University of Houston

From the SelectedWorks of Jessica L. Roberts

July 31, 2013

Privacy as a Tool for Antidiscrimination

Jessica Roberts

Available at: https://works.bepress.com/jessica_roberts/2/
Privacy as a Tool for Antidiscrimination

Jessica L. Roberts

ABSTRACT

Traditionally, laws that protect privacy and laws that prohibit discrimination have been considered distinct kinds of legal protections. This Essay challenges that binary on both practical and theoretical grounds. Using the Genetic Information Nondiscrimination Act (GINA) as a case study, it argues that lawmakers can use privacy law to further antidiscrimination goals. GINA, which prohibits genetic-information discrimination in health insurance and employment, does more than simply outlaw discriminatory conduct. It also prohibits employers from requiring—or even requesting—their employees’ genetic information. While GINA’s privacy and antidiscrimination protections have previously been viewed as discrete, this Essay reads them in concert, arguing that restricting access to information about protected status can thwart future discrimination by denying potential discriminators the very information they would use to discriminate. Informed by this perspective, the Essay explores the advantages and disadvantages of using privacy law as a tool for antidiscrimination, in the context of genetic information and beyond. Finally, the Essay concludes that the weaknesses endemic to privacy law might be addressed by adopting an explicit antidiscrimination purpose. Thus, just as advocates of antidiscrimination may look to privacy law, advocates of privacy protections can look to antidiscrimination.

* Assistant Professor of Law, University of Houston Law Center. Thank you to Aaron Bruhl, Brad Areheart, Jessica Clarke, Dave Fagundes, and Mark Rothstein for reading and commenting on drafts. I presented early versions of this Essay during the 3rd Annual National Conference on Genetics, Ethics, & the Law at the University of Virginia Law School and the 2013 ASU Legal Scholars Conference, so my gratitude likewise goes to the participants of those workshops. Many thanks to Chelsea Averill and Zachary White for research assistance and Emily Lawson for library help.
# Table of Contents

**Introduction** .................................................................................................................. 1

I. PRIVACY & ANTIDISCRIMINATION: THE FALSE BINARY ........................................... 5
   A. Introduction to the Binary ......................................................................................... 5
   B. GINA: An Exception to the Binary ........................................................................... 12
   C. Challenging the Binary ........................................................................................... 15

II. THE PRIVACY & ANTIDISCRIMINATION SYMBIOSIS .............................................. 17
   A. Basic Concepts ........................................................................................................ 17
   B. Pandora’s Box ........................................................................................................ 22
   C. Pandora’s Box and GINA ....................................................................................... 25

III. IMPLICATIONS OF PRIVACY AS AN ANTIDISCRIMINATION TOOL .................. 29
   A. Privacy’s Advantages .............................................................................................. 30
   B. Privacy’s Disadvantages ......................................................................................... 34
   C. Antidiscrimination as a Solution ............................................................................ 40

CONCLUSION ....................................................................................................................... 42
INTRODUCTION

Privacy laws seek to prevent unauthorized access to protected information either by restricting the circumstances of valid disclosures or by prohibiting inquiries by certain kinds of third parties.\(^1\) The underlying norm behind these protections is autonomy: the ability to make personal decisions about one's self and well being free from the intrusions of others.\(^2\) By contrast, antidiscrimination laws attempt to stop disadvantage on the basis of protected status by prohibiting the covered decision-makers from considering that status when making certain types of determinations.\(^3\) The norms driving antidiscrimination legislation are thus equality and fairness.\(^4\) Because of the differences in the underlying norms, legislative purposes, and structures of these protections, statutes designed to protect privacy and statutes designed to stop discrimination have traditionally been considered separate and distinct varieties of law.

This Essay challenges the privacy/antidiscrimination binary, arguing that privacy law can do the work of antidiscrimination. Specifically, privacy protections can prevent access to the very information that discriminators may use to discriminate. Thus, legal protections that at first blush appear geared to further the purpose and norms more readily associated with privacy can likewise further those associated with antidiscrimination. I call this theory the “Pandora’s box approach.” To treat someone differently on the basis of a protected status, one must have some knowledge of that status. For example, to discriminate on the basis of race, an employer must first recognize the presence of racial difference amongst its employees. Now imagine a world in which an employer is limited in her ability to acquire information from a racially ambiguous employee about that

---

\(^1\) *Infra* Part I(A)(1) (explaining the legislative purpose and structure of legal protections associated with privacy law).

\(^2\) *Id.* (identifying autonomy as the underlying norm at stake within privacy law).

\(^3\) *Infra* Part I(A)(2) explaining the legislative purpose and structure of legal protections associated with antidiscrimination law).

\(^4\) *Id.* (identifying equality and fairness as the underlying norms at stake within antidiscrimination law).
employee’s racial identity. It will be markedly more challenging for the employer to base decisions on the employee’s race because she has less information. The same holds true for other antidiscrimination categories such as ethnicity, national origin, religion, age, or disability. Restricting potential discriminators’ access to information dealing with protected status reduces the chances of subsequent discrimination. Thus, in addition to supporting traditional bans on adverse differential conduct, antidiscrimination advocates could also endorse privacy protections that are crafted to limit access to information relevant to protected status. Privacy, therefore, constitutes a new and exciting means to combat discrimination.

In arguing that privacy law can further antidiscrimination goals, this Essay employs the Genetic Information Nondiscrimination Act (GINA) as a case study. When Congress passed GINA in 2008, many agreed that it was not a typical antidiscrimination statute. The law prohibits health insurers and employers from making decisions based on genetic information. Title II, the employment provision, draws strongly from Title VII of the Civil Rights Act. Prohibited conduct includes adverse employment actions such as failing to hire, firing, or otherwise discriminating in compensation or other privileges of employment, as well as segregating or classifying employees, based on their genetic information. What distinguishes GINA, however, is that it goes beyond the traditional employment discrimination protections, preventing employers from requesting, requiring, or purchasing the genetic information of employees and their families. Thus, GINA stops employers from merely attempting to obtain genetic information, even if they take no further action. This additional level of protection has led commentators to refer to GINA as an

---


7 See Roberts, supra note 5, at 452-53 (comparing Title II of GINA and Title VII of the Civil Rights Act).

8 GINA § 202(a).

9 Id. § 202(b); Corbett, supra note 5, at 3 (noting that “[m]ost of GINA’s ancestors are employment discrimination laws that say little about privacy”).
antidiscrimination-privacy hybrid.\footnote{See Corbett, \textit{supra} note 5, at 3 (calling GINA “a hybrid—part antidiscrimination statute and part privacy law”).}

Yet an alternate reading of GINA’s privacy protections holds that violations of genetic privacy can be understood in antidiscrimination terms. Conceptually, the norms of privacy and antidiscrimination are inextricably related as both deal with restrictions on certain kinds of information.\footnote{See discussion, \textit{infra} Part II(A).} Privacy protections may act as a bulwark, precluding potential discriminators from accessing the very information they could use to discriminate. Viewed from this vantage, GINA’s privacy provision is not distinct from its antidiscrimination protections but rather a key aspect of them. Hence, this Essay argues that the statute’s privacy provision is not separate from—but rather constitutive of—GINA’s antidiscrimination mandate. This observation not only illuminates Congress’s intent in passing GINA but also provides champions of civil rights with a real-world example of how privacy protections have the power to stop discrimination, in the case of genetic information and beyond.

The complex yet complementary relationship between privacy and antidiscrimination has important implications for the legal protections of the future. With the unceasing progress of genetic science, the legal and ethical questions surrounding how to best protect genetic information are only beginning to unfold.\footnote{Next-generation sequencing refers to a new scientific approach that allows more rapid, more comprehensive DNA sequencing. This technology has transformed genetic science and simultaneously generated serious legal and ethical concerns. \textit{See, e.g.}, President’s Commission for the Study of Bioethics, Privacy and Progress in Whole Genome Sequencing (Oct. 2012). The first baby screened using next-gen technology was born in the UK in July 2013. Ben Hirschler, \textit{First Test-Tube Baby Born After New, Cheaper Genome Screening}, Reuters.com, July 7, 2013, available at http://www.reuters.com/article/2013/07/07/us-science-fertility-screening-idUSBRE9660LI20130707.} Striking the proper balance between privacy and antidiscrimination is essential both to protecting us from the misuse of our genomes and to ensuring access to care and accommodations that will further our health. Moreover, the notion that privacy protections can do the work of antidiscrimination has purchase outside the realm of genetic information. As with the hypothetical of the racially ambiguous employee, privacy protections may help stop discrimination whenever the nature of the protected status is not completely known to the
potential discriminator.

Privacy offers some definitive benefits as a mechanism for undermining discrimination. Whereas claims of discrimination may at times require claimants to prove discriminatory motive, privacy law requires only a showing that the covered entity inappropriately obtained, or attempted to obtain, the protected information. Protecting privacy is also advantageous because it operates at an earlier stage in the process of discrimination. Whereas traditional antidiscrimination law prohibits discriminatory actions by outlawing certain types of conduct, privacy law renders the offensive conduct practically impossible by impeding access to the information necessary for the unfavorable differentiation.

Despite its clear advantages, privacy law also presents certain drawbacks as a vehicle for stopping discriminators. First, strong privacy protections or norms could impede useful disclosures. For example, an employer might want to acquire the genetic information of an employee for accommodation purposes but be unable to do so based on GINA’s outright ban on requests. Likewise, if the popular perception of genetic information holds that it is “private,” individuals may choose to stay in the genetic closet, as opposed to sharing their status with others to raise consciousness or build social solidarity. Beyond the silencing of potentially beneficial disclosures, privacy law faces other practical impediments as an antidiscrimination instrument. In particular, because invasions of privacy are often dignitary in nature there exists a general disdain for providing relief for those violations—absent some other kind of associated harm—thereby impeding enthusiasm for this approach at the legislative and judicial levels. Yet in these instances, antidiscrimination can assist privacy.

To start, antidiscrimination supports certain kinds of positive disclosures. Thus, a strong antidiscrimination purpose affiliated with a privacy protection could encourage desirable disclosures, such as in the cases of accommodation or consciousness raising. Moreover, recognizing that privacy law can do the work of antidiscrimination by preempting future wrongdoing could make lawmakers more amenable to safeguarding sensitive information. Consequently, judges and legislators may be more likely to draft and enforce a privacy protection when it is tethered to an antidiscrimination initiative, as in the case of GINA. Antidiscrimination could thus further privacy by creating incentives to share protected information when it could have a beneficial impact and by providing an additional justification for legal intervention.
This Essay proceeds in three parts. Part I describes the false binary between privacy law and antidiscrimination law. It then uses GINA as a case study to illustrate how a single statute fuses both kinds of protections. Part II outlines the conceptual relationship between privacy and antidiscrimination, exploring how the normative foundations of both operate symbiotically. It then introduces the Pandora’s box approach, demonstrating how privacy protections can serve antidiscrimination ends. Again turning to GINA as a case study, I propose that in addition to offering independent protection for violations of genetic privacy, Congress was also adopting the Pandora’s box approach, thus indicating legislative support for the proposition that privacy law can combat discrimination. Part III examines the advantages and disadvantages of using privacy to prevent discrimination, concluding that the symbiosis between privacy and antidiscrimination could work both ways, thereby leading to more comprehensive overall protection. The normative and legal symbioses of antidiscrimination and privacy, therefore, represent an innovative and, previously unacknowledged, means to preserve and maintain civil rights.

