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RACE, SEX AND GENES AT WORK: UNCOVERING THE LESSONS OF *NORMAN- BLOODSAW*

Elizabeth Pendo†

INTRODUCTION

The Genetic Information Nondiscrimination Act of 2008¹ (“GINA”) is the first federal, uniform protection against the use of genetic information in both the workplace and health insurance. Signed into law on May 21, 2008, GINA prohibits an employer or health insurer from acquiring or using an individual’s genetic information, with some exceptions.

One of the goals of GINA is to eradicate actual, or perceived, discrimination based on genetic information in the workplace and in health insurance. Although the threat of genetic discrimination is often discussed in universal terms—as something that could happen to any of us—the use of genetic information implicates other types of discrimination as well. Congress recognized this problem in GINA’s legislative findings:

† Professor of Law, Saint Louis University School of Law. Thank you to my fellow panelists on “Race, Culture, Class and Health Care,” at the SE/SW People of Color Legal Scholarship Conference hosted by Phoenix School of Law, March 28, 2009, and to Nick Brescia and Stacy Connelly for excellent research assistance.

¹ Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, 122 Stat. 881, 881-921 (codified in scattered sections of 26, 29, and 42 U.S.C.) [hereinafter GINA]; 42 U.S.C. § 2000ff.

Although genes are facially neutral markers, many genetic conditions and disorders are associated with particular racial and ethnic groups and gender. Because some genetic traits are most prevalent in particular groups, members of a particular group may be stigmatized or discriminated against as a result of that genetic information.²

Literature discussing issues of race, gender, and genetic information in connection with medical research and health insurance continues to grow.³ Less attention has been given to claims of genetic discrimination in the workplace.⁴ Now is the time to address that gap in the literature, particularly since GINA's employment provisions took effect November 21, 2009.⁵

In its legislative findings, Congress identified the facts of the 1998 case *Norman-Bloodsaw v. Lawrence Berkeley Laboratory*⁶ as a key example of genetic discrimination in the workplace.⁷ *Norman-Bloodsaw* was the first class action suit raising privacy and discrimination claims related to medical and genetic testing in the workplace. In this piece, I focus on the story behind the *Norman-Bloodsaw* case to contextualize some thoughts about the use of genetic information in the workplace after GINA and draw out the troubling connections between genetic information and classifications based on race and sex. Part I provides an overview of GINA, including the significant exceptions to the prohibition against employer acquisition

² GINA, *supra* note 1, at § 2(3).

³ See, e.g., Vence L. Bonham, et al., *Community-Based Dialog: Engaging Communities of Color in the United States Genetics Policy Conversation*, 34 HEALTH POL'Y & L. 325 (2009); Mary Crossley, *Discrimination Against the Unhealthy in Health Insurance*, 54 KAN. L. REV. 73 (2005); Karen Rothenberg, *Breast Cancer, The Genetic 'Quick Fix' and the Jewish Community*, 7 HEALTH MATRIX 97 (1997).

⁴ For an early account of genetic discrimination in the workplace, see generally Paul Steven Miller, *Is there a Pink Slip in My Genes?: Genetic Discrimination in the Workplace*, 3 J. HEALTH CARE L. & POL'Y 225 (2000).

⁵ GINA, *supra* note 1, at § 213; see also The United States Equal Employment Opportunity Commission, Background Information for EEOC Notice of Proposed Rulemaking on Title II of the Genetic Information Nondiscrimination Act of 2008, available at http://www.eeoc.gov/policy/docs/qanda_geneticinfo.html (last visited June 10, 2010) [hereinafter EEOC].

⁶ *Norman-Bloodsaw v. Lawrence Berkeley Lab.*, 135 F.3d 1260 (9th Cir. 1998).

⁷ GINA, *supra* note 1, at § 2(4).

of genetic information. In Part II, I uncover the story behind *Norman-Bloodsaw*, drawing upon the published opinions and briefs, as well as contemporary reports in the national and local media, and a variety of professional publications. In Part III, I highlight two important points that arise from the rich context of *Norman-Bloodsaw* that can guide the interpretation of GINA in the future: genetic testing of workers occurs and is likely to continue even after GINA, and the gathering and use of genetic information in the workplace is not neutral and often exacerbates long-standing patterns of discrimination based on race and sex.

I. THE PROMISE OF GINA

Norman-Bloodsaw was decided in 1998. Since that time, Congress has enacted GINA, the first federal, uniform protection against the use of genetic information in the workplace and in health insurance. GINA prohibits an employer or health insurer from discriminating on the basis of an individual's genetic information, with some exceptions. Title I prohibits health insurers from obtaining genetic information as part of the underwriting process and from using genetic information in making decisions relating to coverage, eligibility, or premiums.⁸ Similarly, Title II prohibits employers from requesting, requiring, or purchasing genetic information, and it also prohibits discrimination on the basis of genetic information.⁹ Indeed, employers may not use genetic information to make employment decisions.¹⁰ Both titles define "genetic information" as information about (1) an individual's genetic tests, (2) the genetic tests of family

⁸ GINA, *supra* note 1, at §§ 101-06.

⁹ GINA, *supra* note 1, at § 202. GINA prohibits disparate treatment based on genetic information, but does not currently prohibit policies or practices that have a disparate impact. In general, a plaintiff alleging disparate treatment must show that a facially neutral employment practice "in fact fall[s] more harshly on one group than another and cannot be justified by business necessity," and need not prove discriminatory intent. *Int'l Bhd. Of Teamsters v. United States*, 531 U.S. 324, 335-36 (1977). GINA does create a bipartisan commission to study this issue and make recommendations. 42 U.S.C. § 2000ff-7.

