Anita L. Allen, *Genetic Privacy: Emerging Concepts and Values*, in *GENETIC SECRETS*, *supra* note 67, at 31, 47; Patricia (Winnie) Roche et al., *The Genetic Privacy Act: A Proposal for National Legislation*, 37 *JURIMETRICS J.* 1, 4 (1996) (advocating a property right in one's DNA); Catherine M. Valerio Barrad, Comment, *Genetic Information and Property Theory*, 87 *Nw. U. L. REV.* 1037, 1040 (1993); Michael M.J. Lin, Note, *Conferring a Federal Property Right in Genetic Material: Stepping into the Future with the Genetic Privacy Act*, 22 *AM. J.L. & MED.* 109, 130–32 (1996); Jonathan F. Will, Comment, *DNA as Property: Implications on the Constitutionality of DNA Dragnets*, 65 *U. PITT. L. REV.* 129, 139–41 (2003). Unlike the extensive consideration of privacy protections, only one of the many proposed bills dedicated to genetic information included a personal property right. See Genetic Confidentiality and Nondiscrimination Act, S. 1898, 104th Cong. § 105(2) (1996) ("A DNA sample is the property of the individual.").

Property law is in many ways an intuitive choice for protecting our genetic identities, given the commodification of genetic material. Federal law permits researchers to patent genetic information, including isolated genes and gene fragments. See Sonia M. Suter, *Disentangling Privacy from Property: Toward a Deeper Understanding of Genetic Privacy*, 72 *GEO. WASH. L. REV.* 737, 745–46 nn.28–31 (2004). However, significant drawbacks also exist. For example, with respect to research, scientists rely on large numbers of samples to draw conclusions about genetic information. Personal property interests in genetic material could, therefore, potentially stymie science if all donors needed to consent to each activity conducted with their genetic material. Additionally, property law confers a purely economic right, which fails to acknowledge the dignitary concerns underlying the protection of genetic information. See Suter, *supra*, at 746–47 ("[In a property law model,] genetic information is seen as a commodity, disaggregated from the self, rather than something in which we have a dignitary and personhood interest. In addition, even when the property model successfully protects some of the interests we have in our genetic information, the prop-

GINA as an antidiscrimination statute dedicated solely to outlawing genetic-information discrimination in health insurance and employment. This choice shapes both the rights plaintiffs exercise with respect to their genetic information, as well as what constitutes an actionable claim.

#### A. *GINA as an Antidiscrimination Statute*

Antidiscrimination law offers a particular kind of protection. As an antidiscrimination statute, GINA creates negative restraints on the information that covered entities can consider when making certain relevant decisions.<sup>83</sup> An antidiscrimination model differs significantly from both privacy and property paradigms. Unlike privacy, antidiscrimination protections do not require positive conduct on the part of health insurers and employers, such as disclosure agreements.<sup>84</sup> Furthermore, unlike property, GINA confers no positive rights in our genetic information. GINA does not give us control in deciding when and how our genetic information might be used; it only speaks to conditions under which particular parties cannot use our genetic information.

GINA's supporters explicitly characterized the law as civil rights legislation, often arguing that discrimination on the basis of genetic information is akin to discrimination on the basis of other traditionally protected traits such as race and sex.<sup>85</sup> Congress likewise portrayed GINA as a statute conceived in the American civil rights tradition by linking genetic-information discrimination to the forced sterilization of people with disabilities<sup>86</sup> and racially targeted screen-

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erty model undermines the relationships in which we share this information, pushing them toward arms-length transactions as opposed to relationships of trust.”)

83 See Dawn C. Nunziato, Note, *Gender Equality: States as Laboratories*, 80 VA. L. REV. 945, 946 (1994) (defining the antidiscrimination principle as “one of negative restraint that forbids the government from arbitrarily discriminating against classes of individuals”).

84 GINA's exceptions may in practice require disclosure agreements. However, those disclosure agreements are not the primary tool by which GINA functions.

85 For example, Senator Ted Kennedy called GINA “the first major . . . civil rights bill of the new century” and asserted that “discrimination based on a person's genetic identity is just as unacceptable as discrimination on the basis of race or religion.” *U.S. Blocks Genetic Discrimination*, BBC NEWS (Apr. 25, 2008), <http://www.bbc.co.uk/2/hi/americas/7366264.stm>. Similarly, President George W. Bush stated that “[j]ust as we have addressed discrimination based on race, gender and age, we must now prevent discrimination based on genetic information.” David E. Sanger, *Bush Supports Federal Law Putting Limits on DNA Tests*, N.Y. TIMES, June 24, 2001, at 10.

86 See Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, § 2(2), 122 Stat. 881, 882 (codified at 42 U.S.C. § 2000ff (Supp. II 2008)) (“The early

ings for sickle cell anemia.<sup>87</sup> Although GINA's insurance provisions function like a health care statute such as the Health Insurance Portability and Accountability Act (HIPAA), the spirit of the law is undoubtedly one of antidiscrimination.<sup>88</sup>

However, cabining genetic information as a functional antidiscrimination classification presented Congress with a serious challenge.<sup>89</sup> Arguments have been made for the genetic basis of a variety of attributes<sup>90</sup> including alcoholism,<sup>91</sup> obesity,<sup>92</sup> and—as men-

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science of genetics became the basis of State laws that provided for the sterilization of persons having presumed genetic 'defects' such as mental retardation, mental disease, epilepsy, blindness, and hearing loss, among other conditions. The first sterilization law was enacted in the State of Indiana in 1907. By 1981, a majority of States adopted sterilization laws to 'correct' apparent genetic traits or tendencies. Many of these State laws have since been repealed, and many have been modified to include essential constitutional requirements of due process and equal protection. However, the current explosion in the science of genetics, and the history of sterilization laws by the States based on early genetic science, compels Congressional action in this area.").

87 See *id.* § 2(3) ("Although genes are facially neutral markers, many genetic conditions and disorders are associated with particular racial and ethnic groups and gender. Because some genetic traits are most prevalent in particular groups, members of a particular group may be stigmatized or discriminated against as a result of that genetic information. This form of discrimination was evident in the 1970s, which saw the advent of programs to screen and identify carriers of sickle cell anemia, a disease which afflicts African-Americans. Once again, State legislatures began to enact discriminatory laws in the area, and in the early 1970s began mandating genetic screening of all African Americans for sickle cell anemia, leading to discrimination and unnecessary fear. To alleviate some of this stigma, Congress in 1972 passed the National Sickle Cell Anemia Control Act, which withholds Federal funding from States unless sickle cell testing is voluntary.").

88 Title I bars the use of genetic information by health insurers in determining eligibility or premiums. Although both titles of GINA protect against discrimination on the basis of genetic information, Titles I and II approach the issue differently. Title II constitutes its own stand-alone section of the United States Code, whereas Title I—like HIPAA—amends sections of various significant federal health insurance legislation.

89 See Mark A. Rothstein, *Why Treating Genetic Information Separately Is a Bad Idea*, 4 TEX. REV. L. & POL. 33, 33 (1999) (noting that creating a "working definition" of genetic information is next to impossible, as any definition will be at once over- and underinclusive); see also Morrow, *supra* note 6, at 239–45 (discussing the problems associated with establishing genetic information as a distinct category).

90 Other behaviors that may have genetic bases include: the need for sleep, see Mark Henderson, *Genetic Mutation May Be Why Some People Need Less Sleep than Others*, TIMES (LONDON), Aug. 14, 2009, [http://www.timesonline.co.uk/tol/life\\_and\\_style/health/article6795361.ece](http://www.timesonline.co.uk/tol/life_and_style/health/article6795361.ece); the predisposition for anger, see Felthous & Barratt, *supra* note 45, at 127; and the ability to recognize pitch, see Jen Waters, *Genes May Play a Solo in Pitch Recognition*, WASH. TIMES, Feb. 1, 2007, at B01.

91 See, e.g., Tabakoff & Hoffman, *supra* note 46, at 690–91.

tioned—gang membership.<sup>93</sup> Moreover, because genetic information determines many key aspects of our bodies' physical morphologies, it invariably overlaps with the existing antidiscrimination categories of sex, age, and disability. Congress explicitly sought to define "genetic information" as distinct from those other traits by excluding sex, age, and manifested health conditions from GINA's coverage.<sup>94</sup>

Congress used two key terms to define genetic information as a stand-alone, antidiscrimination category: "genetic information" and "genetic testing." Both titles of GINA define "genetic information" as "(i) such individual's genetic tests, (ii) the genetic tests of family members of such individual, and (iii) the manifestation of a disease or disorder in family members of such individual."<sup>95</sup> Likewise, both titles contain the same definition of "genetic test": "an analysis of human DNA, RNA, chromosomes, proteins, or metabolites that detects genotypes, mutations, or chromosomal changes."<sup>96</sup>

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92 See, e.g., Anthony G. Comuzzie & David B. Allison, *The Search for Human Obesity Genes*, 280 SCIENCE 1374, 1374–76 (1998).

93 See Kingsbury, *supra* note 47.

94 Congress explicitly differentiated genetic information from existing antidiscrimination categories. For example, although sex is a genetically determined trait, GINA excludes sex from the definition of "genetic information." See Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, §§ 101(d), 102(a)(1)(B), 103(d), 104(b), 201(4)(C), 122 Stat. 881, 884, 888, 897, 900, 906 (codified in scattered sections of 26, 29, and 42 U.S.C.). GINA also excludes age from its definition of "genetic information." See *id.* § 201(4)(c). GINA distinguishes between genetically based health conditions and their associated genes. See *id.* § 101(d) (excluding the "analysis of proteins or metabolites that does not detect genotypes, mutations, or chromosomal changes," or "an analysis of proteins or metabolites that is 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" from the definition of "genetic test" in Title I); *id.* § 210 (excluding "the use, acquisition, or disclosure of medical information that is not genetic information about a manifested disease, disorder, or pathological condition," even if such "has or may have a genetic basis" from the definition of "genetic information" in Title II).