I. PRIVACY & ANTIDISCRIMINATION: THE FALSE BINARY

Historically, privacy law and antidiscrimination law have been thought of as distinct kinds of legal protections: one meant to protect sensitive information and another meant to prevent disadvantage on the basis of protected status. The Genetic Information Nondiscrimination Act (GINA), however, breaks down this dichotomy. Among its defining qualities was the law’s prohibition on attempts to acquire genetic information, even if the employer never acts on the information it seeks. This Part establishes the privacy/antidiscrimination binary and invokes GINA as a practical example of the blending of these two substantive legal paradigms within a single antidiscrimination law.

A. Introduction to the Binary

To understand the privacy/antidiscrimination binary, one must first be familiar with three concepts related to lawmaking: (1) underlying norms, (2) legislative purpose, and (3) type of legal protection. Because privacy law and antidiscrimination are typically understood to differ across all of these metrics, they are traditionally regarded as separate and distinct types of law.
1. Privacy

Let us begin with privacy. Philosopher Sissela Bok defines privacy as “the condition of being protected from unwanted access from others.” The norm underlying privacy is autonomy. Autonomy holds that a person should have the freedom and the capacity to make decisions that impact her life, unconstrained by the preferences or idiosyncrasies of others. Autonomy drives privacy by giving an individual control over how much access outside parties may have to the intimate details of her life. Hence, when the law intervenes to protect privacy, the purpose of the legislation is to prevent unauthorized access to the protected information. Privacy statutes, therefore, restrict the circumstances under which third parties may disclose or seek private information. The legal protections associated with privacy law can thereby be further subdivided into two kinds of protections: (1) source-based and (2) recipient-based.

The Privacy Act of 1974, which applies to federal agencies, governs the proper collection, maintenance, usage, and disclosure of records containing personally identifiable information. The relevant sub-section provides:

No agency shall disclose any record which is contained in a system of records by any means of communication to any person, or to another agency, except pursuant to a written request by, or with the prior written consent of, the individual to whom the record pertains . . . .

The Privacy Act thereby represents a source-based privacy protection by restricting the ability of the information-holder, in this case federal agencies, to share or disseminate the protected information.

Conversely, the Employer Use of Social Media, a California state law that went into effect on January 1 of this year, governs an

---

14 OXFORD ENGLISH DICTIONARY (2d ed. 1989) (defining “autonomy” as “liberty to follow one’s will, personal freedom”); “see also BLACK’S LAW DICTIONARY (9th ed. 2009) (defining “autonomy” as “[a]n individual’s capacity for self-determination”).
15 See L. Camille Hébert, 1 EMPL. PRIVACY LAW § 1:4 (updated June 2013) (“The right to privacy is about autonomy—allowing individuals to make their own choices about fundamental aspects of their lives.”).
17 Id. § 552a(b).
18 CAL. LAB. CODE § 980 (Cal. 2012).
employer’s ability to obtain information related to its employees’ activities on social media. The law states:

An employer shall not require or request an employee or applicant for employment to do any of the following:

(1) Disclose a username or password for the purpose of accessing personal social media.
(2) Access personal social media in the presence of the employer.
(3) Divulge any personal social media, except as provided in subdivision (c).

As of summer 2013, eleven states have passed legislation restricting an employer’s ability to access its employees’ social media accounts. These laws are recipient-based because they prohibit certain kinds of third parties who wish to receive the protected information from attempting to acquire it.

Privacy laws not only forbid violations of privacy either by information-holders or potential recipients but also frequently outline the appropriate conditions or processes for information sharing, such as confidentiality policies and disclosure agreements. For instance, the Privacy Act forbids disclosure of the protected information absent the written consent of the subject, unless the disclosure falls within the statute’s twelve enumerated exceptions. Likewise, the Employer Use of Social Media allows an employer to seek information related to an employee’s personal social media when that information pertains to misconduct. Privacy laws can thus be understood to contain both negative and positive constraints on conduct.

---

19 Id. § 980(b).


22 CAL. LAB. CODE § 980(c) (“(c) Nothing in this section shall affect an employer’s existing rights and obligations to request an employee to divulge personal social media reasonably believed to be relevant to an investigation of allegations of employee misconduct or employee violation of applicable laws and regulations, provided that the social media is used solely for purposes of that investigation or a related proceeding.”).
2. Antidiscrimination

Now let us proceed to antidiscrimination. On a basic level, to discriminate simply means to differentiate.\footnote{\textit{See} ROBERT K. FULLINWIDER, THE REVERSE DISCRIMINATION CONTROVERSY: A MORAL AND LEGAL ANALYSIS 11 (1980) (stating that the dictionary meaning of “discrimination” is “morally neutral”).} Yet, when given a normative overlay, discrimination refers to socially undesirable differentiation.\footnote{\textit{Id.} (explaining the political meaning of “discrimination” is “non-neutral, pejorative” and that simply calling a practice “discriminatory” may be sufficient for some people “to judge it wrong”).} Deeming conduct discriminatory in the pejorative sense turns on whether the conduct in question leads to systematic disadvantage on the basis of the relevant characteristic. Because discrimination, defined in this sense, is by its very nature unfair and produces social disparity, the governing norms for antidiscrimination are equality and fairness. The purpose of antidiscrimination legislation is, therefore, to prevent differential treatment on the basis of the protected status to combat the resulting disadvantage. Thus, antidiscrimination statutes restrict the information a covered entity may employ when making certain kinds of decisions.

Title VII of the Civil Rights Act is an example of typical antidiscrimination provision. It reads:

\begin{quote}
It shall be an unlawful employment practice for an employer—

(1) to fail or refuse to hire or to discharge any individual, or otherwise discriminate against any individual with respect to his compensation, terms, conditions, or privileges of employment, because of such individual’s race, color, religion, sex, or national origin; or

(2) to limit, segregate, or classify his employees or applicants for employment in any way which would deprive or tend to deprive any individual of employment opportunities or otherwise adversely affect his status as an employee, because of such individual’s race, color, religion, sex, or national origin.\footnote{Civil Rights Act of 1964, Title VII, § 703(a).}
\end{quote}

The law forbids the covered entity (employers) from considering the designated protected statuses (race, color, religion, sex, or national origin) when making certain kinds of specific determinations.
Antidiscrimination statutes, unlike most privacy protections, impose only negative restraints.\footnote{See Jessica L. Roberts, The Genetic Information Nondiscrimination Act as an Antidiscrimination Law, 86 Notre Dame L. Rev. 597, 619 (2011). (noting “[u]nlike privacy, antidiscrimination protections do not require positive conduct on the part of health insurers and employers, such as disclosure agreements”).}

Table 1. The Privacy/Antidiscrimination Binary.

<table>
<thead>
<tr>
<th>Underlying Norms</th>
<th>Legislative Purpose</th>
<th>Legal Protection</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Privacy</td>
<td>Autonomy</td>
<td>Prevent unauthorized third party access to protected information</td>
<td>Restrictions on valid access to protected information</td>
</tr>
<tr>
<td>Antidiscrimination</td>
<td>Equality Fairness</td>
<td>Prevent disadvantage on the basis of protected status</td>
<td>Restrictions on considerations of protected status</td>
</tr>
</tbody>
</table>

Here, the legal protection of genetic information offers a useful example of the tension inherent in the privacy/antidiscrimination dichotomy. The initial efforts to regulate genetic information were often split between efforts to protect privacy and efforts to prevent discrimination. For example, early state protections against genetic-information discrimination did not stop employers from obtaining that information, only from using it to discriminate.\footnote{Mark A. Rothstein, The Law of Medical & Genetic Privacy in the Workplace, in Genetic Secrets: Protecting Privacy & Confidentiality in the Genetic Era 292 (Mark A. Rothstein ed., 1997). But see Lawrence O. Gostin & James G. Hodge, Jr., Genetic Privacy and the Law: An End to Genetics Exceptionalism, 40 Jurimetrics J. 21, 21 (1999) (“Employment discrimination is also a focal point of state genetics legislation. Employers may be prevented from requiring genetic tests of job applicants or using genetic information for employment decisions” (citing 1999 statutes from New Jersey, Wisconsin, Texas, and Rhode Island)); Silvers & Stein, supra note 33, at 1359 (“Although current state laws lean heavily on precedents of privacy, antidiscrimination provisions have been sprinkled among them.”).} While state laws focused on antidiscrimination measures, the first federal bill dealing with genetic information was the Human Genome Privacy Act.
introduced in 1990.\textsuperscript{28} The legislation, which ultimately died in committee, would have outlawed the unauthorized disclosure of genetic information generated by federal agencies or federally funded entities, offering individuals remedies as well as providing criminal penalties for intentional violations.\textsuperscript{29} The next federal legislation designed to protect genetic information was the Genetic Privacy and Nondiscrimination Act of 1995, a failed bill introduced by Senator Mark Hatfield.\textsuperscript{30} That law sought to “protect against discrimination by an insurer or an employer based on an individual’s genetic information” by limiting the conditions under which genetic information may be lawfully disclosed and expanding the Civil Rights Act of 1964 to cover genetic-information discrimination.\textsuperscript{31} While the Human Genome Privacy Act and the Genetic Privacy and Nondiscrimination Act included privacy protections, the majority of bills proposed to combat genetic discrimination in the workplace simply outlawed the use of genetic information, not its acquisition.\textsuperscript{32}

Likewise, legal scholars have also differentiated between privacy and antidiscrimination as different reasons for protecting genetic information with different concomitant types of legal safeguards.\textsuperscript{33} As explained above, with regard to genetic privacy, the relevant concern was personal autonomy, specifically informational


\textsuperscript{29} Id.

\textsuperscript{30} See Reilly, \textit{supra} note 28, at 361.s

\textsuperscript{31} Id.

\textsuperscript{32} See Rothstein, \textit{supra} note 51, at 478 (“Most of the current proposals to prohibit genetic discrimination in employment merely prohibit employer use of genetic information.”).

