2006

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A VEIL OF GENETIC IGNORANCE? PROTECTING GENETIC PRIVACY TO ENSURE EQUALITY

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I. INTRODUCTION

TWO recent events pose the question: Should individuals have a right of genetic privacy—a right to withhold their genetic information from employers, insurers or the government? In the first event, the General Manager of the Chicago Bulls refused to re-sign one of the team’s players, Eddy Curry, unless he took a DNA test to determine whether he had a heart condition that posed a risk of death if he continued to play basketball.1 Curry was offered $400,000 per year for fifty years if he flunked the test, which is quite a lot of money, but much less than the $32 million he sought from his next contract.2 Yet Curry refused to take the test and instead joined the New York Knicks.3 In the second event, IBM announced in October 2005 that it would not use genetic information in its employment decisions. The company sent a letter to all employees stating: “Business activities such as hiring, promotion and compensation of employees will be conducted without regard to a person’s genetics.”

As the IBM and NBA stories suggest, advances in genetics and technology threaten privacy by making it possible to perform genetic tests to reveal each person’s entire genetic identity easily and precisely.4 Employ-

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1. See Liz Robbins, The Knicks Have a Test Case in Medical Ethics, N.Y. TIMES, Oct. 15, 2005, at D3 (noting that Chicago Bulls gave Curry ultimatum even though NBA found such testing unnecessary).

2. See id. (discussing significant monetary ramifications to Curry if his DNA test showed predisposition to heart disease).

3. See id. (noting that Knicks assessed health risks as well, but refused to stigmatize player with medical condition).


5. See Lorraine Sheremeta & Bartha Maria Knoppers, Beyond the Rhetoric: Population Genetics and Benefit-Sharing, 11 HEALTH L.J. 89, 90 (2003) (listing privacy as one of many concerns raised in present DNA testing). With the successful completion of the project to construct a map of the human genome, we have already gained a great deal of knowledge about our genetic identity. See News Release, National Human Genome Research Institute, International Consortium Completes Human Genome Project: All Goals Achieved; New Vision for Genome Research Unveiled, (Apr. 14, 2003), http://www.genome.gov/11006929. Further
ers and insurers are already conducting genetic tests for a number of traits, while the technology to analyze each individual's unique DNA pattern and match it to crime scene evidence is a common tool of law enforcement. The drive to discriminate—to draw distinctions between individuals and consign them to various categories—pressures privacy by creating enormous incentives to obtain genetic information. And the power to obtain so much detailed genetic information so easily and unobtrusively poses a tremendous threat not just to privacy, but also to equality, as is evident in some recent cases.

As these cases reveal, such invasions of privacy do not occur across the board, stripping everyone of their privacy in a uniform fashion. Instead, society appears to single out particular individuals or groups for genetic testing, selectively invading privacy in a manner that also endangers equality. Moreover, the danger to equality lies even deeper. The danger is that individuals will be judged according to genetic stereotypes and divided into groups based upon their genetic predispositions. Thus, invasions of genetic privacy are not only selective, but also segmenting: they balkanize a population based upon its genes, generating genetic divisions that may produce new structures of inequality. Further, statistical predictions that rest upon perceived biological truths may exert unwarranted power, ultimately constraining an individual's ability to forge his or her own identity and destiny and thereby fulfilling a genetic prophecy.

Some scholars suggest that privacy and equality may be at odds—that inequality flourishes within the private sphere, so that protecting privacy could shield deprivations of equality, while protecting equality could require invasions of privacy. Others contend that privacy and advances in genetics may allow us to learn even more about the location and function of each gene in the human genome. In addition, improvements in technology may enable us to extract a maximum of genetic information with minimal intrusion, for example, by permitting sophisticated genetic tests to be performed based upon a minute sample of sloughed-off skin, or even a dropped hair.

6. Indeed, to the extent that constitutional protection rests upon the circular "reasonable expectation of privacy" principle, technological developments may tend to eviscerate genetic privacy by undermining the expectation that one's genetic identity will remain secret.

7. For a discussion of recent cases, see infra notes 22-41 and accompanying text.


9. For example, Catharine MacKinnon contends that the constitutional right of privacy protected in the abortion cases "is a right of men 'to be let alone' to oppress women one at a time." See Catharine MacKinnon, Roe v. Wade: A Study in Male Ideology in Abortion: Moral and Legal Perspectives, 45, 53 (J. L. Garfield & Patricia Hennessy eds., 1984) (quoting Samuel Warren & Louis Brandeis, The Right to Privacy, 4 Harv. L. Rev. 193, 205 (1890)).