95 See *id.* §§ 101(d), 102(a)(1)(B), 103(d), 104(b), 201(4)(A)(i)–(iii). The definition of genetic information also includes requesting or receiving genetic services, such as participating in clinical research, by an individual or by members of her family. See *id.* §§ 101(d), 102(a)(1)(B), 103(d), 104(b), 201(4)(B).

96 See *id.* §§ 101(d), 102(a)(1)(B), 103(a)(2), 104(b), 201(7). In other contexts, "genetic test" has been defined more broadly. See, e.g., SHAPIRO, *supra* note 54, at 745 ("The earliest forms of genetic diagnosis, still frequently practiced, were based on observation of an individual's clinical findings or constellation of anomalies and on assessment of the family history.").

Importantly, both of GINA's two substantive titles forbid simply acquiring genetic information.<sup>97</sup> Insurers cannot request or require genetic testing.<sup>98</sup> Likewise, employers cannot acquire genetic information through requesting, requiring, or purchasing.<sup>99</sup> Prohibiting the mere obtaining of genetic information respects genetic privacy: to violate GINA, employers or insurers do not need to use the genetic information they acquire—they must only obtain or attempt to obtain it. Because GINA allows no consideration of genetic information, the statute takes what has been described as a “genome-blind” approach to protecting genetic information.<sup>100</sup> GINA thus attempts to level the playing field between the health insurer or the employer and the individual by restricting the covered entities' ability to use genetic information.<sup>101</sup> As a result, one can read GINA as simultaneously reducing the bargaining power of the covered entity and reducing the vulnerability of potential insureds and employees.<sup>102</sup>

While GINA prohibits a very specific form of genetic-information discrimination, Congress alluded to a different kind of genetically based discrimination—eugenics—in its official findings, mentioning sterilization laws like those in *Buck* to justify the need for legislation.<sup>103</sup> Interestingly, GINA would have no effect on Carrie Buck were her case to happen today. The statute protects only against discrimination on the basis of genetic information in health insurance and employment. It says nothing with regard to whether a state may make decisions about a person's health, reproductive rights, or bodily integrity based on her genetic information. Unfortunately, with current

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97 See Genetic Information Nondiscrimination Act § 101(b) (amending Employee Retirement Income Security Act (ERISA)); *id.* § 102(a) (amending Public Health Service Act (PHSA)); *id.* § 103(b) (amending Internal Revenue Code (IRC)); *id.* § 104(a) (amending Social Security Act (SSA)) (adding provisions stating that insurers “shall not request or require an individual or a family member of such individual to undergo a genetic test”); *id.* § 202(b) (providing that an employer may not “request, require, or purchase genetic information with respect to an employee or a family member of the employee”).

98 See *supra* note 97.

99 See *supra* note 97. Notably, § 202(b) includes six exceptions. Genetic Information Nondiscrimination Act §§ 202(b)(1)–(b)(6). The other sections of Title II have similar prohibitions. See *id.* §§ 203(b), § 204(b), 205(b).

100 See Mark A. Rothstein, *Legal Conceptions of Equality in the Genomic Age*, 25 LAW & INEQ. 429, 456 (2007) (describing genetic nondiscrimination and genetic privacy laws as “genome-blind”).

101 I am indebted to Samuel Bray's work on “power rules” for this reading of GINA. See Samuel Bray, *Power Rules*, 110 COLUM. L. REV. 1172, 1181 (2010) (describing Title I of GINA as a “power-decreasing rule”).

102 *Id.*

103 See Genetic Information Nondiscrimination Act § 2(2).

scientific research linking genetics to socially undesirable behaviors and tendencies, decisionmakers other than health insurers and employers may be interested in obtaining genetic information.

### B. *What Makes GINA Different*

Genetic information is unique as an antidiscrimination category. In advocating for the law, GINA's supporters often compared genetic information to traditional antidiscrimination categories like race and sex.<sup>104</sup> However, while genetic information may masquerade as an analogue to more conventional legally protected traits, it differs in key ways.

For example, prior to GINA, characteristics receiving antidiscrimination protection constituted socially recognized groups with associated identities and the potential to become objects of stigma. By contrast, genetic information—at least at present—does not comprise a lived social category in the same way as race, sex, or disability. While much has been written on the subjects of racial identity,<sup>105</sup> gender

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104 The inheritability and perceived immutability of genetic information provided a popular point of comparison. “People do not get to choose their own genes, nor can they change the genes they have been given. This is a civil rights issue as much as are race and gender discrimination. To base judgment on that which is inherited and immutable is simply wrong.” Monique K. Mansoura & Frances S. Collins, *Medical Implications of the Genetic Revolution*, 1 J. HEALTH CARE L. & POL’Y 329, 351 (1998); see also *Protecting Workers from Genetic Discrimination*, *supra* note 25, at 42 (“The reasons for making genetic privacy part of our broader discrimination protections were clear to us. First, we believe that a person’s genetic profile should be treated the same as other innate human characteristics such as one’s race, gender, national origin, sexual orientation, age or physical abilities. Simply stated, a person’s genetic profile is as natural and as inseparable from who they are as any other physical trait or attribute.” (statement of Harriet Pearson, Chief Privacy Officer, IBM Corp.)); Christine Formas Norris, Note, *The Genetic Information Nondiscrimination Act of 2008: History, Successes, and Future Considerations*, 7 U. MD. L.J. RACE, RELIGION, GENDER & CLASS 192, 195 (2007) (“[O]ur genetic profiles are immutable characteristics, because much like race and gender, our genes are inherited and unalterable.”).

105 See, e.g., Paulette M. Caldwell, *A Hair Piece: Perspectives on the Intersection of Race and Gender*, 1991 DUKE L.J. 365, 371–72 (“Racism and sexism are interlocking, mutually-reinforcing components of a system of dominance rooted in patriarchy.”); Devon W. Carbado & Mitu Gulati, *Working Identity*, 85 CORNELL L. REV. 1259, 1262 (2000) (exploring how outsider groups, such as women and minorities, “are often likely to perceive themselves as subject to negative stereotypes . . . [and] feel the need to do significant amounts of ‘extra’ identity work to counter those stereotypes”); Camille Gear Rich, *Performing Racial and Ethnic Identity: Discrimination by Proxy and the Future of Title VII*, 79 N.Y.U. L. REV. 1134, 1159 (2004) (arguing that courts should “abandon the current definitions of race and ethnicity under Title VII that exempt from protection ‘voluntary’ aspects of racial and ethnic identities”).

identity,<sup>106</sup> and disability identity,<sup>107</sup> genetic identity still remains largely a mystery. Because genetic science is still in its infancy, genetic information is too young as a social category to have developed a recognized identity group or stigma based on group membership.<sup>108</sup> Furthermore, acquiring genetic information requires testing,<sup>109</sup> whereas other groups tend to rely on social and cultural signals and morphological traits as indicators of group membership.<sup>110</sup> Even if people were actively seeking genetic testing, the parameters of our genetic identities would still be unclear by virtue of the fact that science is currently unable to decipher the exact meaning of much of that information.<sup>111</sup> At present, we can only speculate about the type and number of identity groups that might arise with respect to genetic information or who will be considered a member.<sup>112</sup>

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106 See, e.g., Katharine T. Bartlett, *Only Girls Wear Barrettes: Dress and Appearance Standards, Community Norms, and Workplace Equality*, 92 MICH. L. REV. 2541, 2544–45 (1994) (arguing that community norms are too discriminatory “to provide a satisfactory benchmark for defining workplace equality”); Ann C. McGinley, *Creating Masculine Identities: Bullying and Harassment “Because of Sex,”* 79 U. COLO. L. REV. 1151 (2008) (discussing “gender norms” in the context of workplace harassment); Janie Allison Sitton, *Introduction*, 7 WM. & MARY J. WOMEN & L. 1, 3 (2000) (concluding that gender is fixed in the workplace, and “that harassing behavior at work is often rooted in perceptions of gender difference”).

107 See, e.g., Laura L. Rovner, *Disability, Equality, and Identity*, 55 ALA. L. REV. 1043 (2004) (noting that modern disability theory is moving towards the view of disability as a socially constructed condition); Michael Ashley Stein, *Foreword: Disability and Identity*, 44 WM. & MARY L. REV. 907 (2003) (discussing perceptions of disability).

108 See Diver & Cohen, *supra* note 16, at 1476–77. Stigma is the notion that a particular characteristic is “deeply discrediting” within a particular social context. ERVING GOFFMAN, *STIGMA* 3 (1986). It is an important aspect in the creation and maintenance of group subjugation that the antistigma principle aims to eradicate. With no recognized social group and no widely recognized history of discrimination, stigma has not yet attached to genetic information as a category. That is not to say, however, that there is no stigma attached to certain genetically based health conditions. See Klitzman, *supra* note 18, at 81 (describing the potential stigma associated with Huntington’s).

109 See *infra* notes 118–120 and accompanying text.

110 See, e.g., Bruce A. Ackerman, *Beyond Carolene Products*, 98 HARV. L. REV. 713, 728–29 (1985) (discussing the means by which membership in a minority group is perceived).

111 See Diver & Cohen, *supra* note 16; *supra* note 16 and accompanying text.

112 Some researchers are currently exploring the formation of genetic identity amongst individuals at risk for certain genetic conditions. See Robert Klitzman, “Am I My Genes?": *Questions of Identity Among Individuals Confronting Genetic Disease*, 11 GENETIC MED. 880 (2009). However, the concept of genetic identity remains a relatively new phenomenon and not yet widely recognized by society at large.