¹⁰ GINA, *supra* note 1, at § 202. According to the EEOC, this includes decisions based on anticipated costs of employee health plan benefits. EEOC, *supra* note 5.

members, and (3) the manifestation of a disease or disorder in family members.¹¹

There are important exceptions to the prohibition on employer acquisition of genetic information. GINA is not violated where: (1) the information is inadvertently provided as part of the individual's medical history or the medical history of a family member; (2) the information is provided to the employer as part of a service, such as a wellness program that contains certain protections in terms of voluntariness and confidentiality; (3) the information is provided to the employer as part of a request for leave under federal or state law; (4) the information is publicly available, as defined by the statute; (5) the information is gathered as part of a genetic monitoring program of the biological effects of toxic substances in the workplace, with certain safeguards; and (6) the employer operates as a law enforcement entity and requires the individual's DNA for quality control purposes in a forensic lab or human remains identification.¹² Any genetic information an employer possesses must be kept confidential and separate from general employee records.¹³

Title II of GINA provides the same remedies available under Title VII of the Civil Rights Act of 1964¹⁴ ("Title VII"), including reinstatement, hiring, promotion, backpay, injunctive relief, compensatory damages, punitive damages, and attorneys' fees and costs.¹⁵ Title VII's cap on damages applies, and punitive damages are not available against public employers.¹⁶

II. A NEW LOOK AT THE STORY OF *NORMAN-BLOODSAW*

Norman-Bloodsaw is significant because it is the first class action

¹¹ GINA, *supra* note 1, at §§ 102(f)(16)(A), 201(4)(A).

¹² GINA, *supra* note 1, at § 202(b)(1)-(6).

¹³ GINA, *supra* note 1, at § 206.

¹⁴ Civil Rights Act of 1964, Pub. L. 88-352, 78 Stat. 241, Title VII (codified in subchapter VI of chapter 21 of 42 U.S.C. § 2000e).

¹⁵ *Id.*

¹⁶ GINA, *supra* note 1, at § 207; EEOC, *supra* note 5.

that claimed discrimination and invasion of privacy related to genetic and medical testing in the workplace. It drew national attention at the time of filing,¹⁷ argument,¹⁸ and decision on appeal.¹⁹ As noted above, it was also identified by Congress as an example of genetic discrimination in GINA's findings. It continues to be cited, often as a right to privacy case.²⁰

Current citations to *Norman-Bloodsaw* in cases, legislative findings, and legal literature give us a sense of what the case is understood to mean today. But taking a closer look at the circumstances that surrounded this case can help us understand what this story meant to the people involved and their community as it occurred. To that end, in this section I draw upon the case's published opinions and briefs, contemporary reports in the national and local media, and a variety of professional publications in an

¹⁷ See, e.g., Geoffrey Cowley, *Flunk the Gene Test and Lose Your Insurance*, NEWSWEEK, Dec. 23, 1996, at 49. ("Employees of [LBL] recently discovered that the organization had for three decades been quietly testing new hires' blood and urine samples for evidence of various conditions. They claim blacks were screened for the sickle-cell trait, Latinos for syphilis and women for pregnancy."); Dana Hawkins, *A Bloody Mess at One Federal Lab – Officials May Have Secretly Checked Staff for Syphilis, Pregnancy, and Sickle Cell*, U.S. NEWS & WORLD REPORT, June 23, 1997, at 26.

¹⁸ See Pamela McLean, *9th Circuit May Find New Right of Genetic, Biomedical Privacy*, L.A. DAILY J., June 11, 1997, at 4.

¹⁹ See Claire Cooper, *Employees' Privacy Rights Will Get Test – Workers Deserve Trial on Issue, Court Says*, SACRAMENTO BEE, Feb. 4, 1998, at A4; Rick Weiss, *Genetic Tests in Workplace Can be Privacy Breach*, WASH. POST, Feb. 5, 1998, at A8; Victoria Slind-Flor, *Court: Workers Have Right to Privacy*, NAT'L L. J., Feb. 16, 1998, at A8; Dana Hawkins, *Court Declares Right to Genetic Privacy*, U.S. NEWS & WORLD REPORT, Feb. 16, 1998, at 4; Stephanie Armour, *Workers Fear Genetic Discrimination*, USA TODAY, Feb. 25, 1998, at 4B; Julie Gannon Shoop, *Workers are Entitled to Genetic Privacy at Work, Ninth Circuit Holds*, 34 TRIAL 14 (1998); Case Digests, *Court Allows Title VII and Privacy Rights Case Against University of California*, HUM. RESOURCES L. INDEX (2000).

²⁰ A citation report run on November 7, 2009, showed that the *Norman-Bloodsaw* case had been cited 27 times for its holding on mootness (defendant can show that the action cannot reasonably be expected to recur, or that the violation has been remedied); 23 times for its holding on the right to privacy under federal law, state law, or both (plaintiffs did not authorize the test, or defendant revealed the information at issue); 4 times for its holding on the statute of limitations; and a few times on the question of whether Title II of the Americans with Disabilities Act of 1990 (ADA) created a cause of action for employment discrimination.

attempt to recover the story behind the case.²¹

A. "Routine Examinations"

In late 1986, Marya Norman-Bloodsaw, a thirty-three year old African-American woman, applied for a clerical position with the Lawrence Berkeley Laboratory (LBL), a research facility operated by the University of California under contract with the United States Department of Energy (DOE).²² LBL, founded in 1931, is the oldest DOE National Laboratory and is located on a 200 acre site in the hills above the University of California, Berkeley campus.²³

Since 1981, the DOE has required federal contractors such as LBL to establish an occupational medical program, which included "preplacement examinations" of employees. The stated objectives of the program were the following:

... to protect employees from possible health hazards in their work environment; to assure placement in work that can be performed in a reliable and safe manner; to promote early detection, treatment and rehabilitation; and to apply preventative medical measures toward the maintenance of good physical and mental health of LBL employees through health promotion and education.²⁴

The occupational medical program required "preplacement examinations" in order to determine "'the health status and the physical fitness of the individual' to aid in a suitable job placement which would not present a 'health hazard of accident risk' to the individual, other employees, plant facilities, or the public."²⁵

²¹ This approach was inspired by Paul A. Lombardo's work in *Teaching Health Law, Law Archeology: Recovering the Stories behind the Cases*, 36 J.L. MED. & ETHICS 589; see also SANDRA H. JOHNSON ET AL., *HEALTH LAW & BIOETHICS: CASES IN CONTEXT* (ASPEN 2009).