10. Thus, Anita Allen suggests that invading privacy by monitoring of the workplace may be necessary in order to protect women's equal right to work. See Anita L. Allen, Uneasy Access: Privacy for Women in a Free Society (1988).
equality protect distinct values that must be disentangled. I believe that privacy and equality are not necessarily opposed. To the contrary, I see a fundamental connection between privacy and equality. I maintain that privacy and equality are linked, at least in the genetic

11. In *Untangling the Strands of the Fourteenth Amendment*, Ira Lupu argues that: “[T]he judicial selection of values for special protection against the majoritarian processes has wavered . . . between a liberty base and an equality base.” See Ira C. Lupu, *Untangling the Strands of the Fourteenth Amendment*, 77 Mich. L. Rev. 981, 982-83 (1979). “This doctrinal imprecision has bred unpredictability, disrespect, and charges of outcome-orientation.” See id. at 985. “The equal protection clause and the due process clause are complementary—not interchangeable—safeguards . . .” See id. “[J]udicial discovery of fundamental libertarian values outside the constitutional text [should be grounded in the due process clause].” See id. “[T]he equality strand . . . should not bear a substantive content . . . equal protection . . . should remain substantially rooted in the pure anti-discrimination concerns that sparked the textual embrace with equality.” See id. Jeffrey Rosen also draws a sharp distinction between privacy and equality, suggesting that the constitutional privacy cases are really about sex equality, whereas the sexual harassment cases are really about invasions of privacy. See Jeffrey Rosen, *The Unwanted Gaze: The Destruction of Privacy in America* 15 (2000) (finding fault in Supreme Court’s “amorphous vision of privacy”).

12. This connection between privacy and equality was made explicit for the first time by the Supreme Court in *Lawrence v. Texas*, 539 U.S. 558 (2003), which protected the privacy rights of same-sex couples in part because of concerns regarding discrimination:

Equality of treatment and the due process right to demand respect for conduct protected by the substantive guarantee of liberty are linked in important respects, and a decision on the latter point advances both interests. If protected conduct is made criminal and the law which does so remains unexamined for its substantive validity, its stigma might remain even if it were not enforceable as drawn for equal protection reasons. When homosexual conduct is made criminal by the law of the State, that declaration in and of itself is an invitation to subject homosexual persons to discrimination both in the public and in the private spheres.

*Id.* at 575.


I regard it as a salutary doctrine that [governments] must exercise their powers so as not to discriminate between their inhabitants except upon some reasonable differentiation fairly related to the object of regulation. [There] is no more effective practical guaranty against arbitrary and unreasonable government than to require that the principles of law which officials would impose upon a minority must be imposed generally. Conversely, nothing opens the door to arbitrary action so effectively as to allow those officials to pick and choose only a few to whom they will apply legislation and thus to escape the political retribution that might be visited upon them if larger numbers were affected.

*Id.* at 112 (Jackson, J., concurring). And Justice Scalia made a similar argument in his concurring opinion in *Cruzan v. Director, Missouri Department of Health*, 497 U.S. 261 (1990), where he asked:

Are there, then, no reasonable and humane limits that ought not to be exceeded in requiring an individual to preserve his own life? There obviously are, but they are not set forth in the Due Process Clause. What assures us that those limits will not be exceeded is the same constitutional guarantee that is the source of most of our protection—what protects us, for example, from being assessed a tax of 100% of our income above the
context, and that protecting genetic privacy may serve as a mechanism to ensure a measure of genetic equality.

Exploring the link between privacy and equality enhances our understanding of why protecting privacy through the vehicle of property law seems so problematic. In general, property laws imply alienability—the right to buy, sell, or trade property to others. As applied to privacy, however, this would mean that some people might be able to purchase others’ rights to privacy. As a result, some people would own a great deal of privacy, while others would end up with little or none, which obviously offends our sense of equality. Thus, the treatment of privacy as a form of property is quite likely to lead to inequality.

The connection between privacy and equality is most obvious in the genetic context, where invasions of privacy go hand-in-hand with discrimi-

subsistence level, from being forbidden to drive cars, or from being required to send our children to school for 10 hours a day, none of which horribles is categorically prohibited by the Constitution. Our salvation is the Equal Protection Clause, which requires the democratic majority to accept for themselves and their loved ones what they impose on you and me. This Court need not, and has no authority to, inject itself into every field of human activity where irrationality and oppression may theoretically occur, and if it tries to do so it will destroy itself.

Id. at 300-01 (Scalia, J. concurring).

14. In this Paper, I address only genetic privacy, but the idea that privacy and equality are linked may possess interesting implications for other aspects of privacy, such as government surveillance and data privacy.