Additionally, there is only a limited history of genetic disadvantage.<sup>113</sup> Previous statutes, such as Title VII of the Civil Rights Act of 1964<sup>114</sup> and the Americans with Disabilities Act of 1990<sup>115</sup> were retrospective, looking to existing discrimination to justify protecting against future harm.<sup>116</sup> Yet instead of reacting to current discrimination like its predecessors, GINA is a forward-looking statute—designed to preempt a variety of discrimination before it becomes entrenched.<sup>117</sup> However, the absence of current discrimination could be a function of the unique nature of genetic information.

Much genetic difference is not readily identifiable—even for potential claimants. Unlike other bases for discrimination, genetic-information discrimination often requires medical testing and professional expertise.<sup>118</sup> In many circumstances,<sup>119</sup> an insurer or an employer could not discriminate—nor could an individual know that she warrants protection—but for the intervention of medical science. Therefore, current rates of genetic-information discrimination could be low because people refuse genetic testing to avoid becoming the objects of discrimination.<sup>120</sup>

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113 See Roberts, *supra* note 2, at 457–71.

114 Pub. L. No. 88-352, 78 Stat. 241 (codified as amended at 42 U.S.C. §§ 2000e–2000e-17 (2006)).

115 Pub. L. No. 101-336, 104 Stat. 327 (codified as amended at 42 U.S.C. §§ 12101–12213 (2006)).

116 See Roberts, *supra* note 2, at 457–70.

117 See *generally id.* (arguing that GINA is the first preemptive antidiscrimination statute in American history); see also Rothenberg & Terry, *supra* note 19, at 197 (arguing in favor of enacting federal legislation before genetic-information discrimination takes hold); cf. Cass R. Sunstein, *Sexual Orientation and the Constitution: A Note on the Relationship Between Due Process and Equal Protection*, 55 U. CHI. L. REV. 1161, 1163 (1988) (characterizing the Due Process Clause as backward-looking and the Equal Protection Clause as forward-looking).

118 See Norris, *supra* note 104, at 198 (“Unlike race, ethnicity, religion, or gender, genetic predispositions are not readily apparent without laboratory genetic testing, physical medical examinations, or the disclosure of family medical histories.”); see also Diver & Cohen, *supra* note 16, at 1445 (“One obviously cannot base discrimination on a person’s genetic profile unless one has first obtained information about that profile.”); David F. Partlett, *Misuse of Genetic Information: The Common Law and Professionals’ Liability*, 42 WASHBURN L.J. 489, 490–91 (2003) (noting medical science’s increasing ability to perform genetic testing).

119 Family history is the notable exception here, as it is a type of genetic information that does not always require genetic testing. For example, a parent’s developing cancer might indicate a child’s genetic proclivity for developing cancer, even though neither party ever had a genetic test.

120 See Anita Silvers & Michael Ashley Stein, *An Equality Paradigm for Preventing Genetic Discrimination*, 55 VAND. L. REV. 1341, 1351 (2002) (“The first obvious line of defense is to evade genetic testing. If people adopt this strategy, as they are likely to

The lack of a widely recognized social identity group, the low rate of existing discrimination, and the role of testing make protecting genetic information patently different from protecting other antidiscrimination categories. Despite these significant differences, GINA can be understood in terms of antidiscrimination theory.

### III. THEORIZING GENETIC INFORMATION

Although genetic information differs from traditional antidiscrimination categories in certain fundamental ways, GINA is undoubtedly an antidiscrimination statute. However, to date, virtually no scholars have devoted significant attention to how antidiscrimination theory informs or effectuates GINA's purpose. Building on the conclusion that GINA is an antidiscrimination statute, this Part argues that understanding GINA in terms of existing antidiscrimination principles could improve its protections.

#### A. *Traditional Antidiscrimination Principles*

For decades scholars have debated what should be at the heart of the American antidiscrimination project: a principle based on ending group subordination or a principle based on prohibiting any classification on the basis of certain forbidden traits.<sup>121</sup> Thus, the antidiscrimination principle<sup>122</sup> is often described in terms of two sometimes

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do, they will impede the realization of genomics' contributions to both personal welfare and social good."); see also Kim, *supra* note 6, at 698 (stating that, with regard to genetic information, "unlike race or sex, the traits that would be the basis for discrimination are not readily detected through casual observation, and systematic discrimination cannot occur unless information about genetic characteristics becomes widely available").

121 See generally Jack M. Balkin & Reva B. Siegel, *The American Civil Rights Tradition: Anticlassification or Antisubordination?*, 58 U. MIAMI L. REV. 9 (2003) (providing detailed history of the development and application of two distinct antidiscrimination trends in American jurisprudence); Reva B. Siegel, *Equality Talk: Antisubordination and Anticlassification Values in Constitutional Struggles over Brown*, 117 HARV. L. REV. 1470 (2004) (contextualizing the development of competing theories on equal protection law).

122 When used here, "antidiscrimination principle" does not exclusively refer to anticlassification or antidifferentiation norms as is sometimes true in the literature. See, e.g., Paul Brest, *In Defense of the Antidiscrimination Principle*, 90 HARV. L. REV. 1, 1 (1976); Owen M. Fiss, *Groups and the Equal Protection Clause*, 5 PHIL. & PUB. AFF. 107, 108 (1976); Robert Post, *Prejudicial Appearances: The Logic of American Antidiscrimination Law*, 88 CALIF. L. REV. 1, 8-9 (2000); Cass R. Sunstein, *The Anticaste Principle*, 92 MICH. L. REV. 2410, 2440-41 (1994). Instead, the term is all-encompassing, referring to the goals undergirding antidiscrimination law. See Balkin & Siegel, *supra* note 121, at 10 ("In hindsight, [Fiss's] choice of words was quite unfortunate, because there is no

competing, sometimes complementary, interpretations: antisubordination and anticlassification.

These two versions of the antidiscrimination principle employ differing accounts of the meaning of equality. The antisubordination principle<sup>123</sup> roughly holds that covered entities should not act in a way that reinforces the social status of subjugated groups.<sup>124</sup>

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particular reason to think that antidiscrimination law or the principle of antidiscrimination is primarily concerned with classification or differentiation as opposed to subordination and the denial of equal citizenship. Both antisubordination and anticlassification might be understood as possible ways of fleshing out the meaning of the antidiscrimination principle, and thus as candidates for the ‘true’ principle underlying antidiscrimination law.”).

123 The antisubordination principle has been the subject of numerous interpretations and alternate nomenclatures. For example, Owen Fiss’s original incarnation of the antisubordination principle was named the “group-disadvantaging principle,” which he defined as requiring that laws not aggravate or perpetuate “the subordinate status of a specially disadvantaged group.” Fiss, *supra* note 122, at 157. Other variants include the “antisubjugation” principle, *see* LAURENCE H. TRIBE, *AMERICAN CONSTITUTIONAL LAW* 1515 (2d ed. 1988) (arguing in favor of an “antisubjugation principle, which aims to break down legally created or legally reinforced systems of subordination that treat some people as second-class citizens”), the “equal citizenship” principle, *see* Kenneth L. Karst, *Equal Citizenship Under the Fourteenth Amendment*, 91 *HARV. L. REV.* 1, 46 (1977) (stating that “[t]he central concern of the equal citizenship principle is equality of personal status in the society”), and the “antidomination” principle, *see* Christine A. Littleton, *Reconstructing Sexual Equality*, in *FEMINIST LEGAL THEORY* 39 (Katharine T. Bartlett & Rosanne Kennedy eds., 1991) (asserting that Catharine A. MacKinnon’s work advocates “[t]he reconceptualization of equality as antidomination”).

Cass Sunstein has developed a related concept, the “anticaste” principle. *See* Sunstein, *supra* note 122, at 2413 (noting similarities to theories advanced by Tribe and Fiss but arguing that the anticaste principle differs in its account of equality and its application to legislative—opposed to judicial—enforcement). As defined by Sunstein, the anticaste principle has two requirements: the defining trait must be (1) visible and (2) morally irrelevant. *Id.* at 2411–12. Genetic information—as was discussed—is neither highly visible, as it requires voluntary medical testing to be revealed, nor morally irrelevant, as it can result in eventual physical and functional—as well as social—disadvantage. Thus, because of these prerequisites, members of a genetic underclass may never be the beneficiaries of this particular version of the antisubordination principle.

124 *See* Siegel, *supra* note 121, at 1472–73 (explaining the antisubordination principle as “the conviction that it is wrong for the state to engage in practices that enforce the inferior social status of historically oppressed groups”). Additionally, the anticaste principle differs slightly from other interpretations of the antisubordination principle in that it relies on actual numerical disparities in certain tangible social goods like education, employment, and income, not simply historical disadvantage or subordinated social status. *See* Sunstein, *supra* note 122, at 2443–44. For example, a group may be disadvantaged and experience social subordination in the sense that it is an object of discrimination but—because its social welfare status is elevated or compara-

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,<sup>125</sup> maintains that covered entities should not consider certain classes of forbidden traits under any circumstance,<sup>126</sup> adopting a formal equal treatment model of equality.<sup>127</sup> Thus, the antisubordination principle expresses a commitment to protect subjugated groups from status harms (whether explicit or unintended), while the anticlassification principle demonstrates a commitment to

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ble to that of out-group members—not be considered members of a lower caste. *See id.* Such a group could potentially benefit from an antisubordination regime but not an anticaste one.

125 The anticlassification principle is also known as the “antidiscrimination” principle, *see supra* note 122; *see also* Paul Brest, *supra* note 122, at 1 (defining the antidiscrimination principle as “the general principle disfavoring classifications and other decisions and practices that depend on the race (or ethnic origin) [or other forbidden traits] of the parties affected”), or the “antidifferentiation” principle, *see* Sunstein, *supra* note 122, at 2439–40 (asserting that “[t]he anticaste principle was transformed into an antidifferentiation principle,” shifting the focus from “the elimination of second-class citizenship” to “whether people who were similarly situated had been treated similarly”).