²² LBL webpage, <http://www.lbl.gov/Publications/75th/> (last visited Mar. 4, 2010).

²³ *Id.*

²⁴ Brief of Defendants-Appellees, Regents of the University of California, University of California, Lawrence Berkeley National Laboratory, Charles V. Shank, Henry H. Stauffer, M.D., Lisa Snow, M.D., T. F. Budinger, M.D. and William G. Donald, Jr., M.D., at 9-10, *Norman-Bloodsaw v. Lawrence Berkeley Laboratory*, No. 96-16526 (9th Cir. 1997). [hereinafter Defendants-Appellees Brief].

²⁵ Defendants-Appellees Brief, *supra* note 24, at 10. The order was revised effective June 26, 1992, presumably to comply with the ADA, to require that pre-placement examinations be

Examinations were to be conducted “in accordance with current sound and acceptable medical practices” and include completion of a “medical history, a physical examination, and laboratory studies.”²⁶ Until 1995, it also required contractors to offer optional subsequent “periodic health examinations.”²⁷

Accordingly, Marya received a written offer of employment conditioned upon completion of a “medical examination,” “medical approval,” or “health evaluation.”²⁸ She accepted the offer, and underwent a medical examination in LBL’s medical department on December 16 or 17, 1986.²⁹ Prior to the examination, Marya and other new hires filled out a medical history form, which included questions regarding a number of medical conditions, including “venereal disease,” “sickle cell anemia,” and “menstrual disorders.”³⁰ During the examination, blood and urine samples were taken. Marya was not informed of the specific purpose of the blood and urine testing.³¹ According to news reports, workers thought they were being checked for high cholesterol levels or other common health problems.³² Marya was not provided with the results of the examination or testing.³³

conducted after the offer but before performance of duties. *Id.*

²⁶ Defendants-Appellees Brief, *supra* note 24, at 11.

²⁷ *Norman-Bloodsaw*, 135 F.3d at 1264.

²⁸ *Id.* at 1267.

²⁹ *Id.* at 1265 n.2.

³⁰ *Id.* at 1267.

³¹ Plaintiffs-Appellants Brief at 1-2, *Norman-Bloodsaw v. Lawrence Berkeley Laboratory*, No. 96-16526 (9th Cir. 1996) [hereinafter Plaintiffs-Appellants Brief]; see also Sarah Lavender Smith, *Berkeley Lab Sued Over Medical Tests of Workers*, L.A. DAILY J., Sept. 14, 1995 (“I had no idea what I was being tested for,” said Marya Norman-Bloodsaw).

³² See Samuel Greengard, *Genetic Testing: Should You Be Afraid? It's No Joke*, WORKFORCE, July 1997, at 38 (“All along, workers thought they were giving urine and blood samples for cholesterol screening.”); Hawkins, *supra* note 17, at 26.

³³ *Norman-Bloodsaw*, 135 F.3d at 1265 (noting plaintiffs’ allegation that the tests were conducted without knowledge or consent, and “without any subsequent notification that the tests had been conducted”). There was an issue as to whether one employee had received or reviewed his test results. *Id.* at 1268, n.11 (“Although Covington’s declaration states that he ‘requests and received’ his medical file in 1992, he also stated that he ‘did not open the envelope containing the file after receiving it.’ That Covington received his medical records in 1992 does not, therefore, resolve issues of fact as to whether he learned of

Several employees also underwent examinations before and during the course of their employment.³⁴

B. A Chance Discovery

Eight years after that first examination, Marya requested her LBL medical records as part of a workers' compensation case.³⁵ According to news reports, she "didn't think twice about the letters 'RPR' typed on a page of her employee medical file. Not until her mother, a retired nurse, told her it was a code listing for a syphilis test."³⁶ Marya, then a forty-one year old accounting clerk, was "horrified."³⁷ "It was just hurtful," she reported. "My mother, my brothers and sisters – all of them – its [sic] an intrusion into all of their lives, too."³⁸ Marya became concerned that the testing was part of a "larger, secret DOE experiment."³⁹ She asked some of her colleagues to request their medical records to see if similar tests were conducted.

Another named plaintiff, Vertis Ellis, reported a similar experience:

"Vertis Ellis remembers clearly that evening in late 1994 when she opened the large envelope containing her medical records from work. There, in large type on the top of one form, were the letters "RPR" – medical code for a syphilis exam. But she has never requested or authorized such a test. As the 47-year old African-American came to learn, her employer, [LBL], was testing employees for syphilis. She had also been tested for the sickle cell gene and for pregnancy, and never received results from any of the tests. And not just once, Ellis

the tests before 1995."); see also Matt Fleischer, *Protecting Genome Privacy Proves Hard: Congress is Torn Between Personal Fears, Research Needs*, 22 (48) NAT'L L. J. (2000) ("The doctors did tell plaintiff Mark Covington that he had high blood pressure – but they neglected to say that he had tested positive for sickle-cell trait as well.").

³⁴ Seven current and former LBL employees discovered that they had been tested for these conditions at numerous times before and during employment. *Norman-Bloodsaw*, 135 F.3d at 1264.

³⁵ Greengard, *supra* note 32, at 38; Hawkins, *supra* note 17, at 26.

³⁶ Tony Pugh, *Medical Bias, Experiments Make Blacks Fearful*, CONTRA COSTA TIMES, Aug. 3, 1998, at A1.

³⁷ Hawkins, *supra* note 17, at 27.

³⁸ Fleischer, *supra* note 33.