\textsuperscript{33} Corbett, \textit{supra} note 5, at 9 (distinguishing between privacy law versus antidiscrimination law); see also Colin S. Diver & Jane Maslow Cohen, \textit{Genophobia: What is Wrong with Genetic Discrimination?}, 149 U. PA. L. REV. 1439, 1444 (2001) (identifying “two principal regulatory instruments to protect against feared abuses of genetic information: restrictions on disclosure and restrictions on use”); Gostin & Hodge, \textit{supra} note 27, at 48-51 (distinguishing between “information management” protections for genetic information designed to regulate disclosure and “harm avoidance” protections designed to outlaw discrimination); Anita Silvers & Michael Stein, \textit{An Equality Paradigm for Preventing Genetic Discrimination}, 55 VAND. L. REV. 1341 (2002) (asserting that “two lines of thought about the grounds for protection against genetic discrimination have been pursued” privacy and antidiscrimination).
control, whereas with respect to antidiscrimination the concern was fair and equal treatment. Given these distinct goals, legal protections for genetic information were widely understood by scholars and legislators alike as either protecting access to genetic information or preventing its misuse by third parties but not a combination of the two.34 By contrast, this Essay seeks to expose the broadly accepted

34 For instance, in a 1999 article, Lawrence Gostin and James Hodge differentiated between “information management” (privacy) and “harm avoidance” (antidiscrimination) as two distinct kinds of legal protections for genetic information. See generally Gostin & Hodge, supra note 27.

In 2002, Anita Silvers and Michael Stein noted that both the actual pre-GINA protections for genetic information and the scholarly discussions of the underlying right at stake were split between privacy and equality interests. Silvers & Stein, supra note 33, at 1344 (asserting that pre-GINA “statutes, orders, and guidelines have been designed either to protect against violations of individual’s privacy or to ensure their equal treatment in obtaining social goods, services, and opportunities by prohibiting discriminatory actions” and that “[e]thicists and legal scholars divide on whether these harms are properly conceptualized as ‘discrimination’ and whether privacy or equal opportunity is the main right we need to protect”).

Colin Diver and Jane Cohen put it simply in their 2001 piece, stating that privacy and antidiscrimination protections for genetic information are “analytically and morally distinct.” Diver & Cohen, supra note 33, at 1445; see also Kim, supra note 5, at 703 (distinguishing between “privacy right and antidiscrimination norms”).

Pauline Kim argued that antidiscrimination was not the appropriate legal vehicle to protect genetic information. Pauline Kim, Genetic Discrimination, Genetic Privacy: Rethinking Employee Protections for a Brave New Workplace, 96 NW. UNIV. L. REV. 1497, 1515-37 (2001-2002). Identifying personal autonomy—and not equality—as the relevant norm at stake, she advocated privacy as the best means for shielding employees from the misuse of their genetic profiles. Id. at 1537 (“If employer use of genetic information primarily threatens individual autonomy, then privacy law likely offers a better model for addressing that concern than the traditional antidiscrimination paradigm.”); see also Corbett, supra note 5, at 8-9 (“Before GINA became law, genetic information was viewed by many as a privacy issue, and it was argued that privacy law offered a more appropriate treatment than antidiscrimination law.”).

Although Kim acknowledged the conceptual relationship between privacy and antidiscrimination, she viewed their normative purposes and associated legal protections as separate and distinct, with privacy as the more desirable option. Conversely, Silvers and Stein argued in favor of antidiscrimination protection on the basis of genetic identity as an
privacy/antidiscrimination binary as false on both practical and theoretical levels.

B. GINA: An Exception to the Binary

GINA provides an excellent illustration of the practical breakdown of the split between privacy and antidiscrimination law. It is an example of a statute that simultaneously incorporates both kinds of protections in its attempt to thwart disadvantage.

Title II of GINA prevents employers, and other employment-related entities, from certain conduct pertaining to an individual’s genetic information. It defines “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.” Thus, Title II permits consideration of an individual’s manifested genetic conditions but outlaws the consideration of the manifested genetic conditions of her family members, i.e. family history.

1. GINA’s Privacy Provision

As noted, Title II contains a prohibition on the solicitation of genetic information by an employer. Section 202(b) states that an employer may not “request, require, or purchase genetic information with respect to an employee or a family member of the employee.” Although the subsection is entitled “Acquisition of Genetic Information,” an employer need not acquire—let alone act—on an employee’s genetic information to run afoul of the statute. The employer need only ask. Because of the broad definition of genetic information described above, GINA outlaws not only inquiring into an individual’s genetic test results but also asking about her family’s health history. Given the statute’s prohibition on acquisition, GINA’s alternative to the privacy paradigm. See generally Silvers & Stein, supra note 33.

35 GINA § 201(4)(A)(i)-(iii). While including the genetic information of fetuses and embryos, it excludes information related to sex or age from its definition of genetic information. Id. § 201(4)(C).

36 With respect to manifested genetic conditions, Title II clarifies that “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” by employers is acceptable under the statute. Id. § 210.

37 GINA § 202(b).
Section 202(b) follows the structure of a recipient-based privacy law. It forbids employers from attempting to receive the protected information.

Perhaps due to the potential breadth of privacy provision’s applicability, GINA builds in several exceptions. In particular, Title II shields employers who inadvertently request or require information related to family history.\(^{38}\) It also protects employers from liability for the incidental acquisition of genetic information in some situations. Imagine a distraught employee tells her supervisor that the employee’s mother has just been diagnosed with breast cancer. Under GINA, the employer has just obtained that employee’s genetic information. This variety of unintended genetic disclosure was dubbed the “water cooler problem”: Employers may inadvertently acquire genetic information through casual workplace conversation. GINA therefore contains an exception to protect them from liability.\(^{39}\) Title II also includes a provision that shields employers who unintentionally obtain genetic information through commercially available documents, for instance buying a newspaper that contains the obituary of an employee’s family member.\(^{40}\) Additionally, GINA allows employers to knowingly obtain the genetic information of their employees under certain limited circumstances, such as to administer wellness programs, to comply with medical leave laws, and to monitor the effects of toxic substances.\(^{41}\)

Outside of Section 202, GINA also protects the genetic privacy of employees, albeit from a source-based perspective. Section 206 provides that lawfully obtained genetic information must be treated as part of an employee’s confidential medical record, but should be recorded on separate forms and kept in separate files.\(^{42}\) The provision also outlines which disclosures are proper, including to the employee herself, to authorized health researchers, and when done in response to official requests such as court orders or to otherwise comply with the law.\(^{43}\)

\(^{38}\) Id.
\(^{39}\) Id. § 202(b)(1).
\(^{40}\) Id. § 202(b)(4).
\(^{41}\) Id. §§ 202(b)(2), 202(b)(3), 202(b)(5).
\(^{42}\) Id. § 206(a). GINA adopts the same standards for employee medical privacy as adopted by the ADA. Id.
\(^{43}\) Id. § 206(b).
2. GINA’s Antidiscrimination Provision

Unlike the novel privacy provision, GINA’s prohibition on employment discrimination tracks the language found in other federal antidiscrimination statutes. Section 202(a) deems it unlawful for an employer

(1) to fail or refuse to hire, or to discharge, any employee, or otherwise discriminate against any employee with respect to 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.44

Hence, Title II prohibits both adverse employment actions and differentiation on the basis of genetic information that would adversely affect the status of an employee. GINA thus draws heavily from the antidiscrimination mandate found in Title VII.45 Section 202(a) therefore represents a typical antidiscrimination protection, a provision that puts negative restraints on a covered entity’s ability to consider the protected status when making particular decisions.46

44 Id. § 202(a).
45 See Kim, supra note 5, at 697 (“[A]t first glance, [GINA] seems like a typical antidiscrimination law. It adds a new category of forbidden discrimination, and its employment provisions are modeled on Title VII of the Civil Rights Act.”). Moreover, like Title VII, GINA requires potential claimants to pursue administrative relief through the EEOC, or relevant state agency, before filing suit. See GINA § 207. However, unlike Title VII, GINA does not permit actions for disparate impact: challenges to facially neutral policies that adversely affect a protected group to a disproportionate degree. Id. § 208.
46 See Roberts, supra note 26, at 619 (explaining that “[a]s an antidiscrimination statute, GINA creates negative restraints on the information that covered entities can consider when making certain relevant decisions”); see also Diver & Cohen, supra note 33, at 1445 (“Use restrictions . . . focus on the uses to which genetic information may be put. By far the most common form of use restriction is a prohibition on so-called ‘genetic discrimination.’”).
Finally, Section 202(c) includes a stopgap provision, which links the previous two subsections.\textsuperscript{47} When an employer lawfully obtains genetic information through one of Section 202(b)’s many exceptions, the employer may not use that information to discriminate, as defined in Section 202(a) or in such a way that violates the employee’s right to confidentiality, as outlined in Section 206.\textsuperscript{48}

\textit{C. Challenging the Binary}

As will be discussed in greater detail in the following Part, the legal protection of genetic information simultaneously implicates privacy and antidiscrimination concerns. Hence, it is not surprising that GINA’s employment title both protects against genetic-information discrimination and prohibits attempts to obtain an employee’s genetic information.

GINA’s ban on requesting, requiring or purchasing the protected information sets it apart from its antidiscrimination predecessors.\textsuperscript{49} No federal law prohibits employers from seeking—or even disclosing—information related to other kinds of protected statuses, such as an employee’s race, sex, national origin, or age.\textsuperscript{50} Instead, most employment discrimination legislation simply outlaws adverse employment actions on the basis of the protected trait. For example, Title VII outlaws acting on—but not acquiring—the relevant information.\textsuperscript{51} Hence in most circumstances, employers may thereby inquire into an employee’s protected status without discriminating against her as a matter of law.\textsuperscript{52}

\textsuperscript{47} Id. § 202(c).
\textsuperscript{48} Id.
\textsuperscript{49} See Corbett, supra note 5, at 9 (asserting that GINA “is written in the language of a workplace privacy law”).
\textsuperscript{50} Corbett, supra note 5, at 3 (noting that “Title VII of the Civil Rights Act of 1964 and the Age Discrimination in Employment Act of 1967 (ADEA) do not prohibit employers from inquiring about or revealing to others an employee’s color, race, sex, religion, national origin, or age”).
\textsuperscript{51} Mark A. Rothstein, Genetic Secrets: A Policy Framework, in GENETIC SECRETS: PROTECTING PRIVACY & CONFIDENTIALITY IN THE GENETIC ERA 459-60 (Mark A. Rothstein ed., 1997) (“Title VII bans using the information in a discriminatory manner rather than collecting the information.”)
\textsuperscript{52} While such conduct is legally permissible it is still practically undesirable. See id. (noting that “[t]echnically, it is lawful for an employer to ask an applicant to reveal information such as race or sex, although hardly
To be sure, GINA’s inclusion of a privacy protection alongside an antidiscrimination mandate is distinctive. Thus, when the law passed, it garnered significant attention as an atypical antidiscrimination statute. Yet understanding Title II’s privacy and antidiscrimination provisions as separate and distinct oversimplifies the relationship between these two parts of the legislation.

Instead of reading Sections 202(a) and 202(b) as different kinds of protections that serve different underlying norms and legislative purposes, this Essay asserts that GINA’s privacy provision serves the statute’s antidiscrimination objective. Perhaps tellingly, Congress included its ban on acquiring genetic information in the antidiscrimination—not the confidentiality—portion of the statute. Thus, I propose in the next Part that in drafting Section 202, Congress was not seeking to protect against separate and distinct privacy and

any employers do so because there are few circumstances under which such information can be used lawfully”.