126 *See* Balkin & Siegel, *supra* note 121, at 10 (defining the anticlassification principle as the idea that “the government may not classify people either overtly or surreptitiously on the basis of a forbidden category: for example, their race”).

127 Conversely, antisubordination may embrace the functional equal treatment, equal outcome, and equal access—as well as formal equal treatment—models of equality. I borrow these four particular conceptualizations of equality from Susan Sturm. *See* Susan Sturm, *Equality and Inequality: Legal Aspects*, in *INTERNATIONAL ENCYCLOPEDIA OF SOCIAL AND BEHAVIORAL SCIENCES* 4717, 4717–22 (2001). Formal equal treatment forbids explicit and intended differential treatment. Functional equal treatment attempts to account for inequality that is the result of intended, as well as unintended, bias. Equal outcome examines material differences based on group membership, such as differences in income and education level. Equal access targets structural inequalities that create differential treatment in formally equal policies. As an example, take an employer’s policy on tardiness and its effect on sex discrimination. Under a formal equal treatment model, the lateness policy would be unequal only if it contains explicit provisions treating men and women differently on the basis of sex. Under a functional equal treatment model, even if the policy is neutral on its face, if the employer enforces it differently because supervisors assume that women tend to be late more often than men because of a belief that women are frequently responsible for taking their children to school, the policy would not be equal. Under an equal outcome model, if women tend to be promoted less frequently than men as a result of the lateness policy, it would be unequal. Finally, if the employer’s assumption was correct and women are more likely to be responsible for taking their children to school, under equal access, the employer might need to make some kind of accommodation so as not to disadvantage its female workers.

protect individuals from all forms of differential treatment based on a proscribed trait (including so-called benign or reverse discrimination).<sup>128</sup> Whereas antisubordination emphasizes group membership, anticlassification advances an individualized account of equality.<sup>129</sup>

That said, anticlassification as an antidiscrimination principle cannot stand alone: while maintaining that decisions cannot be made against individuals on the basis of certain forbidden traits, it does nothing to explain why those particular traits are forbidden. The anticlassification principle can thereby be understood as an empty vessel that other normative values must “fill” by dictating which traits to forbid. Although the concepts are sometimes treated as competing, antisubordination could—and in fact often does—drive anticlassification-based laws.<sup>130</sup> In their work on the legacy of *Brown v. Board of Education*, Jack Balkin and Reva Siegel propose that antisubordination values have been, at times, indispensable to the practical application of the anticlassification principle.<sup>131</sup> Thus, while at times portrayed as a simple dichotomy, the connection between anticlassification and

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128 Siegel explains the two models in terms of group versus individualized accounts of equality. Siegel, *supra* note 121, at 1472–73 (“For many, the belief that anticlassification commitments are fundamental entails the view that our tradition embraces a particular conception of equality, one that is committed to individuals rather than to groups. . . . The fundamentality of the anticlassification principle thus explains various features of our equal protection tradition, foremost among them its commitment to protect individuals against all forms of racial classification, including ‘benign’ or ‘reverse’ discrimination.”).

129 Justice Thomas articulated the Court’s preference for an individual-oriented account of equality over a group-oriented one in its interpretation of Equal Protection:

At the heart of this interpretation of the Equal Protection Clause lies the principle that the government must treat citizens as individuals, and not as members of racial, ethnic, or religious groups. It is for this reason that we must subject all racial classifications to the strictest of scrutiny, which (aside from two decisions rendered in the midst of wartime) has proven automatically fatal.

Missouri v. Jenkins, 515 U.S. 70, 120–21 (1995) (Thomas, J., concurring) (citations omitted).

130 See Siegel, *supra* note 121, at 1477; see also Balkin & Siegel, *supra* note 121, at 13 (“[A]ntisubordination values have played and continue to play a key role in shaping what the anticlassification principle means in practice.”). Antisubordination is not, however, the only underlying norm that may motivate anticlassification protection.

131 See Balkin & Siegel, *supra* note 121, at 28 (“[A]pplication of the anticlassification principle often depends on judgments concerning the presence, absence, or degree of status-harm—the very sorts of judgments with which the antisubordination principle is concerned.”).

antibsubordination is far more complex.<sup>132</sup> For instance, an antibsubordination statute might protect certain racial groups because those particular groups experience discrimination on the basis of group membership. On the other hand, an antibclassification statute would forbid the use of race in making any decision—positive or negative—regardless of whether particular individuals have faced discrimination on the basis of race. However, the very selection of “race” as a forbidden trait may reflect a desire to address the sort of status concerns that are more readily associated with antibsubordination. Hence, antibclassification may seek to prevent antibsubordination, albeit not as explicitly.

### B. *Antidiscrimination Principles and Genetic Information*

Protecting genetic information can be understood in either antibsubordination or antibclassification terms. An antibsubordination-based law would seek to prevent the formation of a genetic underclass.<sup>133</sup> Alternatively, an antibclassification-based statute would prohibit any decision—positive, negative, or value-neutral—about individuals based on their genetic information. While either variant of the antidiscrimination principle could have formed the normative foundation for GINA, the statute’s protections align predominantly with antibclassification.

#### 1. Antibsubordination and Genetic Information

Traditionally, the antibsubordination principle asserts that decisionmakers should not act in a way that reinforces the lowered social status of a historically disadvantaged group.<sup>134</sup> Thus, GINA could not be an antibsubordination statute in the traditional sense, as there is no currently disadvantaged, widely recognized social group associated with genetic-information discrimination. However, Congress could have drafted GINA as an antibsubordination statute—even absent an

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132 Both antibsubordination and antibclassification prohibit intentional discrimination that could lead to subjugated group status. However, antibsubordination also prohibits facially neutral policies that could lead to subjugated status, while antibclassification does not. Additionally, antibclassification prohibits intentional discrimination that does not have an adverse impact, such as affirmative action.

133 Because genetic-information discrimination is not occurring on a widespread basis and no group has yet been identified as genetically disadvantaged, the antibsubordination principle as applied to genetic information could only prevent the creation of a subordinated class rather than eliminate existing subjugation.

134 See *supra* notes 121–122 and accompanying text.

existing genetic underclass<sup>135</sup>—by seeking to preempt the formation of a genetically disadvantaged social group. Subordination occurs when one attribute becomes widely valued over another attribute.<sup>136</sup> If society begins to favor particular genes or genetic profiles, we risk creating a group who is disadvantaged purely on the basis of genetic information. Antisubordination protections for genetic information would, therefore, anticipate possible status harms and seek to prevent them.

Because genetic disadvantage is so pervasive—we are all predisposed to between five and fifty serious genetic conditions—we are all potential members of a genetic underclass.<sup>137</sup> As a result, who will comprise a genetically disadvantaged group depends less on actual genetic material and more on which tests are developed and used.<sup>138</sup> 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.

While we may be unable to predict exactly who might form a genetic underclass, we know enough about social subjugation in other contexts to take preventative measures. Stigma forms in four distinct, predictable phases: labeling difference, linking difference to undesirable traits, categorizing people by label, and status loss and discrimina-

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135 See Sunstein, *supra* note 122, at 2433 (“[A] history of discrimination is not a necessary condition for status as a lower caste, though in practice such a history is highly probable.”).

136 See Bruce G. Link & Jo C. Phelan, *Conceptualizing Stigma*, 27 ANN. REV. SOC. 363, 367–75 (2001) (arguing that stigma forms in four stages: (1) distinguishing and labeling personal differences, (2) creating stereotypes by linking certain labeled people to undesirable traits, (3) placing labeled people into distinct categories, and (4) causing labeled people to experience status loss and discrimination based on their label). Moreover, animus or an intent to discriminate need not be present. Status hierarchies may result when small preferences accrue over time to result in subjugation. See Susan Sturm, *Second Generation Employment Discrimination: A Structural Approach*, 101 COLUM. L. REV. 458, 469 (2001) (“[B]ehavior that appears gender neutral, when considered in isolation, may actually produce gender bias when connected to broader exclusionary patterns.”).

137 See Louise McIntosh Slaughter, *Genetic Testing and Discrimination: How Private Is Your Information?*, 17 STAN. L. & POL’Y REV. 67, 69 (2006) (“No human being has a perfect set of genes. In fact, every one of us is estimated to be genetically predisposed to between five and fifty serious disorders. Every person is therefore a potential victim of genetic discrimination.”).

138 See Alexander Morgan Capron, *Which Ills to Bear?: Reevaluating the “Threat” of Modern Genetics*, 39 EMORY L.J. 665, 690 (1990) (noting that while all people have potentially fatal genes, those who carry the genes for which genetic screens are first developed will suffer disproportionately).

tion based on labeling.<sup>139</sup> Consequently, steps could be taken to counteract that process. For example, antisubordination policies, such as diversity initiatives, have been proposed for other antidiscrimination categories with respect to work and education.<sup>140</sup> Likewise, an antisubordination approach to genetic information might emphasize genetic diversity<sup>141</sup> to prevent negative stereotypes based on genetic difference from forming. Thus, antisubordination would draw lessons from the past to target practices that could lead to subordinated social status. Additionally, like antisubordination protections for race, sex, and disability, an antisubordination approach to genetic information would likewise allow positive differential treatment and disparate impact claims.

## 2. Anticlassification and Genetic Information

An anticlassification approach, on the other hand, would prohibit entities from ever considering genetic information. Because GINA bans all intentional, differential treatment on the basis of genetic information, the statute is more in keeping with the anticlassification norm.

GINA comprehensively prohibits health insurers and employers from considering genetic information. While GINA prohibits the *adverse* use of genetic information in employment,<sup>142</sup> it also proscribes *classifying* on the basis of genetic information.<sup>143</sup> As a result, employ-

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139 See Link & Phelan, *supra* note 136, at 367–75.