15. Genetic privacy encompasses many different categories of privacy, including informational privacy, physical privacy, decisional privacy and proprietary privacy. See Anita L. Allen, Genetic Privacy: Emerging Concepts and Values, in GENETIC SECRETS: PROTECTING PRIVACY AND CONFIDENTIALITY IN THE GENETIC ERA 31, 33-34 (Mark Rothstein ed., 1997). Genetic testing implicates at least two of these types of privacy because it may require a physical invasion of the body in order to obtain a blood sample, in addition to involving the disclosure of intimate information.

16. In a much-publicized example of the application of property laws to private genetic information, in January 2000, deCODE Genetics purchased the medical records of the entire country of Iceland for approximately $250,000 and the right to receive any drugs derived from this research without charge for the patent period. See Michael D. Lemonick, The Iceland Experiment; How a Tiny Island Nation Captured the Lead in the Genetic Revolution, TIME, Feb. 20, 2006, at 50. Iceland is particularly well suited to such genetic research because the country has had very few immigrants since the Vikings settled there in the ninth century, so that the genetic similarities between its 275,000 citizens combined with the existence of detailed medical records dating back to 1915 and a general cultural interest in genealogy make it an ideal population to study in order to isolate genetic markers for disease. For an equally prominent example of a case that impliedly rejects the application of property law to genetic information, see Moore v. Regents of the University of California, 793 P.2d 479 (Cal. 1990) (denying Moore’s claim for conversion of his spleen cells).

17. See Pamela Samuelson, Privacy as Intellectual Property?, 52 STAN. L. REV. 1125, 1137-38 (2000) (describing some flaws in move to protect data privacy through vehicle of intellectual property that are also connected to alienability).

nation. We are all vulnerable to the risk of genetic discrimination, although history demonstrates that this risk may not be distributed equally throughout the population.\textsuperscript{19} The only sure-fire way to prevent genetic discrimination is to safeguard genetic privacy—to construct a veil of genetic ignorance\textsuperscript{20} around each individual. In so doing, we promise that everyone, regardless of his or her rank in the genetic lottery or place in society, will be protected from the possibility of predictive judgments based upon the fortuity of genetic circumstance in a wide variety of contexts, ranging from employment and insurance to criminal law.\textsuperscript{21}

II. LINKING PRIVACY AND EQUALITY

A. Genetic Privacy and Discrimination

Let us now turn to a case that illustrates the link between privacy and equality, demonstrating how invasions of genetic privacy can facilitate discrimination. In \textit{Norman-Bloodsaw v. Lawrence Berkeley Laboratory},\textsuperscript{22} a group of clerical and administrative workers brought suit alleging that Lawrence Berkeley Laboratory ("LBL") tested their blood and urine for syphilis, pregnancy and the gene for sickle-cell anemia during the course of routine employee health examinations over previous decades. The tests were

\textsuperscript{19} In the 1970s, for example, testing for the gene for sickle-cell anemia, which is disproportionately found in African-Americans, often served as the basis for racial discrimination in employment, insurance, and other contexts. As Vernellia Randall explains:

The military considered banning all African Americans from the armed services. African American airline stewardesses were fired. Insurance rates went up for carriers. Some companies refused to insure carriers. During that period, many African Americans came to believe that the sickle-cell screening initiative was merely a disguised genocide attempt, since often the only advice given to African Americans with the trait was, "Don't have kids."


\textsuperscript{20} Cf. JOHN RAWLS, \textit{A THEORY OF JUSTICE} 453-54 (rev. ed. 1999) (deriving principles of justice from agreements made behind "veil of ignorance").

\textsuperscript{21} I envision the categorization of individuals based upon genetic propensities as simultaneously violating both equality and privacy, although others may perceive it primarily as a violation of autonomy. Thus, Julie Cohen grounds her argument for the protection of data privacy in the idea that a certain degree of freedom from monitoring, scrutiny and categorization by others is necessary in order to ensure meaningful autonomy. \textit{See} Julie E. Cohen, \textit{Examined Lives: Informational Privacy and the Subject as Object}, 52 STAN. L. REV. 1373, 1423-24 (2000) (stating "informational autonomy comports with important values concerning the fair and just treatment of individuals within society"); \textit{see also} Pauline T. Kim, \textit{Genetic Discrimination, Genetic Privacy: Rethinking Employee Protections for a Brave New Workplace}, 96 NW. U. L. REV. 1497, 1501 (2002) (arguing that "employer use of genetic information primarily threatens the value of individual autonomy . . . because personal genetic information has the potential to be used by employers, as well as other institutional actors, in a way that seriously and systematically constrains an individual's life choices").