The major pre-GINA exception to this basic generalization is the ADA, which offers limited privacy protections alongside its prohibition on employment discrimination on the basis of disability. See Rothstein, supra note 51, at 460 (contrasting Title VII of the Civil Rights Act with “Title I of the Americans with Disabilities Act, which prohibits discrimination in employment on the basis of disability, also restricts access to information”). The ADA’s Title I forbids pre-offer inquiries into an individual’s disability status, yet permits employers to predicate conditional offers of employment on passing necessary, job-related medical exams. 42 U.S.C. § 12112(d) (barring employers from conducting preemployment medical exams and post-offer medical exams that are job-related and consistent with business necessity); see also Rothstein, supra note 51, at 460 (“For example, by limiting an employer’s preemployment inquiries about disabilities, the law attempts to exclude irrelevant health criteria from the employer’s decision-making process. Unfortunately the ADA also permits complete access to an individual’s medical records after a conditional offer of employment. . . ”). While the ADA does prohibit certain medical inquiries, that law still functions almost exclusively as antidiscrimination legislation. Corbett, supra note 5, at 3 (stating that while the ADA “prohibits inquiries regarding disabilities,” “the statute language of the Act and the litigation thereunder are predominantly about nondiscrimination”).

53 See, e.g., Corbett, supra note 5, at 2 (describing GINA as “a mutant antidiscrimination statute, differing in significant ways from prior antidiscrimination laws”); Kim, supra note 5, at 697 (stating that “GINA is a strange sort of antidiscrimination law”).

54 Compare GINA, § 202 with GINA, § 206.
antidiscrimination harms but instead was intentionally using privacy as an additional, and novel, tool in the antidiscrimination armory.

***

Privacy law and antidiscrimination law have historically been understood as distinct kinds of legal protections with different underlying goals and norms. GINA, therefore, made history by including a privacy provision in its employment discrimination title. Section 202 contains both a traditional antidiscrimination protection, modeled on Title VII, and an unprecedented prohibition on requesting, requiring, or purchasing genetic information. Frequently, these subparts are treated as distinct, offering protections that are different in kind. However, this Essay proposes that the two sub-sections can be read together as both serving the statute’s antidiscrimination purpose. Part II will consider the conceptual relationship between privacy and antidiscrimination, arguing that Section 202(b) can be read not only as prohibiting violations of genetic privacy but also as preventing genetic-information discrimination.

II. THE PRIVACY & ANTIDISCRIMINATION SYMBIOSIS

This Part begins with a deeper exploration of the normative foundations of privacy and antidiscrimination. It then proposes that privacy laws can be understood in decidedly antidiscrimination terms, a theory I call “the Pandora’s box” approach. The Pandora’s box approach holds that certain information is so potentially disadvantageous—or perhaps so tempting to consider—that it serves antidiscrimination goals to forbid not just employers’ actions based on the protected status but their knowledge of the protected status itself. Thus, privacy protections function to keep Pandora’s box firmly closed. Lastly, this Part again turns to GINA as an illustrative example, arguing that the statute has an antidiscrimination purpose and that Congress employed the Pandora’s box approach when it chose to include a ban on obtaining genetic information within the statute’s antidiscrimination provision.

A. Basic Concepts

As concepts, privacy and antidiscrimination are linked. Both implicate certain types of protected information. Privacy deals with our ability to control access to intimate information. Similarly,
antidiscrimination maintains that information related to protected statuses should not form the basis of particular kinds of decisions.

1. Privacy

Privacy centers on the notion that we are entitled to a certain amount of control over our bodies, our environments, and information about ourselves.\textsuperscript{55} Consequently, as stated in Part I, autonomy is the normative value most readily associated with the legal protection of privacy.\textsuperscript{56} Privacy is central to autonomy for a number of reasons.

Protecting privacy allows us to more freely construct our identities and negotiate our social interactions. Being able to keep some things private is arguably essential to living communally.\textsuperscript{57} To allow free access to everything about our lives would erode our sense of self and our differentiation from those around us.\textsuperscript{58} Thus, to coexist with others, people must be able to craft and maintain their identities. Controlling access to certain kinds of information is thereby an important aspect to having an independent sense of self. So much so, that some scholars have even gone as far as arguing that an absence of privacy has the potential to interfere with sanity.

Hence, privacy is essential to our relationships. What we reveal to an employer will differ from what we reveal to a family

\textsuperscript{55} The core value of privacy can be broken down into informational, physical, decisional, and proprietary aspects. See Anita L. Allen, Genetic Privacy: Emerging Concepts and Values in Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era 331, 33-34 (Mark A. Rothstein ed. 1997) excerpted in GENETICS: ETHICS, LAW, AND POLICY 3d 788-89 (Lori B. Andrews, Maxwell J. Mehlman, Mark A. Rothstein, eds. 2010).

\textsuperscript{56} See, e.g., Corbett, supra note 5, at 9 (asserting that “[p]rivacy is a complicated concept and includes interests such as secrecy of information and autonomy”); Kim, supra note 34, at 1537 (identifying autonomy as the norm behind legal protections of privacy); Roberts, supra note 26, at 616 (stating that “[v]iolating privacy as a wrong unto itself relates to norms of autonomy and self-definition”).

\textsuperscript{57} BoK, supra note 13, at 20 (“Control over secrecy provides a safety valve for individuals in the midst of communal life—some influence over transactions between the world of personal experience and the world shared with others. With no control over such exchanges, human beings would be unable to exercise choice about their lives.”).

\textsuperscript{58} Id. (“Those who lose all control over these relations cannot flourish in either the personal or the shared world, nor retain their sanity. If the experience in the shared world becomes too overwhelming, the sense of identity suffers.”).
member, which will likewise differ from what we reveal to a lover. Privacy is, therefore, viewed as an indispensable aspect of our most fundamental liberties.\textsuperscript{59}

Privacy may take many forms: informational, decisional, physical, and proprietary.\textsuperscript{60} This Essay focuses on privacy's informational aspects. Protecting certain information as “private” indicates that this particular information is personal and intimate and should thus remain in the control of the individual. Violations of informational privacy can be either \textit{intrinsic} or \textit{extrinsic}. An intrinsic privacy harm occurs when an unauthorized third party acquires private information.\textsuperscript{61} An extrinsic privacy harm occurs when that third party acts on it.\textsuperscript{62}

Invoking genetic information as an example, privacy protections safeguard individuals by either restricting the entities that may lawfully access genetic information or by outlining how those entities must handle genetic information once it is obtained, or some combination of the two. As described in Part I, GINA contains both a privacy provision preventing employers from requesting, requiring, or purchasing the genetic information of their employees, as well as a confidentiality provision governing how to treat genetic information after it has been lawfully acquired. Thus, legal protections for genetic privacy tend to deal primarily with how and when covered entities may access this particular kind of protected information and the way they must handle it once it is obtained.

2. Antidiscrimination

As mentioned, equality and fairness are the underlying norms most frequently associated with antidiscrimination. Importantly, like privacy, antidiscrimination also implicates particular kinds of information. Traditional antidiscrimination categories include race and ethnicity, sex, religion, age, and disability.\textsuperscript{63} Depending upon

\textsuperscript{59} See Silvers & Stein, \textit{supra} note 33, at 1353 (explaining that emphasis of privacy rights in constitutional law “is on preserving individuals’ control over that intimate information that affects the core of personal liberty”).

\textsuperscript{60} Supra note 55 (identifying these four kinds of privacy).

\textsuperscript{61} See Roberts, \textit{supra} note 26, at 616 (explaining that “a privacy violation . . . constitutes its own inherent wrong, regardless of how that information is used or not used”).


\textsuperscript{63} See, \textit{e.g.}, Title VII of the Civil Rights Act, ADEA, \& ADA.
whether the information related to protected status is readily available, antidiscrimination laws can be understood as prohibitions on certain extrinsic privacy harms, as those laws prevent decision-makers from using covered information to an individual’s detriment.

Yet which statuses to protect is only the beginning. When deciding how the law should safeguard those traits or statuses designated for protection, scholars have often invoked two different images of the antidiscrimination vision: antisubordination and anticlassification.\textsuperscript{64} Antisubordination holds that the goal of the antidiscrimination project should be elevating the social status of historically disadvantaged groups.\textsuperscript{65} Anticlassification, however, maintains that individuals should not face intentional discrimination on the basis of certain protected traits, regardless of a history of social subjugation.\textsuperscript{66} Thus, an antisubordination approach would advocate ending disparities, both intended and unintended, faced by racial minorities, including through positive differential conduct like affirmative action or diversity initiatives; whereas anticlassification would support outlawing any consideration, positive or negative, of “race” generally. I have previously argued that GINA, as written, favors an anticlassification approach, due to its anticlassification


\textsuperscript{65} Siegel, supra note 64, at 1472-73 (defining 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”). Because no widely acknowledged genetic underclass yet exists, antisubordination in this context would thus advocate preventing its formation. Roberts, supra note 26, at 630 (“GINA could not be an antisubordination 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 antisubordination statute—even absent an existing genetic underclass—by seeking to preempt the formation of a genetically disadvantaged social group.”).

\textsuperscript{66} Balkin & Siegel, supra note 64, at 10 (defining the anticlassification principle as the notion that “the government may not classify people either overtly or surreptitiously on the basis of a forbidden category: for example, their race”).
These two visions of antidiscrimination implicate privacy differently. On one hand, anticlassification—with its ban on any differentiation on the basis of a protected trait—favors strong privacy protection. In fact, anticlassification norms are often referred to in terms of “blindness.” That is, anticlassification holds that employers should behave as though they cannot see the individual’s race, sex, disability, etc., making them “blind” to the protected status. Strong privacy protections take the blindness trope a step further: Covered entities need not be blind to the individual’s protected status when making decisions if the covered entity never has access to the protected information in the first place.

On the other hand, antisubordination sometimes may require the relinquishing of privacy to realize its objectives. As explained, this iteration of the antidiscrimination principle seeks to elevate the social status of historically subjugated groups. For instance, instead of merely outlawing all considerations of race or sex, antisubordination attempts to raise the social standing of people of color and women. In so doing, the antisubordination principle targets both intentional and unintentional discrimination and advocates affirmative action to promote equality, integration, and access. Thus, support for disparate impact actions to address facially neutral policies that produce discriminatory results, as well as positive differential treatment for members of the protected group, distinguishes antisubordination from anticlassification. To assess whether a policy disproportionately impacts a particular group, or to provide benefits related to a protected status, the covered entity must have some knowledge of the relevant information. Thus, while a robust privacy protection may be

---

67 Specifically, I have proposed that GINA is predominantly an anticlassification statute because it excludes claims for unintended discrimination and outlaws all consideration—including positive—of genetic information. Roberts, supra note 26, at 632-34. Hence I have argued the statute could benefit from incorporating disparate impact claims and allowances for reasonable accommodations and genetic diversity initiatives. Id. at 634-47.