³⁹ Hawkins, *supra* note 17, at 26.

discovered as she read on, but at each of her six company exams during the past 29 years. "I felt so violated," says Ellis. "I thought, 'Oh, my god. Do they think all black women are nasty and sleep around?'"⁴⁰

At least seven current and former LBL employees—including Eulalio Fuentes, Vertis Ellis, Mark Covington, John Randolph, Adrienne Garcia, and Brendolyn Smith—discovered that they had been tested for these conditions at numerous times before and during employment.⁴¹ Marya and her coworkers concluded that all new hires at LBL were tested for syphilis, Blacks were tested for the sickle cell gene,⁴² and women were tested for pregnancy.⁴³

C. The District Court Decision

Mayra and her coworkers sought the help of The Legal Aid Society - Employment Law Center, which litigates cases that help reform the legal system to better minority and low income workers, including issues of race, gender, and disability discrimination in the workplace.⁴⁴ After receiving a right-to-sue letter from the EEOC,

⁴⁰ *Id.*

⁴¹ *Norman-Bloodsaw*, 135 F.3d at 1264–65. According to the Ninth circuit opinion, between them, plaintiffs underwent fourteen examinations on dates between 1968 and 1999. *Id.* at n.2 (listing dates of examination(s) for each plaintiff).

⁴² Sickle cell anemia is a condition in which the body makes sickle or C-shaped red blood cells instead of round red blood cells. The C-shaped cells can slow or block blood flow and oxygen to parts of the body, causing serious symptoms and complications. Sickle cell *trait* is a genetic condition in which an individual carries the gene that causes sickle cell anemia. The sickle cell gene is only semi-dominant, meaning that both the mother and the father must pass on the gene for a child to be affected. People with sickle cell trait have one normal hemoglobin gene and one defective form of the gene, so their blood may contain some sickle cells and some round cells. They generally don't experience symptoms, but they can pass the gene on to their children. According to the National Institutes of Health, the prevalence of the disease in the U.S. is approximately 1 in 5,000 people. Sickle cell anemia occurs in about 1 out of every 500 African American births, and 1 out of every 36,000 Hispanic American births in the U.S. U.S. Dept. of Health & Human Services, What is Sickle Cell Anemia (Aug. 2008), http://www.nhlbi.nih.gov/health/dci/Diseases/Sca/SCA_WhatIs.html.

⁴³ Hawkins, *supra* note 17, at 26.

⁴⁴ *Norman-Bloodsaw*, 135 F.3d at 1266–67 (9th Cir. 1998); see generally Legal Aid Society, Employment Law Center, <http://www.law-elc.org/index.html> (last visited March 1, 2010).

Marya and six others filed the case on September 13, 1995, on behalf of themselves and other similarly situated employees.⁴⁵

Plaintiffs named the following defendants: LBL, the LBL Director, four physicians in LBL's medical department, and the Regents of the University of California (collectively, the "LBL Defendants"), and the Secretary of the DOE.⁴⁶ Based on the facts above, the plaintiffs asserted three claims: (1) violation of the ADA by requiring or assisting in medical testing that was not job-related; (2) violation of the right to privacy under the federal and California constitutions by conducting the testing, maintaining the results of the testing, and failing to provide adequate safeguards against disclosure; and (3) violating Title VII by targeting Black employees for sickle cell trait testing and women for pregnancy testing.⁴⁷

Meanwhile, other current and former employees continued to request and review their LBL medical files.⁴⁸ Through that process and the LBL defendants' initial disclosures, plaintiffs learned that although all new hires were tested for syphilis, Black and Latino employees were targeted for repeat testing during the course of employment.⁴⁹ Blacks were also targeted for repeat testing for sickle cell trait, and women for repeat testing for pregnancy.⁵⁰ Plaintiffs moved to amend their complaint to include a claim for discrimination under Title VII in connection with the race-targeted retesting for syphilis.⁵¹

While that motion was pending and prior to full discovery, the

⁴⁵ Plaintiffs-Appellants Brief, *supra* note 31, at 2-3; *Norman-Bloodsaw*, 135 F.3d at 1265.

⁴⁶ See Plaintiffs-Appellants Brief, *supra* note 31, at 1. The LBL Director is Charles V. Shank; physicians in LBL's medical department are Henry H. Stauffer, M.D., Lisa Snow, M.D., T. F. Budinger, M.D., William G. Donald, Jr., M.D., and the Regents of the University of California are all collectively, the "LBL Defendants." *Id.* They also named Federico Pena, Secretary of the Department of Energy ("The Federal Defendant"). *Id.*

⁴⁷ *Norman-Bloodsaw*, 135 F.3d at 1265-66; Plaintiffs-Appellants Brief, *supra* note 31, at 2.

⁴⁸ See *Norman-Bloodsaw*, 135 F.3d at 1265 n.5; Plaintiffs-Appellants Brief, *supra* note 31, at 2-3.

⁴⁹ Plaintiffs-Appellants Brief, *supra* note 31, at 2, 38-39.

⁵⁰ Hawkins, *supra* note 17, at 26.

⁵¹ See *Norman-Bloodsaw*, 135 F.3d at 1265 n.5; Plaintiffs-Appellants Brief, *supra* note 31, at 39.

LBL defendants moved for summary judgment.⁵² The district court granted defendant's motion in full on June 10, 1996, dismissing plaintiffs' claims.⁵³ Plaintiffs were granted leave to amend the complaint only if they could allege unauthorized disclosure of the results of the tests.⁵⁴ The primary basis for the district court's dismissal was that plaintiffs' claims were time-barred because the limitations period began to run at the time the tests were conducted—the latest test was conducted on August 16, 1993.⁵⁵ In the alternative, the court found the privacy and Title VII claims were without merit.⁵⁶

As to the ADA claims, the district court held that the medical history questionnaires inquired into areas such as "venereal disease," "sickle cell anemia," and "menstrual problems," and thus put employees on notice that the testing was not job-related or consistent with business necessity.⁵⁷ Given that the most recent examination of any named plaintiff occurred over two years before the filing of the complaint,⁵⁸ any claims under the ADA were therefore time-barred.⁵⁹ The court also rejected the argument that maintenance of the test results in employee medical files constituted a "continuing violation" of the ADA that tolled the limitations period.⁶⁰

The district court held that the privacy claims under federal and state law were barred by the one-year statute of limitation.⁶¹ The court found that the blood and urine analysis occurred as "part of a

⁵² Plaintiffs-Appellants Brief, *supra* note 31, at 4.