140 See Kate McCormick, *The Evolution of Workplace Diversity*, HOUS. LAW., Mar.–Apr. 2007, at 10 (discussing diversity initiatives and the meaning of “diversity”).

141 See Bruce T. Lahn & Lanny Ebenstein, *Let’s Celebrate Human Genetic Diversity*, 461 NATURE 726, 727 (2009) (arguing that we should value genetic diversity along with cultural diversity).

142 Section 202(a)(1) of GINA provides that an employer cannot “fail or refuse to hire, or to discharge, any employee, or otherwise to discriminate against any employee with respect to the compensation, terms, conditions, or privileges of employment of the employee, because of genetic information with respect to the employee.” 42 U.S.C. § 2000ff-1(a)(1) (Supp. II 2008). While this provision has an antisubordination tone, it forbids only intentional negative use of genetic information. Thus, § 202(a)(1) does not encompass certain fundamental elements traditionally associated with the antisubordination principle—affirmative action and disparate impact. *Id.*

143 Title II prohibits classification on the basis of genetic information. See *id.* § 2000ff-1(a)(2) (providing that employers may not “limit, segregate, or classify the employees of the employer in any way that would deprive or tend to deprive any employee of employment opportunities or otherwise adversely affect the status of the employee as an employee, because of genetic information with respect to the employee”); *id.* § 2000ff-2(a)(2) (similarly regulating employment agencies); *id.* § 2000ff-3(a)(2) (similarly regulating labor organizations); *id.* § 2000ff-4(a)(2) (simi-

ers cannot treat employees differently—either positively or negatively—based on their genetic information. Similarly, health insurers cannot use genetic information when determining eligibility, premiums, or benefits.<sup>144</sup> GINA prevents any adjustment to an insurance premium based on genetic information. Thus, by outlawing positive, as well as negative, differential treatment, GINA takes a formal equal treatment approach to protecting genetic information. Further, GINA offers an individualized account of equality. Because all people are potential beneficiaries, the statute is geared more toward protecting individual traits than averting group harm.

Additionally, GINA only outlaws intentional discrimination. Other antidiscrimination statutes, such as Title VII, allow claimants to challenge facially neutral policies that create discriminatory results, absent an intent to discriminate.<sup>145</sup> This type of claim is commonly referred to as a “disparate impact” action.<sup>146</sup> In keeping with antisubordination values, Title VII’s disparate impact jurisprudence is one-sided: it applies only to legal actions brought by members of historically subordinated groups.<sup>147</sup> At present, GINA expressly precludes disparate impact actions,<sup>148</sup> thereby only allowing the victims of

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larly regulating on-the-job training programs). A similar provision in Title VII laid the groundwork for that statute’s anticlassification interpretation. See 42 U.S.C. § 2000e-2(a)–(d) (2006).

144 See Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, §§ 101(a), 102(a), (b), 103(a), 122 Stat. 881, 883, 888, 892, 896 (codified in scattered sections of 26, 29, and 42 U.S.C.). As of 2014, when the Patient Protection and Accountable Care Act, Pub. L. No. 111-148, 124 Stat. 119 (2010), goes into full effect, many of GINA’s insurance provisions will become obsolete. See FURROW ET AL., *supra* note 15.

145 See 42 U.S.C. § 2000e-2(k)(1)(A)(i); see also *Griggs v. Duke Power Co.*, 401 U.S. 424, 431 (1971) (“[Title VII] proscribes not only overt discrimination but also practices that are fair in form, but discriminatory in operation.”).

146 See BLACK’S LAW DICTIONARY 538 (9th ed. 2009) (defining “disparate impact” as “[t]he adverse effect of a facially neutral practice (esp. an employment practice) that nonetheless discriminates against persons because of their race, sex, national origin, age, or disability and that is not justified by business necessity”).

147 While disparate impact claims traditionally have only been employed on behalf of historically subordinated groups, this tenet of antidiscrimination law may in fact be changing. See generally Charles A. Sullivan, *The World Turned Upside Down?: Disparate Impact Claims by White Males*, 98 NW. U. L. REV. 1505 (2004) (discussing the historical development of Title VII disparate impact claims and rejecting the argument for application of the doctrine to white males).

148 Genetic Information Nondiscrimination Act, 42 U.S.C. 2000ff-7(a) (Supp. II. 2008) (“Notwithstanding any other provision of this Act, ‘disparate impact,’ as that term is used in section 703(k) of the Civil Rights Act of 1964 (42 U.S.C. 200e-2(k)), on the basis of genetic information does not establish a cause of action under this Act.”).

intentional discrimination to recover. Although not currently allowing disparate impact claims, GINA provides that six years after its enactment, a commission will revisit this issue.<sup>149</sup>

Because GINA provides individualized protection, prohibits any consideration of genetic information—positive or negative—and only outlaws intentional discrimination, the statute currently favors anticlassification.

### *C. Benefits of Antisubordination Theory for Genetic Information*

Although GINA is largely an anticlassification statute, Congress drafted it in response to what is ultimately a concern about social subjugation—the fear of a genetically deterministic society. Therefore, amending GINA to include certain “antisubordination” protections would better safeguard genetic information. Importantly, given the comprehensive post-GINA changes to the American health insurance system effective in 2014,<sup>150</sup> the problems and solutions proposed in this subpart focus primarily on employment discrimination.

To start, under GINA’s current provisions, entities could arguably still use genetic information to limit opportunities; discriminators would just have to wait until the associated impairment manifests. As noted, GINA does not protect manifested genetic health conditions.<sup>151</sup> When a piece of genetic information shifts from being merely a characteristic of an individual’s genotype to a medical condition diagnosable by other means, the resulting health condition does not constitute “genetic information” and is, therefore, not covered by

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149 See *id.* § 2000ff-7(b) (“On the date that is 6 years after the date of enactment of this Act, there shall be established a commission, to be known as the Genetic Non-discrimination Study Commission (referred to in this section as the ‘Commission’) 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.”).

150 The Patient Protection and Affordable Care Act (PPACA) includes provisions designed to eliminate health-status discrimination in health insurance. See, e.g., Patient Protection and Affordable Care Act of 2010, Pub. L. 111-148, § 1201, 124 Stat. 119, 154 (prohibiting discrimination based on preexisting condition or health status, prohibiting discrimination against individual participants based on health status, and banning health insurers in the individual and group markets from setting “discriminatory premium rates”); see also Jessica L. Roberts, “Healthism”: A Critique of the Antidiscrimination Approach to Health Insurance and American Health-Care Reform (Feb. 18, 2011) (unpublished manuscript), available at [http://papers.ssrn.com/sol3/papers.cfm?abstract\\_id=1757987](http://papers.ssrn.com/sol3/papers.cfm?abstract_id=1757987) (arguing that Congress took an antidiscrimination approach to reforming health care). Thus, manifested genetic health conditions will enjoy antidiscrimination protection in the context of health insurance.

151 See *supra* note 94.

the statute.<sup>152</sup> While such policies would affect fewer people and at a later time in their lives, allowing discrimination on the basis of manifested genetic disorders could still generate a socially subjugated class. Many individuals who complained of genetic-information discrimination against themselves and their families pre-GINA actually described discrimination on the basis of a manifested condition.<sup>153</sup> Additionally, people avoid genetic testing because they fear discovering their, or their families', genetic proclivity for a disease.<sup>154</sup> Should their test results reveal an increased risk, knowing that GINA would only protect them until the disease manifests might compound that fear rather than alleviate it.

Although the ADA may provide some protection for manifested genetic health conditions in the context of employment, some individuals could fall through the cracks. The ADA prohibits employment discrimination against qualified individuals with disabilities.<sup>155</sup> It defines a "disability" as "(A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (B) a record of such an impairment; or (C) being regarded as having such an impairment."<sup>156</sup> Thus, to qualify as a disability under the ADA, an impairment must substantially limit a major life activity.<sup>157</sup> In the past, courts have interpreted the definition of disability very narrowly. For example, courts have previously denied ADA claims for impairments such as terminal cancer<sup>158</sup> and multiple sclero-

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152 See Rothstein, *supra* note 2, at 176 ("This absence of protection for affected individuals is not a loophole or oversight.").

153 See Email from Pam Kennedy to Amanda Sarata (Aug. 20, 2004, 6:27 PM), reproduced in PUBLIC PERSPECTIVES, *supra* note 21, at 47 (describing her son's struggles with ectodermal dysplasia as an example of genetic-information discrimination).

154 Woody Guthrie died of Huntington's disease. His son, Arlo Guthrie, although having a fifty percent chance of developing the disease, has publically stated he does not want to be tested. See *Don't Permit Abuses of Genetic Testing*, USA TODAY, July 19, 1990, at 10A.

155 See 42 U.S.C. § 12112(a) (2006).

156 *Id.* § 12102(2).

157 *Id.* If an impairment is not substantially limiting, it does not constitute a disability. See *infra* notes 158–159 and accompanying text.

158 See *Hirsch v. Nat'l Mall & Serv., Inc.*, 989 F. Supp. 977, 980–82 (N.D. Ill. 1997) (denying posthumously an ADA claim because the claimant failed to establish that his fatal non-Hodgkins lymphoma was substantially limiting); see also *Ellison v. Software Spectrum, Inc.*, 85 F.3d 187, 191 (5th Cir. 1996) (holding that a plaintiff with breast cancer was not substantially limited in the major life activity of working despite the "nausea, fatigue, swelling, inflammation, and pain she experienced as a result of the treatment and the medication").

sis<sup>159</sup> because claimants failed to establish that those impairments substantially limited them.