\textsuperscript{22} 135 F.3d 1260 (9th Cir. 1998).
administered without the employees' knowledge or consent, apparently under the auspices of the United States Department of Energy. While all new employees were examined for syphilis, only African-Americans were screened for the sickle-cell gene and, of course, only women were monitored for pregnancy. African-American and Latino employees were subsequently retested for syphilis during periodic exams, while female employees were regularly checked for pregnancy. Such periodic monitoring was not performed upon white male employees, with one notable exception: a white man married to a black woman was repeatedly screened for syphilis. LBL never explained the discriminatory pattern of testing, nor is there any evidence as to whether the information gathered from these tests was ever used in hiring or firing decisions. Plaintiffs alleged that this testing violated Title VII of the Civil Rights Act of 1964 ("Title VII"), the Americans with Disabilities Act (ADA) and the right to privacy guaranteed to them under both the United States and California Constitutions.23

The district court dismissed all of plaintiffs' claims on statute of limitations grounds, concluding that each cause of action was time-barred because the statutory period began to run at the time the tests were performed.24 In the alternative, the court proceeded to address and reject the Title VII and constitutional privacy claims on the merits. The district court ruled that plaintiffs failed to state a cognizable Title VII claim, reasoning that they had "neither alleged nor shown any connection between these discontinued confidential tests and [their] employment terms or conditions, either in the past or in the future,"25 and holding that "[p]laintiffs' charge of stigmatic harm, stripped of hyperbole, speculation, and conjecture . . . evaporates."26 The court also found no violation of federal and state constitutional privacy rights because the tests were performed as part of a full-scale physical examination that also included a questionnaire covering many of the same topics, so that the additional incremental intrusion posed by the testing was too minimal to amount to an invasion of the plaintiffs' constitutionally protected privacy.

The United States Court of Appeals for the Ninth Circuit reversed, holding that there were genuine issues of material fact as to when the plaintiffs knew or had reason to know that they were being tested and whether the testing was authorized that precluded summary judgment on the statutes of limitation and the constitutional privacy claims. In so doing, the Ninth Circuit became the first federal court of appeals to recognize a constitutional right to genetic privacy, declaring that "[o]ne can think of few subject areas more personal and more likely to implicate privacy interests than that of one's health or genetic make-up."27 The court

23. See id. at 1264-66 (discussing background).
24. See id. at 1266 (discussing district court's holding).
25. See id.
26. See id.
27. See id. at 1269.
reasoned that consent to a general medical examination "does not abolish one's privacy right not to be tested for intimate, personal matters involving one's health—nor does consenting to giving blood or urine samples, or filling out a questionnaire." Thus, even though the plaintiffs had answered written questions as to whether they had ever been afflicted with "venereal disease," "menstrual problems" or "sickle cell anemia," and had voluntarily provided blood and urine samples, the court ruled that the performance of unauthorized tests was nevertheless a significant invasion of their privacy.

The court also ruled that plaintiffs stated a Title VII claim, despite the absence of evidence indicating that the information gathered from the tests was ever used in any hiring or firing decisions, because the unauthorized gathering of sensitive medical information on the basis of race or sex would itself constitute an injury under Title VII. The court found that LBL selectively invaded the privacy of certain employees on the basis of race and sex by singling out black and female employees for additional tests for sickle-cell anemia and pregnancy, respectively, to which white and/or male employees were not subjected. Additionally, because plaintiffs' offers of employment were explicitly conditioned upon their undergoing these tests as part of their medical entrance exam, the court concluded that this requirement quite literally amounted to discrimination in the terms and conditions of employment.

In Norman-Bloodsaw, the invasion of privacy was blatantly discriminatory. Subtler forms of discrimination, however, could easily evade legal liability. If LBL had examined all employees for the sickle-cell trait instead of singling out only African-Americans, for example, it is not clear whether the court would have found any discrimination despite the obvious racially discriminatory impact of this type of genetic testing. Moreover, Judge Reinhardt explicitly conceded that there would probably be no sex discrimination under Title VII "in a case involving two different but equivalent tests administered to men and women," pointing to the hypothetical example of a test "given to men for testicular cancer and to women for ovarian cancer." By this reasoning, genetic testing of African-Americans for the sickle-cell gene, Ashkenazi Jews for the Tay-Sachs gene, and so on, would not violate equality to the extent that all persons would be subject to equivalent invasions of their privacy. Such analysis appears reminiscent of the argument repeatedly rejected by the Supreme Court in Shelley v. Kraemer and Loving v. Virginia, two cases in which the Court recognized that "[e]qual protection of the law is not achieved through indiscriminate imposition of inequalities."