⁵³ *Id.*

⁵⁴ *Id.*

⁵⁵ *Norman-Bloodsaw*, 135 F.3d at 1265 n.2, 1266.

⁵⁶ *Id.* at 1266.

⁵⁷ *Id.*

⁵⁸ *Id.* at 1266 n.6. It was undisputed that only two of the plaintiffs, Garcia and Fuentes, underwent examinations after January 26, 1992, the effective date of the ADA. *Id.*

⁵⁹ *Norman-Bloodsaw*, 135 F.3d at 1266.

⁶⁰ *Id.*

⁶¹ *Id.* (citing *Trotter v. Int'l Longshoreman & Warehousemen's Union*, 704 F.2d 1141, 1143 (9th Cir. 1983)) (stating that all privacy claims are subject to a one-year statute of limitations under California law).

comprehensive medical examination to which the plaintiffs had consented," and that each had completed a medical history form including "highly personal questions," including inquiries concerning "venereal disease," "sickle cell anemia," and "menstrual problems."⁶² The court concluded that plaintiffs were aware at the time of their examinations "of sufficient facts to put them on notice" that their blood and urine would be tested for syphilis, sickle cell trait, and pregnancy.⁶³ Because the lawsuit was filed more than one year after the last medical examination of a named plaintiff,⁶⁴ the claims were time-barred.⁶⁵

In the alternative, the district court held that the testing had not violated plaintiffs' due process right to privacy because the testing for syphilis, sickle cell trait, and pregnancy "covered the same area" as the medical history questionnaire.⁶⁶ Although defendants' failed to identify any legitimate governmental purpose for the tests, any "additional incremental intrusion" from the tests was so minimal that no constitutional violation could have occurred.⁶⁷

Finally, the court held that the Title VII claims were time-barred for the same reasons the privacy and ADA claims were time-barred.⁶⁸ It also concluded that plaintiffs had failed to state a cognizable Title VII claim because they had failed to show harm—plaintiffs had "neither alleged nor shown any connection between these discontinued confidential tests and [their] employment terms of conditions, either in the past or in the future."⁶⁹

D. The Appellate Court Opinion

On appeal, plaintiffs sought reversal of the district court's order

⁶² *Id.*

⁶³ *Id.*

⁶⁴ *Norman-Bloodsaw*, 135 F.3d at 1265 n.2 (listing examination date for Garcia).

⁶⁵ *Id.* at 1266.

⁶⁶ *Id.*

⁶⁷ *Id.*

⁶⁸ *Id.*

⁶⁹ *Norman-Bloodsaw*, 135 F.3d at 1266.

granting the LBL Defendants' motion for judgment on the pleadings or motions for summary judgment, and the DOE's motion to dismiss.⁷⁰ The appellate court found significant factual questions that precluded the grant of summary judgment as to the federal and state constitutional privacy claims and the Title VII claims, and the appellate court remanded the case to the district court for proceedings consistent with its ruling.⁷¹ The appellate court addressed the four following key issues in developing its opinion.

1. Statute of Limitations

The appellate court first addressed the statute of limitations issue as to all of the claims. The general federal rule is that "a limitations period begins to run when the plaintiff knows or has reason to know of the injury which is the basis of the action."⁷² The appellate court noted that the district court had not clearly stated why the plaintiffs knew or had reason to know of the injury before the end of the statutory period, but determined that the district court must have reasoned that the plaintiffs knew or should have known about the specific testing because plaintiffs submitted to medical examinations, answered related questions on the medical history questionnaire, and gave blood and urine samples.⁷³

The appellate court disagreed, holding that "whether plaintiffs knew or had reason to know of the specific testing turns on material issues of fact that can only be resolved at trial."⁷⁴ Indeed, the appellate court observed that "[t]he record strongly suggests that plaintiffs' submission to the exam did not serve to afford them notice of the particular testing involved."⁷⁵

⁷⁰ *Id.*; Plaintiffs-Appellants Brief, *supra* note 31, at 3-4.

⁷¹ *Norman-Bloodsaw*, 135 F.3d at 1275-76.

⁷² *Id.* at 1266 (citing *Trotter v. Int'l Longshoremen's & Warehousemen's Union*, 704 F.2d 1141, 1143 (9th Cir. 1983)).

⁷³ *Id.* at 1267 n.8. Defendants contend that for many years signs posted in the health examination rooms and, more recently, in the reception area stated the tests at issue would be administered. *Id.* at 1265.

⁷⁴ *Id.* at 1267.

⁷⁵ *Norman-Bloodsaw*, 135 F.3d at 1267.

Concerning what plaintiffs knew, the appellate court noted that plaintiffs denied that they were informed of the nature of the tests to be performed.⁷⁶ It then stated that the letters sent by LBL provided that a “medical examination,” “medical approval,” or “health evaluation” was a condition of employment and “did not inform plaintiffs that they would be subjected to comprehensive diagnostic medical examination, which would inquire into intimate health matters that were unrelated to their responsibilities as administrative or clerical employees.”⁷⁷

In the absence of evidence of actual notice, the appellate court focused on whether plaintiffs reasonably should have expected that blood and urine testing for syphilis, sickle cell trait, and pregnancy would be part of an occupational medical examination performed according to generally accepted medical practice.⁷⁸ The appellate court noted that “[t]he record, indeed, contains considerable evidence that the manner in which the tests were performed was inconsistent with sound medical practice.”⁷⁹

The issue of reasonable expectations is complicated by the fact that from 1976 to 1992, the DOE *required* contractors like LBL to test for syphilis as part of the occupational medical program.⁸⁰ That order was cancelled and replaced with another as of June 22, 1992, which provided that laboratory studies “may” include “urinalysis and

⁷⁶ *Id.* at 1266–67.