68 The most culturally pervasive example of the trait blindness approach to antidiscrimination law is, of course, “colorblindness.” As a disability studies scholar I do not personally advocate the language of blindness to describe antidiscrimination norms; however, I acknowledge it here because of its pervasiveness and relevance to the Pandora’s box approach.
ideally suited for anticlassification, it may actually function to undermine certain goals of antisubordination. Again GINA, in its current iteration, reads more like an anticlassification statute.  

B. Pandora’s Box

In Greek mythology, the gods gave Pandora a tantalizing box—or perhaps a jar—and told her never to open it. Unable to resist temptation, Pandora opened the box releasing evil into the world. Once the contents escaped, they could never be returned to the secure confines of their previous enclosure. The myth of Pandora’s box at once teaches us that uncovering that which is concealed can be dangerous and, once it is revealed, that revelation cannot be undone. It is thus a cautionary tale about the nature of secrets and the consequences of revelation.

In many situations, individuals cannot control information indicative of their protected statuses, even if they wanted to. Protections against discriminatory conduct act as a second best when privacy protections are not available. Take race as an example. If an individual’s appearance provides cues of her racial identification, she may not be able to keep that information private (yet if she can pass she may at times choose to do so); however, Title VII prevents her employer from taking this particular information into account when making employment decisions. While the individual may not be able to control who accesses information related to her race, the law can intervene to prevent entities from acting on that information.

So-called “colorblind” policies, such as prohibiting candidates from indicating their race on applications, operate not only as prohibitions on race-based decision-making but also as protections

---

69 Elsewhere I have argued that while GINA is written as an anticlassification law, its ultimate goal can best be understood in terms of antisubordination: preempting the formation of a genetic underclass. Supra note 65. People fear social genetic determinism, the notion that “our genes will somehow determine—for better or worse—the trajectory of our lives,” dividing us as early as at birth or perhaps even in utero, between genetic have-nots and genetic have-nots. See Roberts, supra note 26, at 606.

70 BOK, supra note 13, at 3-4 (telling the story of Pandora’s box).
71 Id.
72 Id.
73 Id. at 4 (describing the story of Pandora’s box as “one of the many tales of calamities befalling those who uncover what is concealed and thereby release dangerous forces that should have been left in darkness and silence”).
against the intrinsic privacy harm of inquiring about an individual’s race. The logic behind these policies is straightforward: If we can prevent access to the protected information (intrinsic privacy harm), we can safeguard against discrimination on the basis of that information further down the line (extrinsic privacy harm). Privacy protections can therefore facilitate antidiscrimination by preventing entities from discriminating by obscuring their knowledge of the protected trait.\textsuperscript{74} I call this “the Pandora’s box” approach. If an employer cannot access a particular kind of information she cannot use it to discriminate. However, once it is revealed it may influence the employer’s decisions in conscious, as well as unconscious, ways.

Privacy is a particularly strong weapon against discrimination in the context of genetic information.\textsuperscript{75} Whereas traditional antidiscrimination categories like race and sex tend to be readily observable, much genetic information is not visible to the naked eye.\textsuperscript{76}

\textsuperscript{74} See Scott Burris & Lawrence O. Gostin, Genetic Screening from a Public Health Perspective: Some Lessons from the HIV Experience, in GENETIC SECRETS: PROTECTING PRIVACY & CONFIDENTIALITY IN THE GENETIC ERA 151 (Mark A. Rothstein ed., 1997) (“In both HIV and genetic realms, privacy has been used as a proxy for antidiscrimination protection, particularly in insurance. That is, the role of the law is not to prevent the collection or proper use of the information but rather to prevent its falling into the wrong hands and being used to deprive the subject of a job, service, or insurance.”)

\textsuperscript{75} See, e.g., Areheart, supra note 5, at 706 (“GINA illustrates how the values of privacy and antidiscrimination may be allies.”); Kim, supra note 5, at 703 (“Robust privacy protections are therefore key to preventing genetic discrimination.”); Radhika Rao, A Veil of Genetic Ignorance? Protecting Genetic Privacy to Ensure Equality, 51 VILL. L. REV. 827, 830, 831 (2006) (asserting “that protecting genetic privacy may serve as a mechanism to ensure a measure of genetic equality” and arguing that “[t]he only sure-fire way to prevent genetic discrimination is to safeguard genetic privacy—to construct a veil of genetic ignorance around each individual”). But see Lior Jacob Strahilevitz, Privacy versus Antidiscrimination, 75 UNIV. CHI. L. REV. 363 (2008) (arguing that intrusions into personal privacy might be necessary to bypass statistical discrimination, as entities will rely on group stereotypes when individual information is not available to them).

\textsuperscript{76} Areheart, supra note 5, at 711 (noting that because “an employer is much more likely to be intuitively (or otherwise) aware of an employee’s race, age, or sex [p]rivacy thus holds less promise under a statute like Title VII or the ADEA—and has more potential values under statutes like the ADA or GINA.”); Kim, supra note 5, at 699-700 (“Race and sex are salient characteristics—attributes of an individual that are usually easily observable
As a result, obtaining genetic information frequently requires taking a genetic test.\textsuperscript{77} Thus, becoming the potential object of genetic-information discrimination frequently necessitates taking positive action: The affected individual must undergo testing to learn the very information that could eventually harm her.\textsuperscript{78} This opt-in quality differentiates genetic-information discrimination from the more traditional antidiscrimination categories and, as a result, makes it a better candidate for using privacy to combat discrimination because it involves the active pursuit of sensitive information.

Table 2. The Pandora’s Box Approach.

<table>
<thead>
<tr>
<th>Pandora’s box approach</th>
<th>Underlying Norms</th>
<th>Legislative Purpose</th>
<th>Legal Protection</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Equality</td>
<td>Prevent disadvantage on the basis of protected status</td>
<td>Restrictions on valid access to information related to protected status</td>
</tr>
<tr>
<td></td>
<td>Fairness</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

To be sure, the Pandora’s box approach is not the only reason to safeguard sensitive information. Privacy protections also generate independent goods, such as supporting individual autonomy and self-differentiation. However, this Essay primarily concerns itself with the work privacy can do with respect to preempting systematic disadvantage, not the benefits of privacy qua privacy. Going back to the distinction between norms, legislative purpose, and legal protections discussed in the preceding Part, the Pandora’s box and difficult to conceal. ... By contrast, ... individuals with genetic predisposition to disease are not currently an identifiable social group. Not only are genetic traits not socially salient, they are not even readily ascertainable about an individual.”). There are of course clear exceptions to this general rule, such as people who pass for different races.  

\textsuperscript{77} Roberts, \textit{supra} note 26, at 624 (“[A]cquiring genetic information requires testing, whereas other groups tend to rely on social and cultural signals and morphological traits as indicators of group membership.”).  

\textsuperscript{78} \textit{Id.} at 625 (“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. In many circumstances, an insurer or an employer could not discriminate—nor could an individual know that she warrants protection—but for the intervention of medical science.”).
approach demonstrates how a type of legal protection that on its face appears to align with privacy may also serve the goals and norms associated with antidiscrimination.

C. Pandora’s Box and GINA

Although Title II includes Section 202(b), which reads like a traditional privacy protection, GINA’s legislative history indicates that Congress was acting with a clear antidiscrimination objective when it passed the law. For instance, the statute’s heading describes the law as “an act to prohibit discrimination on the basis of genetic information and employment,” not as an effort to protect genetic privacy.79 Hence, it appears GINA’s primary legislative purpose is one of antidiscrimination.

Moreover, the congressional findings focus more strongly upon the need for antidiscrimination—not privacy—protection. For example, after lauding recent developments in genetic science, Congress warned that “[t]hese advances give rise to the potential misuse of genetic information to discriminate in health insurance and employment.”80 The findings cite the history of forced sterilization and racially targeted sickle-cell screenings, in addition to present-day evidence of genetic-information discrimination, to demonstrate the need for a federal antidiscrimination law.81

Congress also referenced the chilling effect that the fear of discrimination had on the public’s willingness to take genetic tests when justifying legislative intervention. Interestingly, those fears implicate both antidiscrimination and privacy concerns. Pre-GINA, over ninety-percent of Americans expressed concern regarding the misuse of their genetic information should potential discriminators gain access.82 When asked about her fears related to genetic testing, one person reported:

I was just 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

---

79 See generally GINA.
80 GINA § 2(1).
81 Id. §§ 2(2)-2(4).
82 See Roberts, supra note 26, at 603 (“Despite limited examples of genetic information discrimination, more than ninety percent of Americans expressed concern regarding the misuse of their genetic information. They feared that, if given access, potential discriminators would use genetic information to make decisions.”).
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 projects.’ It would be illegal. But I’m sure a little bit of that goes on.\(^{83}\)

Thus, the individual was concerned that discrimination could quickly follow knowledge. In other words, when “everybody knows” about a vulnerable status, it opens the door for unfavorable differential treatment. Another individual, who tested positive for a genetic variation associated with respiratory disease, likewise chose to keep the results private because she feared future disadvantage: “It just seemed safer to keep it to myself. . . . I didn’t know what somebody would do with it in the future . . . . and I was very concerned about it.”\(^{84}\)

People who have taken genetic tests understand the relationship between testing, revelation, and discrimination. Because individuals have to opt in for genetic-information discrimination in a way they do not for more traditional antidiscrimination categories, people may choose not to take genetic tests,\(^{85}\) or to keep the results of those tests secret to protect themselves. Restricting access to genetic information can thereby safeguard against future disadvantage on the basis of genetic information.\(^{86}\) Hence, two related fears surrounded


\(^{84}\) President’s Commission for the Study of Bioethics, Privacy and Progress in Whole Genome Sequencing (Oct. 2012), at 42 (quoting Victoria Grove).

\(^{85}\) See Roberts, *supra* note 26, at 625 (proposing that “current rates of genetic-information discrimination could be low because people refuse genetic testing to avoid becoming the objects of discrimination.”).

\(^{86}\) See *id.* at 615-16 (“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 information, they cannot use it to disadvantage us.”); see also Kim, *supra* note 34, at 1537 (“In the case of genetic information, this connection between informational privacy and autonomy is clear: an individual’s genetic characteristics cannot become the basis for systematic disadvantage unless
genetic testing: People worried (1) that their genetic information would be disclosed without their consent and (2) that once released, third parties would use that information to discriminate.\textsuperscript{87} These concerns led individuals to avoid genetic tests to shield themselves from possible discrimination.\textsuperscript{88} Because they feared third-party access to their genetic profiles would lead to discrimination, people simply opted not to learn the information. Individuals thus employed their own version of the Pandora’s box approach.