28. See id. at 1270.
29. See id. at 1272.
30. See id.
32. 388 U.S. 1 (1967).
33. See Shelley, 334 U.S. at 22.
B. Privacy and Genetic Discrimination

While *Norman-Bloodsaw* reveals the risk of discriminatory invasions of genetic privacy, another recent case, brought by the Equal Employment Opportunity Commission (EEOC) against Burlington Northern Santa Fe Railway, illustrates how invasions of privacy may be used to perpetrate genetic discrimination. In that case, Burlington Northern Santa Fe Railway conducted blood tests upon employees who filed claims for work-related injuries based on carpal tunnel syndrome, searching for a genetic defect that might predispose the workers to the disease.34 Once again, the workers were allegedly examined without their knowledge or consent. The company even threatened to discipline or to discharge one worker who inadvertently learned the true nature of the blood tests and refused to submit to this type of genetic screening. The EEOC filed a lawsuit to stop the genetic testing as a violation of the ADA.35 The railroad eventually agreed to put an end to this type of genetic testing as part of a workplace discrimination settlement with the EEOC in which the company consented to pay two million dollars to the workers who were subjected to testing.36 Yet the ADA prohibits only discrimination on the basis of genetic information, not the gathering of genetic information itself—even if it goes beyond matters that are job-related and consistent with business necessity.

C. Genetic Privacy Without Discrimination

Individuals have invoked a right of genetic privacy in the criminal justice context as well. All fifty states have enacted statutes to create a DNA database, which requires both the extraction of a blood sample from all who have been convicted of a predicate crime and genetic testing to determine each prisoner's "DNA fingerprint" for the purpose of identifying perpetrators of future crimes.37 Such statutes have been challenged on a number of grounds, including the right to privacy shielded by the


37. *See, e.g.*, COLO. REV. STAT. § 16-11-102.3 (2005) (providing for genetic testing and classification of convicted offenders defined within statute); GA. CODE. ANN. § 24-4-60 (1995) (requiring DNA sample be taken upon conviction of certain sex offenses for inclusion in DNA data bank); MASS. GEN. LAWS ANN. ch. 22E, § 3 (2002) (requiring DNA sample for DNA database within ninety days of conviction for various offenses); MO. REV. STAT. § 650.055 (2005) (providing for blood or other scientifically accepted biological sample for DNA profiling of convicted persons); OR. REV. STAT. § 137.076 (2005) (providing that person convicted of certain defined offenses must provide blood or buccal sample for DNA identification); VA.
Due Process Clause of the Fourteenth Amendment, the freedom from unreasonable searches and seizures guaranteed under the Fourth Amendment and the right to equal protection of the laws provided by the Fourteenth Amendment.

But if the purpose of genetic privacy is to ensure equality, nondiscriminatory uses of genetic information should not receive privacy protection. The genetic information stored in DNA databases is allegedly gathered from “junk DNA”—stretches of DNA that are not associated with predisposition to disease or any other traits. When government uses genetic information solely for the purpose of identification, it does not threaten to categorize individuals based upon their genes or judge them according to genetic stereotypes. Accordingly, courts have uniformly upheld these statutes against constitutional challenges grounded in Fourth and Fourteenth Amendment privacy rights.\(^{38}\) From the perspective of equality, the only remaining problem with such statutes is that prisoners are being singled out for selective DNA testing when such testing is not imposed upon the rest of society. Nevertheless, courts have rejected equal protection chal-

\(^{38}\) See, e.g., D.B. v. Alabama, 861 So. 2d 4, 15 ( Ala. Crim. App. 2003) (holding that taking DNA sample from defendant pursuant to Alabama CODIS statute, which requires that all persons convicted of felony submit blood sample, did not violate Fourth Amendment); In re Leopoldo, 99 P.3d 578, 579 (Ariz. App. Div. 1 2004) (explaining that statutory requirement that minor, who was adjudicated delinquent for attempted felony sexual offenses, provide DNA sample did not violate Fourth Amendment); People v. Edwards, 818 N.E.2d 814, 820-21 (Ill. App. 2004) (reasoning that statute requiring convicted felons to submit blood sample for inclusion in DNA database did not violate Fourth Amendment because defendant had lower expectation of privacy than regular citizens); Smith v. State, 744 N.E.2d 437, 439 (Ind. 2001) (holding that once DNA is collected pursuant to statute authorizing DNA database, DNA can be used by police without violating Fourth Amendment); Landry v. Attorney General, 709 N.E.2d 1085, 1094 (Mass. 1999) (elucidating that involuntary collection of blood sample from all persons convicted of one of thirty-three enumerated offenses, pursuant to DNA database statute, is reasonable search and seizure under Fourth Amendment); Cooper v. Gammon, 943 S.W.2d 699, 704 (Mo. Ct. App. 1997) (reasoning that drawing blood sample from inmates convicted of violent or sex offenses, for purpose of creating DNA profiling database, is reasonable under Fourth Amendment); Ohio v. Cremeans, 825 N.E.2d 1124, 1127 (Ohio. App. 2005) (concluding that compulsory taking of blood sample from defendant pursuant to statute requiring certain offenders to provide DNA specimen did not violate Fourth Amendment right against unreasonable searches); Dial v. Vaughn, 733 A.2d 1, 6 (Pa. Commun. Ct. 1999) (concluding that provision of DNA Detection of Sexual and Violent Offenders Act, under which inmates are required to submit to prerelease withdrawal of blood sample so Commonwealth can maintain DNA identification bank was constitutional); State v. Olivas, 856 P.2d 1076, 1089 (Wash. 1993) (holding that statute requiring involuntary DNA tests of convicted offenders of violent or sex offenses, in order to establish DNA databank, did not violate Constitution); Doles v. State, 994 P.2d 315, 319 (Wyo. 1999) (explaining that statutory requirement that persons convicted of felonies submit DNA samples did not violate Fourth Amendment because collection was reasonable and advanced legitimate state interest in criminal law enforcement).
lenges to such statutes based upon the significant differences between those who have been convicted of a crime and other members of society. Specifically, prisoners pose a greater threat because of the risks of recidivism, while their incarceration justifies according them fewer privacy protections than the rest of society. Recent cases suggest, however, that the rationale for such DNA testing may be expanding beyond prisoners to encompass parolees,\textsuperscript{39} arrestees\textsuperscript{40} and anyone else with a diminished expectation of privacy.\textsuperscript{41}