⁷⁷ *Id.*

⁷⁸ *Id.* at 1267.

⁷⁹ *Norman-Bloodsaw*, 135 F.3d at 1267; *see also* Appellants’ Reply Brief at 7, *Norman-Bloodsaw v. Lawrence Berkeley Lab*, No. 96-16526 (9th Cir. 1998) [hereinafter Plaintiffs-Appellants Reply] (noting that the defendants “failed to find a single independent physician who supports occupational testing for syphilis, sickle cell, or pregnancy, or who has actual knowledge of another employer administering such tests.”). Moreover, the court noted, the experts “further agreed that ‘generally accepted standards of occupational medicine’ require employers to inform their employees of the tests to be performed to specify whether the tests are a condition of employment, and provide notification of the results.” *Norman-Bloodsaw*, 135 F.3d at 1267.

⁸⁰ DOE orders required institutions to include syphilis testing in its medical examinations from 1975 until 1992 in accordance with “generally accepted medical practice.” *See* Brief of Federal Appellee, Secretary of Energy Hazel O’Leary at 5–6, 15, *Norman-Bloodsaw v. Lawrence Berkeley Lab*, No. 96-16526 (9th Cir. 1998) [hereinafter DOE Brief].

serology when indicated.”⁸¹ However, there was no evidence that the DOE required testing for sickle cell trait or pregnancy, or recommended that testing for syphilis be race-targeted.⁸²

Finally, the appellate court rejected defendants’ argument that the medical history form, which included questions regarding a number of medical conditions, including “venereal disease,” “sickle cell anemia,” and “menstrual disorders,” put plaintiffs on notice of testing for syphilis, sickle cell trait, and pregnancy. The appellate court held, “it is not reasonable to infer that a person who answers a questionnaire upon personal knowledge is put on notice that his employer will take intrusive means to verify the accuracy of his answers.”⁸³ The appellate court then turned to the merits of the claims.

2. *The Privacy Claims*

The appellate court reversed the dismissal of the privacy claims under federal and state law, holding that “material issues of fact exist with respect to whether the defendants had any interest at all in obtaining the information and whether plaintiffs had a reasonable expectation of privacy under the circumstances.”⁸⁴ The appellate court explained that when adjudicating privacy claims like the plaintiffs’, it must balance the defendants’ interests in conducting the tests against the plaintiffs’ expectations of privacy while considering

⁸¹ The reason given for the cancellation was “limited usefulness for screening health populations for the presence of syphilis.” DOE Brief, *supra* note 80, at 7 n.2. In its brief, the DOE argued that the claims against it were moot because the only testing the DOE ever required was syphilis testing, the order requiring such testing was cancelled on June 22, 1992 and replaced with an order that required testing of blood and urine “when indicated.” The court rejected this argument. *Norman-Bloodsaw*, 135 F.3d at 1274.

⁸² See DOE Brief, *supra* note 80, at 5–6. At LBL, testing for sickle cell trait was done as early as 1968 and continued until 1995 because, in the opinion of the LBL Medical Director, the inclusion of such a test in a general medical examination was consistent with “good medical practices.” Defendants-Appellees Brief, *supra* note 24, at 14. LBL discontinued syphilis testing in April 1993, and mandatory pregnancy testing in December 1994. See *Norman-Bloodsaw*, 135 F.3d at 1265.

⁸³ *Norman-Bloodsaw*, 135 F. 3d at 1268.

⁸⁴ *Id.* at 1271.

the degree of intrusiveness, the state's interest requiring the intrusion, and the efficacy of the intrusion to meet the state's interest.⁸⁵

As to the federal claim, the appellate court stated that performing unauthorized medical tests is one of the most basic violations of the right to privacy, opining, "[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."⁸⁶ It also noted that the need for protection is even greater when the testing reveals intimate information relating to family and sexual history, as well as reproductive decision-making.⁸⁷

The appellate court also rejected the argument that the additional intrusion of the tests, in the context of a general medical exam, was so minimal that the government need not demonstrate a legitimate interest, or in the alternative, that the additional intrusion was so minimal that the plaintiffs' privacy interest was outweighed by the government's legitimate interest in performing pre-placement examinations.⁸⁸ The only legitimate interest offered for the tests was a statement by the LBL Medical Director that such tests were consistent with good medical practices.⁸⁹ The appellate court ruled the government's legitimate interest was not sufficient to outweigh plaintiffs' privacy interest because the existence of the government's interest in performing pre-placement examinations depended upon an assumption—the pre-placement examinations were part of an ordinary general medical examination—that the appellate court had rejected when it ruled plaintiffs had not been put on notice about the tests.

The court reached a similar conclusion with respect to the state privacy claim.⁹⁰ The appellate court noted, "[t]he only possible

⁸⁵ *Id.* at 1269.

⁸⁶ *Id.*

⁸⁷ *Id.* at 1269-70.

⁸⁸ *Norman-Bloodsaw*, 135 F. 3d at 1269.

⁸⁹ *Id.*; Plaintiffs-Appellants Brief, *supra* note 31, at 22.

⁹⁰ The California Constitution recognizes a right to privacy. CAL. CONST. ART. I, § 1. The

difference . . . is the threshold requirement that the invasion be serious, and for purposes of summary judgment, that requirement has been more than met.”⁹¹

3. Title VII

The appellate court reversed the dismissal of plaintiffs’ claims under Title VII. Title VII prohibits employment practices that “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.”⁹² In 1978, the Pregnancy Discrimination Act amended Title VII to clarify that discrimination “because of sex” included discrimination “because of or on the basis of pregnancy, childbirth, or related medical conditions.”⁹³ Although Title VII does not generally prohibit an employer from conducting or requiring medical examinations of employees, it does prohibit the imposition of medical examinations (or any other terms or conditions) upon an employee or group of employees based on membership in a protected class.⁹⁴

In this case, plaintiffs alleged that the use of testing to “selectively invade the constitutional rights of women and minorities”⁹⁵ violated Title VII.⁹⁶ The LBL Defendants did not dispute that they singled out certain employees for the tests at issue based on sex and race, but argued that plaintiffs could show no tangible job

elements of a claim for invasion of privacy under California law are: (1) the existence of a legally protected privacy interest; (2) a reasonable expectation of privacy; and (3) conduct by the defendant constituting a serious invasion. *Norman-Bloodsaw*, 135 F.3d at 1271 (citing *Hill v. Nat’l Collegiate Athletic Ass’n*, 865 P.2d 633, 657 (Cal. 4th 1994)).