One of the fundamental reasons for protecting genetic privacy is to bypass genetic-information discrimination.\textsuperscript{89} Aware of these and similar kinds of concerns, Congress concluded: “Federal legislation establishing a national and uniform basic standard 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.”\textsuperscript{90} Consequently Congress appears to have passed GINA primarily to protect against genetic-information discrimination, as well as to assuage anxieties regarding the potential for such discrimination.\textsuperscript{91} Interestingly, neither the text of Title II, nor the statute’s purpose, explicitly mentions privacy.

\begin{footnotes}
\footnote{Id. at 1443 (stating that a “common basis for apprehension stems from a fear that information about one’s genetic profile will be disclosed to others without one’s consent and will then be used to one’s personal disadvantage”).}
\footnote{Id. at 1443 (stating that a “common basis for apprehension stems from a fear that information about one’s genetic profile will be disclosed to others without one’s consent and will then be used to one’s personal disadvantage”).}
\footnote{Roberts, supra note 26, at 603 (“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. This anxiety led people to avoid genetic testing because they feared that it could harm them or their loved ones.”).}
\footnote{See Diver & Cohen, supra note 33, at 1445 (“The nondisclosure and nondiscrimination strategies are closely interrelated. One of the primary purposes of protecting a person against disclosure of genetic information is to limit the danger that it will be used to his or her disadvantage in interpersonal relationships or market transactions. One obviously cannot base discrimination on a person’s genetic profile unless one has first obtained information about that profile.”).}
\footnote{Id. §2(5) (emphasis added).}
\footnote{I have previously argued that in passing GINA, Congress acted with both research and antidiscrimination motivations. See Roberts, supra note 5, at 133-42.}
\end{footnotes}
Because the fears related to invasions of genetic privacy simultaneously implicate the fears related to genetic-information discrimination, Congress’s incorporating the Pandora’s box approach into GINA’s antidiscrimination protections addresses the bifurcated nature of the concerns associated with genetic testing:92 Section 202(b) prohibits requesting, requiring, or purchasing genetic information, thus outlawing unauthorized disclosure, whereas Section 202(a) forbids discriminatory actions on the basis of that information. Thus, like the underlying anxieties, the associated legal protections also have dual elements. As a result, beyond preventing unwelcome access to genetic information, GINA’s privacy provision also has a clear antidiscrimination objective.

The relevance of Congress’s intent in drafting GINA is twofold. On a general level, the unequivocally antidiscrimination purpose of the legislation demonstrates that Congress itself understood that privacy and antidiscrimination are conceptually linked and that privacy law may function to prevent discrimination. Otherwise, it would not have placed a provision that structurally conforms to the privacy law paradigm in a sub-section devoted to outlawing discrimination. Yet more specific to the claims of this Essay, GINA’s legislative history indicates that Congress was in fact openly adopting the Pandora’s box approach to address the public fears related to genetic testing that drove the statute’s passing. GINA’s legislative history therefore supports two of the central claims of this Essay: (1) that privacy and antidiscrimination are related concepts and, hence, related types of legal protections and (2) that GINA provides a real-world example of the Pandora’s box approach and how privacy can do the work of antidiscrimination.

Finally, it is worth reiterating that the Pandora’s box approach favors the anticlassification principle. Preventing all access to genetic information undermines an employer’s ability to use that information for positive differential treatment such as reasonable accommodations. By using strong privacy protections as a vehicle of antidiscrimination, GINA thereby adopts a “genome-blind” approach.93 Whereas

92 See Kim, supra note 5, at 700 (noting that “the key to preventing discrimination based on genetic traits lies in protecting the privacy of genetic information” and that “Congress recognized this reality, and therefore GINA also seeks to protect the privacy of genetic information”).

93 Roberts, supra note 26, at 622 (“Because GINA allows no consideration of genetic information, the statute takes what has been described as a “genome-blind” approach to protecting genetic information.”
“colorblind” or “sex-blind” policies require employers to ignore the protected traits by acting—as the metaphor implies—as though they could not see it, GINA prevents awareness of the protected status altogether. Returning to the norm/legislative purpose/legal protection triad introduced in Part I, the Pandora’s box approach demonstrates how a privacy protection can achieve an antidiscrimination purpose, yet the perspective currently taken is largely one of anticlassification. However, this strong favoring of anticlassification could at times undermine the statute’s ability to fully prevent the formation of genetic disadvantage.94 Part III will explore the full implications of using privacy to combat discrimination, noting when the anticlassification and antisubordination perspectives diverge.

* * *

Privacy and antidiscrimination are conceptually linked: both govern actions related to particular types of protected information. Privacy law seeks to preserve an individual’s control over her intimate information, whereas antidiscrimination law seeks to prevent third parties from using certain kinds of information as the basis for their choices. However, the kinds of legal protections traditionally associated with privacy can serve the goal of antidiscrimination by restricting access to information related to the protected status, thus rendering the decision-maker incapable of using that information to a person’s detriment. Given the structure of GINA’s protections, Congress was well aware of the utility of using privacy law to stop discrimination when drafting GINA’s Section 202. The Pandora’s box approach is, therefore not mere speculation, but an actual real-world legislative strategy that has already been employed in at least one federal antidiscrimination law.

III. IMPLICATIONS OF PRIVACY AS AN ANTIDISCRIMINATION TOOL

After having outlined Section 202’s privacy and antidiscrimination provisions and the conceptual linkage between privacy and antidiscrimination as both theoretical concepts and kinds of legal protections, the Essay now turns to the implications of using

(citing Mark A. Rothstein, Legal Conceptions of Equality in the Genomic Age, 25 LAW & INEQ. 429, 456 (2007)).

94 See generally Roberts, supra 26.
privacy law as a tool for antidiscrimination goals. Using privacy protections to prevent potential discriminators from accessing protected information adds an additional layer of antidiscrimination protection. Further, privacy offers certain advantages that traditional antidiscrimination protections lack. However, privacy may at times overprotect the information in question, leading people to fail to disclose information when it would be beneficial to them or to society as a whole. Further, legislatures and the courts have at times been reluctant to provide protection or relief, respectively, for privacy independently, that is absent an associated harm. Yet antidiscrimination’s strengths could help to mitigate privacy’s weaknesses. In the case of overprotection, pairing privacy protections with antidiscrimination goals, particularly those associated with antisubordination, could encourage disclosure for accommodation or consciousness-raising purposes. Additionally, linking antidiscrimination to privacy could thereby provide an added incentive for lawmakers to safeguard sensitive information. Thus, while privacy law supports antidiscrimination purposes, antidiscrimination purposes may similarly support privacy law.

A. Privacy’s Advantages

Privacy law has distinct advantages as a legal strategy for combating discrimination. To start, traditional employment discrimination claims are notoriously difficult to prove. The Supreme Court famously stated that Title VII is not “a general civility code,” meaning that employment discrimination statutes do not require employers or fellow employees to be nice: The laws merely provide that employers not discriminate on the enumerated bases. Consequently, an employer may choose not to hire the most qualified person, for any number of reasons, including simply if the employer does not like her. Given the infinite number of potentially acceptable reasons for most employment decisions, to establish a legal violation, a plaintiff must frequently show that the employer used the protected status as the basis for its decision. Thus, to answer an allegation of

96 Notably, there are exceptions to this statement. While an individual may struggle to establish a particular employment decision was on the basis of a protected status, employment discrimination cases may proceed when litigants are able to demonstrate that the employer—or one of her policies—categorically excludes members of a protected class. For example, in pattern or practice disparate treatment cases claimants can present statistical
discrimination, the employer may need only to establish a believable alternate rationale for its actions. Imagine that the only applicant of color for a particular job also went to the hiring chair’s rival school. While institutional loyalty may not be a “good” reason to fail to hire a qualified applicant, it is also not a discriminatory one. Because no two employees or applicants are completely identical with the exception of the relevant protected status, litigants frequently have difficulty proving their claims because they lack a perfect comparator, for example a non-minority candidate with identical educational credentials. By contrast, demonstrating that an employer attempted to obtain a certain kind of information is markedly easier. It is a straightforward factual inquiry, opposed to an attempt to divine a potential discriminator’s true intent and to the exclusion of all other possible explanations.

The first GINA case settled by the EEOC illustrates this very point. The claimant held a temporary clerk position with the employer. However, when she applied for permanent employment, the company extended her an offer contingent on a pre-employment medical examination. During the evaluation, the medical examiner asked the claimant for her family history of a number of conditions, as well as tested her for carpal tunnel. Despite her personal evidence. See Teamsters v. United States, 431 U.S. 324 (1977). Similarly, when a facially neutral policy disparately impacts a protected class, plaintiffs do not have to establish intent. See Griggs v. Duke Power Co., 401 U.S. 424 (1977).


98 See Corbett, supra note 5, at 9; see also Kim, supra note 34, at 1543 (“If regulating employer use of genetic information is primarily a problem of protecting informational privacy, rather than preventing invidious discrimination, the appropriate legal response looks quite different. Any legal effort will focus on defining and controlling the flow of critical information, rather than determining the motive of the employer in taking adverse personnel actions.”); see also Kim, supra note 5, at 700 (explaining that “proving that genetic information has influenced an employment decision is challenging”).


101 Id.
physician’s determination to the contrary, the employer rescinded its offer based on its medical examiner’s diagnosis of carpal tunnel.\textsuperscript{102} However, in establishing her GINA claim, she did not have to establish \textit{why} she was denied employment or whether that denial was appropriate, just that the employer made an inquiry related to her genetic information by asking for her family history.\textsuperscript{103} Hence, privacy violations may have a practical benefit, as they are easier to establish than their antidiscrimination counterparts.

As noted, privacy is a particularly powerful tool against discrimination on the basis of genetic information. Because traditional antidiscrimination categories often have associated visual or sociocultural cues, employers can frequently ascertain protected status through casual observation. Thus, early antidiscrimination protections had little choice but to focus on outlawing discriminatory conduct because the relevant underlying information was readily available.\textsuperscript{104} While laws banning discriminatory conduct offer some protection, employers remain aware of their employees’ race, sex, or disability and may make decisions based on this information—both on conscious and unconscious levels—regardless of the law. Importantly, despite Title VII and the ADA, discrimination on the basis of the protected categories still persists.\textsuperscript{105} Likewise, if employers have open access to genetic information, they may be tempted to use it, perhaps even unknowingly.\textsuperscript{106} Yet without the relevant knowledge, employers simply cannot discriminate on the basis of genetic information, even if they wanted to. Therefore, in the context of genetic information, robust privacy protections can obscure knowledge of the protected

\begin{footnotes}
  \item[102] Press Release, \textit{supra} note 99.
  \item[103] The claimant also raised an ADA claim, for which she would have had to establish that she was denied the position on the basis of a disability. \textit{See} EEOC \textit{v. Fabricut}, compl., ¶9.
  \item[104] \textit{See} Kim, \textit{supra} note 34, at 1537 (“Because employer knowledge of an employee’s race or sex is nearly unavoidable, preventing race discrimination requires direct prohibition of discriminatory motive.”).
  \item[105] Rothstein, \textit{supra} note 51, at 475 (noting that “since the mid-1960’s there have been laws enacted prohibiting discrimination based on race, color, religion, sex, national origin, and age” but asserting that “[n]obody would seriously contend that discrimination on the basis of those factors has been eliminated”).
  \item[106] \textit{See} Kim, \textit{supra} note 5, at 700 (“If genetic information is available, it may be difficult for decision-makers to ignore, and yet proving that genetic information has influenced an employment decision is challenging. On the other hand, if genetic information is unavailable, employers simply cannot discriminate on the basis of latent genetic traits.”).
\end{footnotes}
trait, thereby acting as a prophylactic that has typically been unavailable for the traditional categories.