III. THE LIMITATIONS OF EQUALITY

The preceding examples suggest that the risk of genetic discrimination is real, but any attempt to avert such discrimination cannot rest upon antidiscrimination laws alone\textsuperscript{42} because of the limitations inherent in the ideal of equality.

A. Proper Comparison Groups

The very concept of equality implicitly calls for a comparison—equal to what? Thus, the first problem in any equal protection case is in defining the relevant groups for the purpose of making this comparison. Equal protection doctrine is quite good at providing equality when people are similarly situated; in such cases, all that it requires is that all people be treated the same. Equal protection doctrine, however, has had much greater difficulty in addressing situations where people are differently situ-

\textsuperscript{39} See U.S. v. Kincade, 379 F.3d 813 (9th Cir. 2004) (en banc) (upholding DNA testing of individual on parole).


\textsuperscript{42} Professor Pauline Kim makes a similar argument that “the problem of genetic discrimination in the workplace is better understood using the model of privacy rights rather than the traditional antidiscrimination paradigm.” See Kim, supra note 21, at 1501. Kim believes that “the analogy between genetic discrimination, and race and sex discrimination, is fundamentally flawed.” Id. at 1500. She advocates protecting genetic privacy rather than proscribing genetic discrimination on the grounds that “employer use of genetic information primarily threatens the value of individual autonomy . . . because personal genetic information has the potential to be used by employers, as well as other institutional actors, in a way that seriously and systematically constrains an individual’s life choices.” Id. at 1501.

Unlike Kim, my focus is upon the value of equality rather than autonomy because I fear that invasions of genetic privacy are quite likely to be both selective and segmenting. But, because this type of discrimination resists redress directly as a matter of equality, I argue that we should protect genetic privacy as a mechanism to prevent genetic testing that is likely to result in discriminatory invasions of autonomy.
ated, especially if there is no clear basis for comparison. The best example of this phenomenon is in the area of sex discrimination. Because pregnancy is *sui generis*, it is difficult to see laws regulating pregnancy as discriminatory precisely because there is no real basis for making a comparison. In *Roe v. Wade*, the Supreme Court dealt with this problem by protecting a woman's right to terminate pregnancy as part of her constitutional right of privacy. Thus, privacy provides a vehicle to protect sex equality by affording women a right for which we lack any analogy.

Equality jurisprudence faces a dilemma when there is no adequate basis for comparison, yet it has just as much difficulty dealing with situations when there are too many rather than too few bases for comparison. In *Skinner v. Oklahoma*, for example, an Oklahoma law authorized involuntary sterilization of those thrice convicted of a felony involving moral turpitude, thus allowing the sterilization of chicken thieves but not embezzlers. Once again, this kind of law poses a problem because it is difficult to draw a comparison. What is the relevant classification for the purposes of defining discrimination with respect to involuntary sterilization? Is the relevant comparison between chicken thieves and embezzlers or between those convicted of a crime and the mentally retarded or between prisoners and other persons in society? In *Skinner*, the Court ostensibly struck down Oklahoma's law on the grounds that the distinction between chicken thieves and embezzlers violated the Equal Protection Clause. I would argue, however, that this holding actually recognizes a right to "equal protection privacy"—a privacy right that is premised upon the danger of discrimination and the difficulty in defining the relevant group for the purposes of equality. Indeed, the *Skinner* Court expressly acknowledged that it was protecting a right to be free from involuntary sterilization in large part because of the dangers of discriminatory regulation of procreation.