Effective in January 2009, Congress amended the ADA to counteract restrictive court decisions and reinstate the expansive definition of disability it originally intended.<sup>160</sup> Although Congress recognized that determining what constitutes a substantial limitation previously allowed the courts to restrict the ADA, it was unable to settle on a definition of the term itself, ultimately leaving the question up to the Equal Employment Opportunity Commission (EEOC).<sup>161</sup> The EEOC's proposed rules explain that an impairment is a disability when it substantially limits a person's ability to perform a major life activity, as compared to "most people in the general population" and that the impairment need not prevent or severely restrict an individual's ability to perform a major life activity to be substantially limiting.<sup>162</sup> However, the EEOC regulations are merely advisory and do not bind the courts. Thus, the courts will again have to address the issue of what constitutes a substantially limiting impairment.

Fortunately, a claimant who has an impairment that does not rise to the level of a disability, even under the new revisions, could still recover if she is "regarded as" having a disability.<sup>163</sup> Under the newly amended ADA, a claimant is regarded as having a disability if she faced discrimination "because of an actual or perceived physical or mental impairment whether or not the impairment limits or is perceived to limit a major life activity."<sup>164</sup> As a result, the extent of the

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159 See *Kocsis v. Multi-Care Mgmt., Inc.*, 97 F.3d 876, 884 (6th Cir. 1996) ("Although both arthritis and MS can be disabling in some instances, they were not so substantially limiting in this case.").

160 See ADA Amendments Act of 2008, 42 U.S.C. § 12102(4)(A) (2006 & Supp. II 2008) (rejecting the courts' narrow definition of disability and stating that "[t]he definition of disability in this chapter shall be construed in favor of broad coverage of individuals under this chapter, to the maximum extent permitted by the terms of this Act").

161 See Alex B. Long, *Introducing the New and Improved Americans with Disabilities Act: Assessing the ADA Amendments Act of 2008*, 103 Nw. U. L. REV. COLLOQUY 217, 219–20 (2008), <http://www.law.northwestern.edu/lawreview/colloquy/2008/44/LRColl2008n44Long.pdf>.

162 Regulations to Implement the Equal Employment Provisions of the Americans with Disabilities Act, as Amended, 74 Fed. Reg. 48,431, 48,440 (proposed Sept. 23, 2009) (to be codified at 29 C.F.R. pt. 1630). The regulations also provide a list of conditions that should consistently constitute a disability, such as autism, cancer, and cerebral palsy, as well as examples of conditions that may be substantially limiting for some—but not all—people, like asthma, high blood pressure, learning disabilities, and carpal tunnel syndrome. *Id.* at 48,441–42.

163 See *supra* note 156 and accompanying text.

164 42 U.S.C. § 12102(3)(A).

new coverage will depend upon how broadly courts construe the phrase “because of an . . . impairment.” However, claimants who only meet the “regarded as” prong of the definition of disability are not entitled to reasonable accommodations.<sup>165</sup>

Depending on how expansively the courts interpret both “substantially limits” and “regarded as,” newly diagnosed but asymptomatic patients may find themselves unprotected. Individuals who take genetic tests would be more aware of the diseases they might develop and, therefore, more likely to monitor their health and catch a genetically based health condition early in its manifestation. Depending upon how the courts apply the ADA, those same people could lie in the gap between GINA’s and the ADA’s coverage.<sup>166</sup> GINA would not protect their manifested genetic health conditions, yet those conditions might not yet rise to the level of disabilities. While Congress and the EEOC did their best to close the potential window between diagnosis and symptoms, the courts will ultimately decide the bounds of the ADA’s protection. Because GINA does not apply to a diagnosable genetic health condition, an expansive interpretation of the newly amended ADA is the only possible protection against employment discrimination on the basis of a manifested genetic impairment.

An antisubordination approach would lead to more comprehensive and consistent protection for genetic information. Unlike GINA’s current protections, an antisubordination paradigm mandates including those conditions alongside their underlying genes. Take three employees. Employee *A* has a genetic variant giving her a fifty percent chance of developing cancer and she developed cancer two years ago. Employee *B* has the same variant and will develop cancer in five years. Lastly, Employee *C* has the same variant as Employees *A* and *B* but will never develop cancer. Although all three individuals possess the exact same genetic information, GINA may not treat them equally. If a policy discriminates on the basis of their shared genetic variant, GINA would most likely protect *B* (who does not presently have cancer but will develop it in five years) and *C* (who will never develop cancer), but probably not *A* (who currently has cancer) because Employee *A* would have to differentiate her genetic information from her associated health condition to have a viable claim. Conversely, an antisubordination approach to protecting genetic information would

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165 *Id.* § 12201(h).

166 See Klitzman, *supra* note 18, at 72 (noting that individuals with mild symptoms are afraid that neither GINA nor the ADA will protect them); see also Rothstein, *supra* note 6, at 839 (noting the possible gap in coverage between GINA and ADA); see also Maurice Wexler et al., *The Law of Employment Discrimination from 1985–2010*, 25 A.B.A. J. LAB. & EMP. L. 349 (2010) (describing the interplay of the ADA and GINA).

view Employees *A*, *B*, and *C* all as members of a potential genetic underclass, regardless of whether they manifest the underlying condition. When *B* develops cancer in five years, she will not leave the potential genetic underclass. Rather, she will join an additional group, people with cancer. Because nothing about her genes will have changed, she is just as genetically disadvantaged as she was before. Even if her health status gives her protection against discrimination via health care reform<sup>167</sup> and the ADA, offering dual protection makes sense because she is dually disadvantaged.<sup>168</sup> Thus, according to antisubordination, discrimination on the basis of a manifested genetic disorder is just as problematic as discrimination on the basis of the genetic information alone.

Antisubordination would also allow positive differential treatment. Employers must be able to consider genetic information to protect it properly. As mentioned, genetic difference is ubiquitous,<sup>169</sup> and all people carry some unfavorable genetic traits.<sup>170</sup> Because of the wide range of genetic difference, genetic advantage/disadvantage exists on a continuum. As a result, society will ultimately determine which kinds of genes or genetic profiles are “normal” or “desirable.” Of the existing antidiscrimination categories, these qualities make genetic information most similar to disability.<sup>171</sup> Instead of eliminating disparities, treating people with disabilities exactly like their able-bodied counterparts frequently creates inequality.<sup>172</sup> Thus, equality for people with disabilities often relies on accommodation,<sup>173</sup> something that cannot occur without some knowledge of the disability. Likewise, allowing entities to consider genetic information might actu-

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167 See *supra* note 150.

168 The EEOC even hints at the possibility of dual protection in its regulations. See Regulations Under the Genetic Information Nondiscrimination Act of 2008, 75 Fed. Reg. 68,912, 68,929 (Nov. 9, 2010) (to be codified at 29 C.F.R. pt. 1635.11).

169 See Lahn & Ebenstein, *supra* note 141, at 728 (“[N]o two people’s DNA is the same, except identical twins.”).

170 See Capron, *supra* note 138, at 690 (noting that while all people have potentially fatal genes, those who carry the genes for which genetic screens are first developed will suffer disproportionately).

171 Like the idea of “genetic disadvantage,” what constitutes disability is based in the conceptualization of normalcy. See Mary Crossley, *The Disability Kaleidoscope*, 74 NOTRE DAME L. REV. 621, 656 (1999).

172 See Rovner, *supra* note 107, at 1057–58; see also Jessica L. Roberts, Note, *An Area of Refuge: Due Process Analysis and Emergency Evacuation for People with Disabilities*, 13 VA. J. SOC. POL’Y & L. 127, 137–40 (2005) (arguing that the equal protection demanded by the Fourteenth Amendment does not do enough to alleviate the difficulties faced by disabled people).

173 See Rovner, *supra* note 107, at 1044.

ally lead to more meaningful equality. Take, for example, a genetic predisposition to developing carpal tunnel syndrome. GINA's prohibition on classifying on the basis of genetic information would prevent an employer from treating employees with that variant differently than employees with another variant.<sup>174</sup> However, treating both groups identically could result in the carriers' developing carpal tunnel and needing to leave their jobs or take time off to recover while the group without the variant continues working. Alternatively, if the employer could consider genetic information, the employees with the genetic predisposition could work longer hours but with more breaks to allow their joints to rest or could switch positions throughout the day.<sup>175</sup> By treating the employees differently on the basis of their genetic information, employers could avoid work-related injury and any resulting gaps in employment. Additionally, allowing employers to consider genetic information leaves the door open for genetic diversity initiatives that would teach us to value genetic difference early in the creation of this new antidiscrimination category. Thus, a complete ban on obtaining genetic information does not make sense because it ignores the reality of genetic difference and prohibits the consideration of genetic information for accommodation or diversity purposes.<sup>176</sup>

Further, permitting claimants to recover for facially neutral policies that could produce discriminatory results is important to protecting genetic information adequately. Although genetic-information discrimination as conceived by GINA is a relatively new phenomenon,

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174 Arguably, allowing an accommodation for employees with a genetic predisposition disadvantages the employees without that genetic predisposition. According to this line of reasoning, providing a more flexible work schedule to employees with a heightened genetic proclivity for developing carpal tunnel would disadvantage employees without that genetic variant. This position would be akin to the plaintiff's successful argument in *Ricci v. DeStefano*, 129 S. Ct. 2658, 2687–89 (2009), holding that an employer who rejected test results that would have formed the basis of disparate impact claim for its employees of color in so doing discriminated against its white employees. However, the employer could offer the accommodation universally on another basis, such as work/life balance.

175 Similarly, Robert Klitzman suggests accommodations for individuals at risk for alpha-1 antitrypsin deficiency, such as limiting possible exposures to environmental irritants. See Klitzman, *supra* note 18, at 73.