Additionally, protecting genetic privacy could also bypass the creation of widespread genetic stigma. The first step in stigma formation is distinguishing and labeling personal differences. Yet without knowledge of the relevant difference, one cannot label individuals based on that difference. Again because genetic information is not immediately apparent, privacy protections could go even a step further in preventing genetic disadvantage. By keeping genetic information private, society would not have knowledge of genetic difference, perhaps stopping the underlying stigma that could lead to a genetic underclass from ever forming.

Yet while genetic-information is uniquely suited with respect to the effectiveness of using privacy to bypass disadvantage, laws protecting other antidiscrimination categories could similarly benefit from bans on requesting, requiring, or purchasing information about the protected status. As discussed above, often a person’s race or sex is apparent upon meeting her. Although that is not always the case. For example, in Mitchell v. Champ Sports, the plaintiff, who self-identified as a black woman, had light skin, leading her supervisor to assume she was white. Yet when black friends and relatives visited her at work, her supervisor was surprised to discover that the plaintiff was, in fact, black. Following that revelation, her supervisor demoted her to a part-time associate, despite her highly positive performance reviews, leading her to sue under Title VII.

Although the supervisor in Mitchell did not make a specific race-related inquiry, he obtained previously unknown information regarding the plaintiffs’ race, which he then used as the basis for discrimination. Thus, prohibiting requests for information related to race or ethnicity could prevent discrimination when a person’s racial or ethnic identity is not immediately ascertainable. Congress could therefore consider adding a prohibition on such inquiries to Title VII. While such an amendment might not do much work in terms of sex or color, it could preempt discrimination on the basis of religion and national origin because those statuses may be less visible to the casual observer.

Symphony auditions provide another meaningful—albeit

---

109 Id.
110 Id.
temporary—example of how restricting access to information related to a protected status could bypass certain kinds of discrimination. Historically, women faced significant disadvantages being hired to symphony orchestras. As of 1970, roughly ten percent of orchestra members were women.\(^{111}\) However, when those entities introduced blind auditions (having prospective members play behind screens), the number of female musicians increased to thirty-five percent by the mid-1990s.\(^{112}\) Researchers have attributed a significant portion of these gains to the blind audition process.\(^{113}\) While female musicians would be hard pressed to conceal their gender once joining the orchestras, at a minimum, the blind auditions demonstrate how obscuring information related to a protected status can help eliminate previous disparities at least at the hiring stage.

**B. Privacy’s Disadvantages**

While privacy has some clear advantages as a vehicle to avert discrimination, it also has its drawbacks. For example, privacy may at times overprotect. Again GINA provides a good illustration.\(^{114}\) In the context of genetics, as in the context of disability, difference is the norm. Aside from identical twins, no two people share the same genetic information. Importantly, antidiscrimination notions of equality and fairness do not always mandate identical treatment. Perhaps counter-intuitively, we must at times treat people differently to treat them equally or fairly.\(^{115}\)

Returning to the concepts of anticlassification and antisubordination is helpful here. As explained in Part II, these

---


\(^{112}\) *Id.*

\(^{113}\) *Id.*

\(^{114}\) See, e.g., Scott Burris & Lawrence O. Gostin, *Genetic Screening from a Public Health Perspective: Some Lessons from the HIV Experience*, in *Genetic Secrets: Protecting Privacy & Confidentiality in the Genetic Era* 152 (Mark A. Rothstein ed., 1997) (“In spite of the adage about the ounce of prevention, trying to control records in the hands of the good to forestall misbehavior by the bad could prove both burdensome for the good and ineffective against the bad.”).

\(^{115}\) Given the potential salience of genetic information to our daily lives, I have previously asserted that “allowing entities to consider genetic information might actually lead to more meaningful equality.” Roberts, *supra* note 26, at 638.
principles represent two distinct variations on the proper goal of the American antidiscrimination project.\textsuperscript{116} Anticlassification holds that no distinction on the basis of protected trait is desirable, whereas antisubordination maintains that positive differential treatment is helpful when it combats disadvantage.\textsuperscript{117} Thus, anticlassification would always support nondisclosure, while antisubordination might require access to information to facilitate affirmative action.\textsuperscript{118}

A comparison to disability rights law further illuminates this point. Bradley Areheart has explained that a person with an invisible disability who requires an accommodation must decide between privacy (i.e., keeping her disability a secret) and antidiscrimination (i.e., requesting an accommodation).\textsuperscript{119} Thus, at times protecting privacy can stand in the way of addressing disadvantage. For example, a factory worker with a genetic proclivity for carpal tunnel might request a longer workday with more frequent breaks to avoid repetitive stress on her wrists, effectively a genetic-information accommodation. While the exceptions for Title II and the accompanying EEOC regulations permit voluntary disclosure in the context of wellness programs and do not penalize employers for inadvertent acquisition, GINA at present does not include a reasonable accommodation provision. Employers may wish to accommodate their employees’ genetic difference but are currently stopped from requesting genetic information outside the context of the very specific circumstances outlined by the statute and the regulations. Although the regulations permit employers to request genetic information when accommodating a disability,\textsuperscript{120} they cannot make similar requests to accommodate an employee’s genetic difference under the current law.\textsuperscript{121}

\textsuperscript{116} Supra Part II(A)(2) (distinguishing between the anticlassification and antisubordination readings of the antidiscrimination principle).

\textsuperscript{117} Id.

\textsuperscript{118} Id.

\textsuperscript{119} Areheart, supra note 5, at 715.

\textsuperscript{120} See 29 C.F.R. §1635.8.

\textsuperscript{121} To be clear, GINA does not stop employees from giving their employers genetic information. As described in Part I, the statute exempts the employer from liability under just those conditions. However, following a voluntary disclosure, if the employer wishes to acquire additional genetic information with the goal of accommodating the employee on the basis of her genetic difference, the employer cannot make that request.
Expanding the discussion beyond genetic information, one can envision other circumstances in which robust privacy protections might thwart antisubordination efforts. As discussed, inquiries into disability status are essential to accommodation. Thus, a robust privacy protection for disability status might stand in the way of furthering disability rights. Diversity initiatives, another kind of positive differential treatment associated with antisubordination, could likewise be undermined if privacy protections are too strong. For example, an employer might wish to have a racially diverse work force but be prohibited from inquiring into race. Consequently, while privacy works extremely well under an anticlassification paradigm, using privacy as a tool of antidiscrimination could be undesirable when useful antisubordination measures exist.

Moreover, privacy by its very nature hinders disclosure. When information is widely understood as private, people may be unwilling to share it, thereby stifling their expression. Similarly, risk-averse employers may discourage—or outright ban—disclosing protected information to avoid potential liability. With respect to traditional antidiscrimination categories, individuals have historically been encouraged by their employers to obscure their identity status, even when that identity status is known to the employer, a phenomenon known as “covering.” An individual covers her identity status when she claims that status yet makes special efforts to downplay it. 122 For example, a person may self-identify as a member of a particular racial group but intentionally not adopt a style of dress, speech pattern, or other behaviors typically associated with that group. That individual is covering her race. Kenji Yoshino famously applied the concept of covering to the incentives faced by gays to assimilate into straight culture, arguing that coerced assimilation constitutes an antidiscrimination harm. 123 He then expanded his discussion to explore how both racial minorities and women face similar pressures to downplay certain aspects of their identity in the workplace. 124 If genetic information becomes very closely associated with privacy, employers may likewise adopt policies designed to encourage their

---

123 Id. at 783-875.
124 Id. at 875-924.
employees to conceal outright or, alternatively to cover,\textsuperscript{125} their genetic information. An inability to freely discuss one’s genetic profile could have detrimental effects. A person may want to share her experience with genetic testing to inform or empower others but could feel it is socially inappropriate to do so.

While norms against disclosure may be damaging when associated with existing identity groups, it may appear to be less of a risk in the context of genetic information. Genetic information, of course, does not currently form the foundation of widely recognized identity groups.\textsuperscript{126} However, that fact may soon change. Studies show that individuals who have taken genetic tests incorporate the results of those tests into their self-concept.\textsuperscript{127} Depending on the value the individual places on her genetic information and the extent to which it becomes relevant to her sense of self, genetic information could thereby constitute the basis of a new identity category.\textsuperscript{128} Take, for example, actress Angelina Jolie’s recent revelation that she carried a BRCA-1 mutation, which greatly raised her chances of developing breast and ovarian cancer, and her consequent decision to undergo a double mastectomy.\textsuperscript{129} Several women with risk profiles similar to Jolie’s lauded her decisions both to undergo genetic testing and to take preventive measures with respect to her health.\textsuperscript{130} This strong sense of solidarity indicates that these women relate to Jolie and consider themselves members of a particular population: women at a genetic

\textsuperscript{125} It is important to note that the motivation behind covering would be different, as I describe it here, in the genetic context. Policies designed to encourage people to cover their race, sex, or orientation stem from a preference for majority culture. Conversely, I propose that employers may encourage the covering of genetic information to shield themselves from liability or to reflect social beliefs regarding the private nature of genetic information.

\textsuperscript{126} Roberts, \textit{supra} note 26, at 623-24 (discussing the absence of a strong sense of genetic identity).

\textsuperscript{127} \textsc{Robert L. Klitzman, Am I My Genes? Confronting Fate & Family Secrets in the Age of Genetic Testing} 169-182 (2012) (discussing the incorporation of genetic information into an individual’s self-concept and the formation of genetic identity).

\textsuperscript{128} \textit{Id.}; see also Roberts, \textit{supra} note 26, at 623-24 (discussing the possibility of genetic identity).

\textsuperscript{129} To read Jolie’s story in her own words, see Angelina Jolie, \textit{My Medical Choice}, N.Y. TIMES, May 14, 2013.

\textsuperscript{130} See, \textit{e.g.}, Lidia Dinkova, \textit{Opening Up the Conversation About BRCA Testing}, MIAMI HERALD, June 30, 2013.
risk for breast cancer. Should privacy norms surrounding genetic information grow too strong, individuals who could have a positive impact, like Jolie, may choose not to share their genetic profiles. Hence, strong privacy norms associated with genetic information could encourage people not to disclose even when that disclosure could be beneficial, such as if they are in need of accommodation or wish to raise consciousness.