### B. Legitimate Versus Illegitimate Interests

Equal protection doctrine faces a second problem in determining when discrimination is rationally related to a legitimate interest and when it is illegitimate. Equality jurisprudence has had trouble addressing discrimination that appears "rational" and hence justifiable because it is grounded in real differences that may be germane to legitimate and important interests. Hence, the Supreme Court has upheld sex-based classifications when they seem to reflect differences that are viewed as "real"

43. See, e.g., Geduldig v. Aiello, 417 U.S. 484, 496-97 (1974) (rejecting equal protection challenge to California disability insurance program excluding pregnancy from coverage on grounds that it involved no sex discrimination because scheme distinguished between pregnant and non-pregnant persons, not between women and men).
44. 410 U.S. 113 (1973).
45. 316 U.S. 535 (1942).
because they are the result of biology.\textsuperscript{46} Of course, the most obvious biological difference between the sexes relates to pregnancy and childbirth, so it is not surprising that the Court has had particular difficulty in perceiving regulations of these activities as a form of sex discrimination. Again, privacy offers a possible way out of this predicament.

A related dilemma for equal protection doctrine lies in the distinction between status and conduct, because status-based distinctions may also seem “rational” if they are tied to future conduct. Under current equal protection doctrine, distinctions based upon status are viewed as much more troubling than distinctions based upon conduct.\textsuperscript{47} Perhaps this is attributable to the idea that it is illegitimate to punish a person for his or her status, but that conduct is appropriately subject to government regulation. Purely status-based distinctions may be seen as problematic because they are based upon factors which are beyond an individual’s control and which the individual is powerless to change. The problem is how to address conduct that is intimately intertwined with status, and what to do when conduct and status are so closely connected that a distinction based upon the former is effectively one based upon the latter.\textsuperscript{48}

C. \textit{The Concept of Genetic Discrimination}

All of these problems with equality doctrine are likely to plague any law proscribing genetic discrimination. In one way, we are all genetically \textit{sui generis}, so that there is never any real basis for drawing a comparison. Yet discrimination based upon genetic identity faces both the problem of no precise basis for comparison and too many possible or plausible bases for comparison. While we are each genetically distinct and unique individuals, we also possess multitudes of common genes for a vast number of traits. Moreover, each of us is bound to possess some “genetic flaw” which could serve as the basis for genetic discrimination, but the legitimacy of such genetic discrimination is also in doubt. On the one hand, the discrimination may be deemed appropriate because it is based upon real bio-

\textsuperscript{46} See, \textit{e.g.}, Nguyen v. INS, 533 U.S. 53, 64 (2001) (upholding immigration law making it more difficult for child born abroad to become citizen if citizen parent is father rather than mother because of genetic difficulty of proving paternity versus maternity); Michael M. v. Sonoma County Superior Court, 450 U.S. 464, 472-73 (1981) (upholding California statutory rape law making it criminal to have sex with underage females but not underage males because females biologically bear costs of pregnancy).

\textsuperscript{47} For example, discrimination based solely upon the \textit{status} of being homosexual was struck down by the Supreme Court in \textit{Romer v. Evans}, 517 U.S. 620 (1996), on the grounds that it was inexplicable by anything other than animus towards the class affected, even though the \textit{Romer} Court did not overrule \textit{Bowers v. Hardwick}, 478 U.S. 186 (1986), which upheld criminal prohibitions against homosexual \textit{conduct}. Of course, \textit{Bowers} was overruled seven years later in \textit{Lawrence v. Texas}, 539 U.S. 558 (2003).

\textsuperscript{48} See, \textit{e.g.}, Steffan v. Perry, 41 F.3d 677, 687 (D.C. Cir. 1994) (reasoning that Navy ban on homosexuals survived rational basis review because status of homosexuality is closely connected to homosexual conduct).
logical differences that are germane to legitimate and important interests. On the other hand, it may be seen as illegitimate because it punishes people for a status that is beyond their control and which they are powerless to change, even though this status may be relevant to future conduct or consequences.

IV. CREATING A VEIL OF GENETIC IGNORANCE

Recognizing a right to genetic privacy promises, at least temporarily, to paper over the deep disagreements that plague equality jurisprudence as to when discrimination is or is not legitimate and what is the appropriate basis for comparison. It affords all persons a modicum of genetic privacy in order to avert inequality. The hope is that individuals who are shielded by a veil of genetic ignorance may rest assured that their treatment will not depend upon their rank in the genetic lottery or their place in society. As a result, everyone will be guaranteed a minimum of equal personhood or personal equality.