⁹¹ *Id.* at 1271.

⁹² 42 U.S.C. § 2000e-2(a)(1).

⁹³ 42 U.S.C. § 2000e(k).

⁹⁴ See generally Title VII, 42 U.S.C. § 2000e-2 (2008); Plaintiffs-Appellants Brief, *supra* note 31, at 34.

⁹⁵ Plaintiffs-Appellants Brief, *supra* note 31, at 34.

⁹⁶ See *Int’l Bhd. of Teamsters v. United States*, 431 U.S. 324, 335–36 n.15 (1977). A plaintiff alleging disparate treatment must show that her employer intentionally treated her differently than other employees because of her sex. See generally *McDonnell Douglass Corp. v. Green*, 411 U.S. 792 (1973) (discussing a prima facie case of disparate treatment).

detriment as a result of the testing.⁹⁷

The appellate court reversed the district court's grant of summary judgment for LBL on the Title VII claims, holding that plaintiffs had stated a claim under Title VII.⁹⁸ The appellate court reasoned that:

the employment of women and blacks at [LBL] was conditioned in part on allegedly unconstitutional invasions of privacy to which white and/or male employees were not subjected. An additional 'term or condition' requiring an unconstitutional invasion of privacy is, without doubt, actionable under Title VII. Furthermore, even if the intrusions did not rise to the level of unconstitutionality, they would still be a 'term' or 'condition' based on an illicit category as decreed by the statute and this a proper basis for a Title VII action.⁹⁹

4. *The ADA Claims*

The appellate court upheld the dismissal of plaintiffs' claims under the ADA,¹⁰⁰ which provides that no employer "shall discriminate against a qualified individual with a disability because of the disability of such individual in regard to job application procedures, the hiring, advancement, or discharge of employees, employee compensation, job training, and other terms, conditions, and privileges of employment."¹⁰¹ Although the ADA does not explicitly address genetic conditions or genetic testing, it does restrict the employer's ability to make disability-related inquiries¹⁰² and

⁹⁷ See *Norman-Bloodsaw*, 135 F.3d at 1272; Defendants-Appellees Brief, *supra* note 24, at 59.

⁹⁸ *Norman-Bloodsaw*, 135 F.3d at 1272.

⁹⁹ *Id.*

¹⁰⁰ *Id.* at 1274.

¹⁰¹ 42 U.S.C § 12112(a) (2008).

¹⁰² According to the United States Equal Employment Opportunity Commission ("EEOC"), a "disability-related question" is a question (or series of questions) that is likely to elicit information about a disability, including questions concerning genetic information. See generally, U.S. EQUAL EMPLOYMENT OPPORTUNITY COMM'N, ABA ENFORCEMENT GUIDANCE: PREEMPLOYMENT DISABILITY-RELATED QUESTIONS AND MEDICAL EXAMINATIONS, EEOC, Notice No. 915.002 (Oct. 10, 1995) [hereinafter PREEMPLOYMENT QUESTIONS & MEDICAL EXAMINATIONS], <http://www.eeoc.gov/policy/docs/medfin5.pdf>.

conduct medical examinations,¹⁰³ which may include “blood, urine, saliva, and hair analyses to detect disease or genetic markers (e.g., for conditions such as sickle cell trait, breast cancer, Huntington’s disease).”¹⁰⁴

The ADA creates three categories of medical inquiries and examinations by employers: those made pre-offer, post-offer, and during employment.¹⁰⁵ Before an offer is made, an employer is generally prohibited from asking disability-related questions or requiring a medical examination whether or not relevant to the job.¹⁰⁶ After an offer is made, the employer can request a medical examination as a condition of starting work.¹⁰⁷ At this point, an employer may make disability-related inquiries and conduct medical examinations, regardless of whether they are related to the job, as long as it does so for all entering employees in the same job category.¹⁰⁸ During employment, an employer may request medical information and require medical examinations that are “job-related and consistent with business necessity.”¹⁰⁹ At all times, the information must be treated as a confidential medical record,¹¹⁰ and it may not be used as a basis for prohibited discrimination.¹¹¹

¹⁰³ According to the EEOC, a “medical examination is a procedure or test that seeks information about an individual’s physical or mental impairment or health.” PREEMPLOYMENT QUESTIONS & MEDICAL EXAMINATIONS, *supra* note 102, at 13.

¹⁰⁴ U.S. EQUAL EMPLOYMENT OPPORTUNITY COMM’N, EEOC ENFORCEMENT GUIDANCE ON DISABILITY-RELATED INQUIRIES AND MEDICAL EXAMINATIONS OF EMPLOYEES UNDER THE AMERICANS WITH DISABILITIES ACT (ADA), EEOC Notice No. 915.002 (June 27, 2000), <http://www.eeoc.gov/policy/docs/guidance-inquiries.html>.

¹⁰⁵ 42 U.S.C. § 12112(d)(2)–(4) (2008); *Norman-Bloodsaw*, 135 F.3d at 1273.

¹⁰⁶ 42 U.S.C. § 12112(d) (2008); *see also* 29 C.F.R. §§1630.13(a), 1630.14 (1998); PREEMPLOYMENT QUESTIONS & MEDICAL EXAMINATIONS, *supra* note 102, at 5–8.

¹⁰⁷ 42 U.S.C. § 12112(d)(3) (2008).

¹⁰⁸ *Id.* However, if an individual is screened out because of a disability, the employer must show that the exclusionary criterion is job-related and consistent with business necessity. 42 U.S.C. § 12112(b)(6); 29 C.F.R. §§ 1630.10, 1630.14(b)(3) (1998).