176 It should be noted that simply allowing the positive use of genetic information unchecked could lead to systemic advantage on the basis of genetic information, creating a genetic uberclass. While claimants might at some point be able to use disparate impact actions to challenge blanket preferences for uberclass members as unintended discrimination against nonmembers, those claimants would have to prove that the positive treatment was creating systematic disadvantage. Thus, it is important to limit that positive differential treatment to accommodation and diversity initiatives.

disparate impact on the basis of genetic information is already a real possibility. For example, scientists have discovered that a gene associated with height is linked to a genetic variant predisposing its carriers to heart disease.<sup>177</sup> Several jobs require that employees be a particular height.<sup>178</sup> Consequently, height requirements—a traditional area of sex-based disparate impact claims—could also have a disparate impact on the basis of certain genetic information unrelated to height itself. Moreover, because GINA only prevents employers from explicitly discriminating on the basis of genetic information, employers could introduce policies that screen out undesirable genetic traits using other signals, either intentionally or unintentionally.<sup>179</sup> Thus, failing to offer protection against facially neutral policies with discriminatory results may facilitate the creation of a genetic underclass.

Finally, an antidisubordination framework could better target subtle or implicit genetic-information discrimination. A series of small decisions may accumulate to create large scale disparities.<sup>180</sup> For example, imagine that an employer learns that an employee has tested positive for Huntington's. Although the employee may not develop the disease until years later, the employer might make decisions—either out of self-interest or concern that the individual might not be “up for” certain tasks—based on the employee's genetic information. These kinds of minor decisions based on genetic information represent a real fear among individuals at risk for genetic disease.<sup>181</sup> An anticlassification model, which prohibits only intentional discrimi-

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177 See Steve Connor, *Newly Discovered Height Gene Has Disease Link*, INDEPENDENT, Sept. 3, 2007, at 12, available at <http://www.independent.co.uk/life-style/health-and-families/health-news/newly-discovered-height-gene-has-disease-link-401275.html> (quoting Mike Weedon).

178 A variety of jobs involve height requirements, including automobile manufacturers, fire fighters, police officers, truckers, and pilots. Litigants have challenged these requirements. See, e.g., *Boyd v. Ozark Air Lines, Inc.*, 568 F.2d 50 (8th Cir. 1977) (pilots); *Davis v. Los Angeles*, 566 F.2d 1334 (9th Cir. 1977) (fire fighters), *vacated*, 440 U.S. 625 (1979); *United States v. Chicago*, 411 F. Supp. 218 (N.D. Ill. 1976) (police officers), *aff'd in part, rev'd in part*, 549 F.2d 415 (7th Cir. 1977); *Meadows v. Ford Motor Co.*, 62 F.R.D. 98 (W.D. Ky. 1973) (automobile manufacturers), *modified*, 510 F.2d 939 (6th Cir. 1975); *United States v. Lee Way Motor Freight, Inc.*, No. CIV-72-445, 1973 WL 278 (W.D. Okla. Dec. 27, 1973) (truckers).

179 This scenario is more akin to a Title VII disparate treatment claim, in which the employer designs a facially neutral policy as a pretext for discrimination, than a claim for disparate impact, which requires no intent. See *McDonnell Douglas Corp. v. Green*, 411 U.S. 792, 802 (1973).

180 See Sturm, *supra* note 127, at 4719–20 (describing “functional equality of treatment”).

181 See *supra* note 49 and accompanying text; see also Klitzman, *supra* note 18, at 73 (“If the partners knew about this, it might unconsciously affect them: should we make

nation, may not be able to address the cumulative effect of a number of small but discriminatory choices, many of which could be occurring on an unconscious level.<sup>182</sup>

Although an antisubordination approach has clear benefits, it may seem counterintuitive to apply this framework absent a widely recognized, lived social category. First, without an existing status hierarchy, it will be impossible to predict exactly how a genetic underclass might form or operate. However, as noted, we know enough about the formation of stigma and the process of subjugation through experiences with other categories to approximate—albeit not with perfect accuracy—how a genetic underclass might develop.<sup>183</sup> Secondly, there is the concern that merely thinking in terms of antisubordination itself is a step toward creating a genetic underclass.<sup>184</sup> However, when drafting GINA, Congress was legislating in the shadow of eugenics. The fear of a genetically deterministic society is already deep in the social imagination, so much so that it currently leads people to avoid potentially beneficial genetic testing. Because eliminating the fear of a genetically deterministic society includes eradicating anxieties regarding a potential genetic underclass, antisubordination provides a suitable paradigm.

To sum up, including some antisubordination protections is essential to GINA's success as a statute. The fear of a genetically deterministic society is very much a concern—not just about control over our lives—but about possible subordination. Importantly, sharing genetic information can sometimes prevent disadvantage, as in the contexts of accommodation and diversity. Because we are genetically different, it makes sense to acknowledge and adjust for those differences. In prohibiting all classifications based on genetic information, anticlassification does too much. Antisubordination is more in line with the fears surrounding GINA's passage and is thus better tailored to alleviate them.

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this guy partner? They wouldn't say it. They would just think it to themselves, 'I'm gonna vote no,' and raise their hand when the 'no' vote comes along.”).

182 See Linda Hamilton Krieger, *The Content of Our Categories: A Cognitive Bias Approach to Discrimination and Equal Employment Opportunity*, 47 STAN. L. REV. 1161, 1164 (1995) (arguing that Title VII combats intentional discrimination, but not subtle, unconscious biases).

183 See *supra* note 166 and accompanying text.

184 Theorists have proposed that discourse is generative and the very process of classification creates and reifies difference. See MICHEL FOUCAULT, *THE ORDER OF THINGS* (1966); see also JUDITH BUTLER, *GENDER TROUBLE* 180–90 (1999). Thus, merely acknowledging the possibility of a genetic underclass could lead to genetic subordination.

Congress could add antistubordination protections to GINA by amending the statute to be more like traditional antidiscrimination statutes. This Article proposes three possibilities: one modeled on Title VII, one modeled on the ADA, and a hybrid of the two.

### 1. Title VII as a Paradigm

Congress could take an approach to protecting genetic information more like that of Title VII. Title VII includes both anticlassification and antistubordination protections. Although courts have applied the statute absent a history of subordination,<sup>185</sup> the statute allows claimants to challenge facially neutral policies that generate discriminatory outcomes via disparate impact actions.<sup>186</sup> Thus, Congress could amend GINA to include disparate impact claims while preserving its anticlassification provisions. While this approach would eliminate the previously described problems that result from failing to cover facially neutral policies, it would not allow accommodations based on genetic information.

GINA's disparate impact framework could parallel Title VII's process. Under Title VII, after a plaintiff establishes a *prima facie* case by demonstrating that a particular facially neutral policy creates a discriminatory outcome, the defendant has the opportunity to prove that the contested practice serves a business necessity.<sup>187</sup> If the defendant is successful, the plaintiff can then demonstrate an alternative means to accomplish the desired business objective, but with a less discriminatory result.<sup>188</sup> Thus, allowing genetic-information disparate impact claims would not bar employers from using measures of intelligence and aptitude, even if those qualities have a genetic basis, because those factors involve a business necessity: the need to hire qualified workers. Moreover, genetic-information disparate impact claims could extend GINA's coverage to manifested genetic health conditions because employment practices that disproportionately impact individuals with those conditions would also have a disparate impact on the basis of the underlying genes.

Genetic-information disparate impact claims are a real possibility. Although Congress banned them when drafting GINA, it indicated a willingness to consider the need for those actions by establishing a

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185 See, e.g., *McDonald v. Santa Fe Trail Transp. Co.*, 427 U.S. 273, 283 (1976) (applying Title VII to all races); *Yeary v. Goodwill Indus.-Knoxville, Inc.*, 107 F.3d 443, 446 (6th Cir. 1997) (applying Title VII to a man).

186 See *supra* note 145 and accompanying text.

187 See *Griggs v. Duke Power Co.*, 401 U.S. 424, 431 (1971).

188 See 42 U.S.C. § 2000e-2(k)(1)(A)(ii), 2(k)(1)(C) (2006).

commission to revisit this issue six years from the statute's enactment.<sup>189</sup> However, a Title VII-based approach would not allow the positive differential consideration of genetic information. Thus, it has its limitations.

## 2. ADA as a Paradigm

Alternatively, Congress could make GINA more like the ADA.<sup>190</sup> The ADA is, by and large, an antisubordination statute. It seeks to elevate the status of a particular historically disadvantaged group:<sup>191</sup> people with disabilities. The ADA's employment provisions prevent employers from discriminating "against a qualified individual on the basis of disability."<sup>192</sup> A "qualified individual" can perform the essential functions of a job either with or without accommodation.<sup>193</sup> However, if an individual with a disability poses a "direct threat" either to herself or others, the ADA does not apply.<sup>194</sup> The ADA only covers people with disabilities (either past or present),<sup>195</sup> or people regarded as having a disability.<sup>196</sup> People without disabilities, who are not regarded as having a disability, have no cause of action under the stat-

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189 See *supra* note 149 and accompanying text. Importantly, simply adding disparate impact actions as proposed by Congress would only affect GINA's employment provisions, as there are no disparate impact claims for discrimination in health insurance.

190 Mark Rothstein also endorses an approach to genetic-information discrimination based on the protection of disability. See Rothstein, *supra* note 100, at 459–60. Rothstein, however, uses the Individuals with Disabilities Education Act, not the ADA as his model. See *id.* He argues that adopting a difference-oriented approach could provide better protection for genetic information than "genome-blind" policies that attempt to mask the relevance of genetic difference. See *id.* at 462–63.

191 See 42 U.S.C. § 12101(a)(2) (Supp. II 2008) (finding that "historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem"); *id.* § 12101(a)(6) (finding that "people with disabilities, as a group, occupy an inferior status in our society, and are severely disadvantaged socially, vocationally, economically, and educationally").

192 *Id.* § 12112(a).

193 *Id.* § 12111(8).