Of course, recognition of a right to genetic privacy is not a panacea—privacy doctrine possesses its own difficulties. Accordingly, each problem in equal protection is likely to crop up in a different form, mapping onto a corresponding flaw or area of controversy in privacy theory. For example, the question of what is the relevant group may disappear, only to arise again in the question of what measure of privacy is merited in a particular context—in the workplace, in the health care system or in prison. Instead of grappling with the problem of defining the relevant group for the purpose of maintaining genetic equality, the inquiry turns to whether there is a reasonable expectation of genetic privacy in a particular context, or whether an invasion of genetic privacy is otherwise justified by "consent."

49. Some scholars suggest that genetic information is particularly likely to be misunderstood and applied in ways that might result in the stigmatization of those who are deemed to possess "genetic defects," even when they are only carriers of a gene who are unaffected by the disease. To the extent that this is true, there is a danger that genetic discrimination will occur despite the fact that it may be irrational. See Paul Schwartz, Privacy and the Economics of Personal Health Care Information, 76 Tex. L. Rev. 1, 19-22 (1997) (explaining that heterogeneous origins of diseases, genetic polymorphism and fluid state of genetic knowledge make genetic discrimination irrational). Jeffrey Rosen makes a similar argument about private information in general, suggesting that it is likely to be misinterpreted precisely because it is taken out of the context of the individual's entire life. See Rosen, supra note 11, at 9-10 (explaining that genetic information may be misinterpreted because "information taken out of context is no substitute for genuine knowledge that can only emerge slowly over time"). I agree that genetic discrimination is troubling when it is irrational, but I believe that genetic discrimination may be problematic even when it is rational.

50. See, e.g., Ferguson v. City of Charleston, 532 U.S. 67, 94 (2001) (Scalia, J., dissenting, joined by Rehnquist, C.J. and Thomas, J.) (arguing that drug testing of pregnant women by state hospital acting in concert with police was performed with "consent" because women voluntarily gave their urine samples to their doctors in course of medical treatment, even though they were never informed that urine would be tested for drugs or that results of tests would be handed over to police).
Further, technological developments and social practices may effectively eviscerate a right of genetic privacy that rests upon reasonable expectations, for it would be unreasonable for individuals to expect their genetic identities to remain private in the face of pervasive genetic testing.

Similarly, the perplexing problem of when discrimination should be deemed "rational" may be replaced by the problem of what kinds of information should be deemed "private." Thus, questions about the rationality and legitimacy of various forms of genetic discrimination will recede, only to resurface in the guise of distinctions drawn between different types of genetic information. A distinction between content and non-content genetic information, for example, would embody the idea that some forms of information may be less intimate and personal and perhaps more likely to be used in ways that are legitimate rather than discriminatory. Such a distinction would allow DNA to be used as a genetic marker of identity—a "DNA fingerprint"—but not for the purpose of predicting predisposition to disease or other traits. It would permit DNA testing of prisoners solely to identify perpetrators of future crimes, but not to constrain prisoners' choices or limit their opportunities in other, more far-reaching ways.

V. CONCLUSION

Ultimately, the underlying questions regarding the definition of the relevant group and the rationality of genetic discrimination cannot be evaded, nor can the conceptual difficulties with developing a theory of genetic equality be escaped by invoking privacy discourse. But, by changing the focus to examine the expectations of privacy in various contexts and the varying degrees of intimacy of different types of information, the turn to privacy may lead to other, more fruitful and less divisive forms of inquiry. Although the formulation of a right of genetic privacy cannot completely escape the deep conceptual difficulties inherent in a theory of genetic equality, it may serve a pragmatic purpose by uniting egalitarians with libertarians to achieve a common objective. With support from both of these constituencies, there may be a stronger political consensus for shielding genetic privacy than for legislating against genetic inequality. Moreover, the goal of achieving equality may be better served through the mechanism of a privacy right, which does not require the formation of various victim groups in order to exact a remedy.

51. See Paul Schwartz, German and U.S. Telecommunications Privacy Law: Legal Regulation of Domestic Law Enforcement Surveillance, 54 HASTINGS L.J. 751 (2003) (arguing that U.S. Constitutional law draws distinction between "content" and "non-content" telecommunications data). "Non-content" data, which is information that falls short of being the content of a communication, but instead reveals the identities of the parties, their physical locations, electronic addresses and the existence of a communication, falls outside the scope of Fourth Amendment protection. See id. at 752-53; see also Smith v. Maryland, 442 U.S. 735 (1979) (holding that device recording numbers dialed from telephone, but not words spoken in conversation, did not constitute "search" in violation of Fourth Amendment).

52. See supra notes 37-41 and accompanying text.

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