Another potential obstacle to using privacy to further antidiscrimination lies in the legislative reluctance to provide robust independent privacy protection. The legislature in California enacted the California Genetic Information Nondiscrimination Act (CalGINA) in 2011, a law that expanded the prohibition against genetic-information discrimination to life insurance, state programs, housing and mortgage lending, public accommodations, and emergency medical services. However, that same state failed to pass the Genetic Information Privacy Act, S.B. 1267 last year. The proposed law, which would have protected genetic information under the state’s constitutional right to privacy, sought to prohibit obtaining, analyzing, retaining, or disclosing genetic information absent written authorization from the person in question. The bill included both civil and criminal penalties and carved out exceptions for law enforcement, health-care provision, and newborn screening. Although S.B. 1267 died in committee last year, its sponsor introduced a very similar bill this legislative term.

---


133 S.B. 1267, Reg. Sess., introduced Feb. 23, 2012, § 56.19(a) (Cal. 2012) (“Genetic information is protected by the right of privacy pursuant to Article I of Section I of the California Constitution, and . . . shall not be obtained, analyzed, retained, or disclosed without the written authorization of the individual to whom the information pertains . . . ”).

134 Id. 56.19(b)-(f).

135 Id. § 56.19 (i)(1)-(5).

The failure of S.B. 1267 implies that legislatures may be reluctant to pass broad independent protections for privacy. Given the success of CalGINA, a statute that extended the scope of the protections against genetic-information discrimination well beyond the federal level, this insight is particularly salient. The California example tells us that, whereas legislatures may be willing to provide broad antidiscrimination protection, they may not be similarly amenable to providing broad privacy protection. If this explanation is true, it could hinder the use of privacy law to prevent discrimination.

Moreover, in addition to legislative reticence, the dignitary nature of pure privacy violations may present an obstacle to litigants. Thus, one of privacy’s strengths is also one of its weaknesses. Although potential litigants may be able to more readily prove their claims under Section 202(b) because that provision does not require litigants to establish discriminatory intent, claims for violations of Section 202(b) require no associated adverse employment action, making the harm at stake purely dignitary in nature. Courts have notoriously struggled with how to provide adequate remedies for privacy violations absent an associated other harm. Thus, even if claimants enjoy privacy protection, judges may be hesitant to provide them with meaningful relief if the harm they suffer has no other associated harm.

0250/sb_222_bill_20130507_amended_sen_v96.pdf; see also Bill Seeking Greater Genetic Privacy Reintroduced in California, supra note 132.

137 CalGINA extends protection against genetic-information discrimination to a number of areas beyond GINA’s current scope. Id. CalGINA also offers greater remedies than available under Title II. Compare GINA § 207 (capping damages at $50,000-300,000 in accordance with Title VII of the Civil Rights Act) with CalGINA (providing unlimited monetary damages pursuant to the California Fair Housing and Employment Act).

138 See, e.g., Jacqueline D. Lipton, Mapping Privacy Online, 104 NW. UNIV. L. REV. 477, 505 (2010) (“Courts and legislatures have been slow to compensate plaintiffs for nonmonetary harms resulting from a privacy incursion.”); Edward J. Janger, Privacy, Property, Information Costs, and the Anticommons, 54 HASTINGS L.J. 899, 911 (2003) (“Invasions of privacy cause dignitary harm rather than financial harm in most cases, therefore a statute predicated on actual damages will not provide a significant incentive to bring suit.”)
C. Antidiscrimination as a Solution

In sum, two of the major drawbacks of using privacy provisions to achieve antidiscrimination goals are (1) their potential to encourage individuals to keep protected information secret, even when revelations would be beneficial either to the individual or to the public at-large and (2) the hesitance that courts and legislatures have exhibited regarding dignitary violations absent other kinds of harms. Yet just as privacy can do work for antidiscrimination, antidiscrimination can do work for privacy.

Again let us look to genetic information to explore this point. As explained, the antisubordination vision of antidiscrimination supports—at times even requires—access to information regarding protected status. Recall that antisubordination holds that the proper goal of antidiscrimination law should be to elevate the social status of historically subjugated groups.139 With respect to genetic information, which currently has no widely associated social class, an antisubordination approach would seek to preempt genetic disadvantage.140 It would do so with all of the typical tools of antisubordination: prohibitions on both intended and unintended discrimination and the use of positive differential treatment.141 Yet how can society accommodate or value genetic difference without some knowledge of the existence and nature of that difference? It cannot. Disclosure is, therefore, central to the antisubordination vision of the antidiscrimination principle.142

If the governing norm behind protections for genetic privacy is one of antidiscrimination, antisubordination in particular, that purpose would support disclosure when done to thwart genetic disadvantage. For example, the individual with a genetic proclivity for carpal tunnel would feel free to request an accommodation from the employer and the employer could then, as with the ADA, request additional information to honor that request. Similarly, antisubordination would also urge us to value genetic diversity. Thus,

139 Supra Part II(A)(2).
140 Id.
141 Id.
142 Areheart, supra note 5, at 710-11 (“[D]octrines such as disparate impact, reasonable accommodation, and affirmative action require us to consider and make use of information about employee’s identity traits. . . . In short, various antisubordination policies require employers to know of particular identity traits to enable them to compensate for a potentially inequitable practice or state of affairs.”).
consciousness-raising disclosures that are designed to create solidarity and promote acceptance, like Angelina Jolie’s BRCA-1 revelation, would likewise be desirable. If legislators imbue a privacy provision with an antidiscrimination purpose, it would permit or perhaps even encourage disclosure under certain circumstances. To be sure, this approach takes a definitively antisubordination perspective. As discussed in Part II and again this Part, anticlassification embraces the “blindness tropes” so under that regime all disclosures related to protected status are undesirable.

Furthermore, as recently demonstrated in California, legislatures may be more willing to prohibit discrimination than protect privacy. Again tying privacy protections to antidiscrimination might be a useful strategy. It could be more appealing to legislatures to associate privacy protections with antidiscrimination harms. Contrast the California experience with GINA itself. Congress opted to protect genetic privacy by including the prohibition on requesting, requiring, or purchasing genetic information in Title II, making GINA the very first federal employment discrimination statute to restrict access to information related to protected status. Congress was willing to protect privacy to stop discrimination. Thus, had supporters of Genetic Information Privacy Act included those protections within CalGINA, they would have perhaps had greater success. Similarly, if judges understood certain kinds of privacy violations as related to discrimination that could make them open to awarding greater remedies. Hence, advocates of privacy could frame their arguments in terms of the Pandora’s box approach to contextualize the kinds of harms that might come from unauthorized disclosures.

GINA already protects employees from requests for their genetic information. However, other employment discrimination statutes could benefit from bans on requesting, requiring, or purchasing information related to protected status. Title VII again provides a useful case study. As described above not all protected statuses under Title VII are immediately apparent. Consequently, a privacy protection could be useful from the Pandora’s box perspective. However, such a provision could have independent benefits as well by preventing intrusive inquiries into one’s religion, national origin, or racial or ethnic identity. Tethering privacy to antidiscrimination thus simultaneously bypasses discrimination and respects personal autonomy. Privacy law has much to offer antidiscrimination and antidiscrimination has much to offer privacy law. An explicit antidiscrimination purpose can address the weaknesses inherent in the privacy law, thereby leading to more comprehensive protection for genetic information, as well as other protected statuses.
In addition to outlawing invasions of genetic privacy, Congress intended Section 202(b) as a prophylaxis against genetic-information discrimination. Although privacy and antidiscrimination laws have been understood as different kinds of legal protections, this Essay has argued that GINA’s prohibition on requesting, requiring, or purchasing genetic information functions to further the law’s antidiscrimination purpose. Reading the privacy provision in terms of antidiscrimination highlights the work privacy law can do to stop discrimination. Privacy protections offer distinct advantages as tools for antidiscrimination.

However, the possibility that strong privacy norms could discourage useful disclosures and the general apprehension surrounding independent legal protection for pure privacy violations may undermine the utility of such an approach. Thankfully, however, antidiscrimination itself provides a remedy for privacy law’s potential shortcomings. For one, the antisubordination paradigm could guide lawmakers when evaluating which disclosures might be useful both for genetic information and other protected categories, such as to allow accommodation or to promote diversity and solidarity. Further, antidiscrimination—whether from the antisubordination or anticlassification perspective—lends mass to pure privacy law, which is often associated with dignitary harms. By understanding prohibitions on requesting, requiring, or purchasing protected information as designed to preempt discriminatory actions, what appears at first blush to protect against a harm that is solely dignitary in nature is now associated with the another substantive kind of legal wrong. Legislators and judges may thus be more inclined to draft and enforce, respectively, privacy protections when they are linked to the potential for antidiscrimination harms.

CONCLUSION

GINA broke new ground when it included a prohibition on requesting, requiring, or purchasing genetic information in its employment discrimination title. Yet this novel protection does more than safeguard against invasions of genetic privacy. Section 202(b) provides a useful exploration of how privacy law can do the work of antidiscrimination. Specifically, robust privacy protections deny
potential discriminators access to the information that would form the basis of their discriminatory acts. Metaphorically speaking, GINA’s privacy provision serves its antidiscrimination purpose by helping to keep Pandora’s box closed. Thus, while scholars have previously distinguished antidiscrimination and privacy as different kinds of legal protections, GINA’s privacy provision can be understood in explicitly antidiscrimination terms. Recognizing privacy as a powerful weapon against discrimination breaks down the boundary between these two legal paradigms, thereby offering more comprehensive overall protection.

However, despite privacy law’s strong benefits as an alternative antidiscrimination paradigm, norms against disclosure can at times do more harm than good. Additionally, a general disdain surrounding independent privacy violations on the part of legislators or judges could undermine protection. Fortunately, antidiscrimination itself offers the solution. As noted, an antisubordination approach to privacy provides useful insight into when disclosures are desirable. More significantly, tying privacy protections to antidiscrimination allows legislators and judges to understand the kinds of harms that may result from unauthorized disclosures and could, as a result, make them more amendable to providing protection and relief. Thus, invocations of antidiscrimination could help proponents of privacy laws further their cause.

The alliance of privacy and antidiscrimination has powerful implications for genetic information and beyond. Congress and state legislatures ought consider whether bans on requesting, requiring, or purchasing information related to other protected categories, such as race, ethnicity, national origin, religion, age, or disability should be similarly prohibited. Recall the case in which an employer took adverse employment actions after discovering that a racially ambiguous employee was black. One can imagine similar scenarios for other protected statuses. The Pandora’s box approach is therefore a useful antidiscrimination tool in those situations as well. Preventing employers from inquiring into protected status generally could therefore bypass the discrimination that might result if an employer discovers previously unknown information about an employee. While privacy law would be subject to the same shortcomings in these contexts, an explicit antidiscrimination purpose could likewise address the resulting concerns. Thus, the law could provide exceptions to a rule against inquiries into protected status for accommodation or diversity reasons.

In sum, GINA demonstrates how lawmakers can use privacy to prevent discrimination. This observation adds a new weapon to the
antidiscrimination arsenal. Yet like any new armament, privacy law carries with it certain dangers. Thus, while advocates of antidiscrimination should be willing to deploy this exciting new tool, they should likewise remain aware of its drawbacks and never lose sight of their true purpose: to create a more just, equitable world.