194 See *id.* § 12113(b) ("The term 'qualification standards' may include a requirement that an individual shall not pose a direct threat to the health or safety of other individuals in the workplace."); see also *Chevron U.S.A., Inc. v. Echazabal*, 536 U.S. 73, 86–87 (2002) (extending the direct threat defense to the individual with the disability).

195 See 42 U.S.C. § 12102(1)(B) (including the record of a disabling impairment in the definition of disability).

196 See *id.* § 12102(1)(C) (including being "regarded as" having a disabling impairment in the definition of disability).

ute. The ADA also allows positive differential treatment for accommodation purposes,<sup>197</sup> as well as claims for facially neutral policies with discriminatory results.<sup>198</sup> Thus, an ADA-based approach would (1) provide asymmetrical coverage for members of a potential genetic underclass, (2) permit positive differential treatment, and (3) allow challenges to facially neutral policies that produce discriminatory results. That said, this approach also has substantial weaknesses.

If Congress limited GINA's protections to members of a potential genetic underclass, the statute would only apply when a qualified individual faced the possibility of systematic disadvantage on the basis of her genetic information, regardless of intent. Restricting coverage to "qualified individuals" would bypass cases outside of GINA's intended scope, such as suits against the National Basketball Association<sup>199</sup> for genetic discrimination on the basis of genes linked to height. Much like how courts determine whether a person has a disability as defined by the ADA, they could consider whether GINA claimants are members of a potential genetic underclass. GINA would therefore focus exclusively on adverse actions—intended or unintended—against qualified individuals that could lead to group disadvantage. Additionally, Congress could build in a direct threat defense that would allow employers to escape liability if a person's particular genetic profile would put her or her coworkers at a substantial risk.

Confining GINA's coverage to members of a potential genetic underclass could also include individuals with manifested genetic conditions. For example, researchers have linked an increased risk for developing lung cancer to a particular genetic variation.<sup>200</sup> However, several other factors—most significantly smoking—also contribute to the probability of developing lung cancer.<sup>201</sup> As a result, discriminat-

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197 Early on in the ADA's history, the EEOC noted that "[o]nly persons who actually have a substantially limiting impairment are entitled to reasonable accommodation under the ADA. . . . Persons who are regarded as having a substantially limiting impairment are not entitled to reasonable accommodation." EQUAL EMP'T OPPORTUNITY COMM'N, ADA CASE STUDY TRAINING MANUAL, CASE STUDY 1, at 6 (1996).

198 See 42 U.S.C. § 12112(b)(3)(A) (prohibiting practices "that have the effect of discrimination on the basis of disability").

199 For an in-depth analysis of GINA's potential impact on sports employers, see Evans, *supra* note 6.

200 See Denise Gellene, *Genetic Link to Cancer Found*, L.A. TIMES, April 3, 2008, at A12.

201 The study shows that smokers generally have a fifteen percent chance of developing lung cancer. See *id.* While smokers with one copy of the variation have roughly the same probability of cancer as smokers without the variation, smokers with two copies of the genetic variation have an increased risk: they have a twenty-five percent chance of developing cancer. *Id.*

ing against people with lung cancer might not lead to a genetic underclass because those other factors are in play—a person with lung cancer could still, of course, recover under the ADA. Conversely, discriminating on the basis of Huntington's disease could lead a genetic underclass to form because all individuals who carry the particular genetic variant develop the disease. While it need not be as exact as in Huntington's, the correlation between an underlying gene and an associated health condition could inform whether discriminating on the basis of the manifested genetic disorder might lead to a genetic underclass. Furthermore, in those cases in which a potential claimant could sue under both GINA and the ADA simultaneously for the same violation, Congress could cap the overall damages.

In addition to asymmetrical protection, an ADA-based approach would allow positive differential treatment on the basis of genetic information. For example, people could offer their genetic information to receive reasonable accommodations at work. Covered entities could, therefore, only use genetic information insofar as it would benefit the individual offering it.

Although amending GINA to resemble the ADA has its benefits, there are also serious disadvantages. For instance, an ADA-based approach leaves the scope of GINA's protection to the courts, which could interpret it very restrictively, as they initially did with the ADA. Moreover, limiting coverage to members of a potential genetic underclass invites individualized discrimination. To escape liability, an employer only needs to demonstrate that its discriminatory action would not lead to *systematic* genetic disadvantage. This defense would create a hole in GINA's coverage akin to "personal animus" in Title VII cases.<sup>202</sup>

### 3. Best Case Scenario

The best strategy for protecting genetic information combines the ADA-based and Title VII-based approaches with GINA's current structure.<sup>203</sup> To assure people that their genetic information will not lead to discrimination, GINA must alleviate fears both of social genetic determinism and of violations of genetic privacy. GINA's cur-

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202 Title VII does not bar discrimination based on personal animus. *See* St. Mary's Honor Ctr. v. Hicks, 509 U.S. 502, 510–11 (1993). Thus, an employer can escape liability by proving that the adverse action was the result of personal animus, not discrimination.

203 Combining different kinds of statutory protections can inform how the Supreme Court interprets a law. *See, e.g.,* McKennon v. Nashville Banner Publ. Co., 513 U.S. 352, 357 (1995) (holding that courts have treated the ADEA as a hybrid of Title VII and the Fair Labor Standards Act of 1938).

rent protections are well equipped to address the latter: prohibiting the requiring and requesting of genetic information ensures that most genetic information will stay private.<sup>204</sup> However, from an antidiscrimination perspective, GINA is presently too much of an anticlassification statute. Outlawing any consideration of genetic information and failing to cover manifested genetically based conditions may actually lead to systematic genetic disadvantage. Adding antisubordination protections to GINA would allow the statute to better address concerns of social genetic determinism. Although the ADA and Title VII both provide useful templates, neither statute on its own presents a workable framework. The ideal means of protecting genetic information would borrow antisubordination elements from both the ADA and Title VII, while maintaining GINA's ban on requesting or requiring genetic information.

Like the ADA, ideally GINA would allow positive differential treatment for the purposes of accommodation, as well as genetic diversity initiatives. Offering that information would be completely voluntary: people could disclose their genetic information only when it would benefit them. Allowing employers<sup>205</sup> to consider genetic information under limited circumstances would allow individuals to reap the benefits of genetic testing without the fear of discrimination, as well as help cultivate a respect for genetic diversity.

However, simply adopting an ADA approach would not provide the best protection for genetic information. In particular, providing asymmetrical coverage would likely leave the question of whom GINA protects to the courts, creating many of the same difficulties encountered with the ADA. Thus, the ideal protection for genetic information would incorporate some, but not all, aspects of the ADA.

Additionally, the best protection for genetic information would cover facially neutral policies that produce a discriminatory result. Allowing genetic-information disparate impact claims would ensure that employers could only implement policies that negatively impact people with certain genetic traits when those policies are a business necessity. Thus, beyond targeting unintentional genetic-information discrimination, disparate impact claims would prevent employers from using facially neutral policies to screen out unfavorable traits.

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204 Kim, *supra* note 6, at 703 (“[S]imply prohibiting discrimination alone is unlikely to be effective in preventing discrimination on the basis of genetic characteristics.”).

205 Arguments could be made in favor of allowing positive differential treatment in health insurance as well. For example, health insurers could tailor coverage based on health needs (not potential cost). However, that proposal would also involve fundamental changes to the PPACA and is therefore outside the scope of this Article.

Moreover, disparate impact claims would also cover people with manifested genetic conditions, offering dual protection when those conditions also qualify as a disability. However, GINA's disparate impact provision applies only to employment discrimination. Thus, Congress could experiment with ways to protect manifested genetic conditions and prevent unintentional or facially neutral genetic-information discrimination in the insurance context until health care reform takes full effect.

Importantly, GINA should retain some of its anticlassification protections. Keeping the prohibition on requesting or requiring genetic information preserves people's genetic privacy and gives them control over when to disclose their genetic information. Preventing health insurers and employers from asking for genetic information but simultaneously allowing a person to choose when she wishes to disclose that information gives an individual complete authority over her genetic identity.

In sum, the ideal protection of genetic information would allow positive differential treatment for accommodation and diversity initiatives and claims for disparate impact—all while leaving prohibitions on requesting or requiring genetic information intact. GINA should, therefore, combine antistatutory elements with its existing anticlassification structure to offer the best protection for genetic information possible.

#### CONCLUSION

Although genetic information is undeniably a new kind of antidiscrimination category, traditional antidiscrimination theory provides the proper analytical framework for understanding its protections. While Congress took a predominantly anticlassification approach, incorporating antistatutory elements would greatly improve GINA by better addressing the underlying concerns surrounding protecting genetic information in the first place. However, an antistatutory approach has benefits beyond the scope of this Article.

We are entering a world in which parents can select their babies' eye colors<sup>206</sup> and companies offer genetic dating services.<sup>207</sup> While health insurance and employment are part of the picture, the potential problem of genetic-information discrimination extends far

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206 See Gautam Naik, *A Baby, Please. Blond, Freckles—Hold the Colic*, WALL ST. J., Feb. 12, 2009, at A10.

207 See, e.g., GENE PARTNER, <http://www.genepartner.com> (last visited Apr. 21, 2011) (offering matchmaking based on a DNA analysis).

beyond those areas. Schools, banks, government entities, and even restaurants and movie theaters could still discriminate on the basis of genetic information. Anticlassification as a paradigm can be applied very narrowly. It prohibits certain entities from using certain traits in making certain decisions. Conversely, by making the prevention of a genetic underclass its purpose, antismobbing implicates a greater social project. An antismobbing framework compels us to consider how genetic information might lead to systematic social disadvantage and to react accordingly. Put simply, antismobbing tells us where GINA falls short. Thus, in addition to improving GINA's current protections, an antismobbing paradigm advocates expanding GINA past the current bounds of the statute to alleviate concerns of genetic-information discrimination beyond health insurance and employment.