¹⁰⁹ 42 U.S.C.A. § 12112(d)(4)(A) (2008); *see also* 29 C.F.R. § 1630.10 (1998).

¹¹⁰ 42 U.S.C. § 12112(d)(3)(B) (2008).

¹¹¹ 42 U.S.C. §§ 12112(d)(4)(C), (d)(1) (2008) (medical examinations and inquiries must be consistent with the general prohibitions in section 12112(a) against discrimination on the

Only two of the named plaintiffs were subjected to medical examinations after the effective date of the ADA, and both were post-offer, pre-placement exams.¹¹² Accordingly, the court held that plaintiffs did not state a claim under the ADA because examinations conducted after an offer has been made but prior to beginning work need not be limited to job-related functions.¹¹³ Plaintiffs' ADA claims also failed because they did not offer any evidence that defendants improperly disclosed or made use of the tests' information.¹¹⁴

E. Settlement

In sum, the appellate court found significant factual questions that precluded the grant of summary judgment as to the federal and state constitutional privacy claims and the Title VII claims, and remanded the case to the district court for proceedings consistent with its ruling.

The parties then reached a settlement agreement totaling \$2.2 million.¹¹⁵ Pursuant to the agreement, the defendants agreed to implement new procedures prohibiting testing without informed consent of the employees, giving current and former employees the right to review their medical files, and the right to expunge any testing information related to syphilis, pregnancy or any tests, positive or negative, for the sickle-cell trait.¹¹⁶

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basis of disability); *see also* 29 C.F.R. § 1630.14(b)(3) (1998) (if the results of the examination exclude an individual on the basis of disability, "the exclusionary criteria must be job-related and consistent with business necessity").

¹¹² *Norman-Bloodsaw*, 135 F.3d at 1273; Defendants-Appellees Brief, *supra* note 24, at 5.

¹¹³ *Norman-Bloodsaw*, 135 F.3d at 1273.

¹¹⁴ *Id.* at 1274.

¹¹⁵ Pamela A. MacLean, *Lawrence Labs Reaches 2.2M Accord in Biological Privacy Case*, L.A. DAILY J., Dec. 10, 1999, at 1.

¹¹⁶ *Id.* at 2. Fleischer, *supra* note 33, at A1 ("The [9th Circuit] stingingly rebuked the lab last year, and at a July 13 hearing, the lab said that it had agreed to restrictive consent rules for the use of genetic information, to the imposition of a monitor and to a \$4,050 payout to each of the plaintiffs.").

GINA

There is disagreement about the extent of genetic discrimination that occurred prior to GINA. Some have characterized GINA as a preemptive statute, arguing there is little evidence that discrimination based on genetic information occurs.¹¹⁷ Others point to the considerable amount of anecdotal evidence of genetic discrimination in a variety of contexts.¹¹⁸ I won't settle that debate here. I offer that the experiences of Marya Norman-Bloodsaw and her coworkers show that genetic testing in the workplace does impact real people. According to news reports, the class of employees and job applicants affected by the settlement in the *Norman-Bloodsaw* case "stretched back 27 years to 1972 and involve[d] as many as 8,000 people."¹¹⁹ Moreover, a 2004 survey conducted by the American Management Association found that 3% of responding companies reported testing for breast or colon cancer, 2% for sickle cell anemia, and 1% for Huntington's disease—all of which can have genetic links.¹²⁰ Approximately 15% of responding companies also collected family medical histories, which can reveal genetic information about the employee and his or her family.¹²¹ While the numbers may appear relatively small, they suggest that the situation in *Norman-Bloodsaw* is not an isolated incident.

¹¹⁷ See, e.g., Jessica L. Roberts, *Preempting Discrimination: Lessons from the Genetic Information Nondiscrimination Act*, 63 VAND. L. REV. 1 (2010).

¹¹⁸ See generally *id.* at 25–29 (summarizing cases and anecdotal evidence of genetic discrimination); Miller, *supra* note 4, at 232–37 (summarizing evidence of discrimination by employers); Susan M. Wolf & Jeffrey P. Kahn, *Genetic Testing and the Future of Disability Insurance: Ethics, Law & Policy*, 35 J. L., MED. & ETHICS 6 (2007); Paul R. Billings et al., *Discrimination as a Consequence of Genetic Testing*, 50 AM. J. HUM. GENETICS 476 (1992); Karen Kaplan, *U.S. Military Practices Genetic Discrimination in Denying Benefits*, L.A. TIMES, Aug. 18, 2007, at A1; Shaun Assael, *Genetic Property: A new law protecting genetic information could but heads with an MLB policy*, ESPN THE MAGAZINE, Oct. 7, 2009, at 1–2 (discussing the 2005 case in which the Chicago Bulls refused to extend the contract of NBA forward Eddy Curry unless he took a genetic test for susceptibility to cardiomyopathy).

¹¹⁹ Pamela MacLean, *Keeping Your Genes Zipped: Congress Slow to Adopt Genetic Privacy Protections* (July 27, 2000), <http://www.marketwatch.com/story/keeping-your-genes-zipped>.

¹²⁰ AM. MGMT ASS'N, *AMA 2004 WORKPLACE TESTING SURVEY: MEDICAL TESTING 2* (2004).

¹²¹ *Id.*

In addition, completion of the Human Genome Project in 2003 raised the stakes, as clinical genetic tests are becoming available at a rapid rate, with 1,798 clinical genetic tests currently available.¹²² It is fair to say that the risk of genetic discrimination increases as genetic tests become more available, and genetic information is more commonly included in medical records.

Does GINA solve the problem? I would like to highlight two important points from the story of *Norman-Bloodsaw* that can inform our answer to that question, and guide the interpretation of GINA. First, genetic testing of workers occurs, and genetic information is likely to remain available to employers even after GINA. Second, the collection and use of genetic information in the workplace is not neutral, and often exacerbates long-standing patterns of discrimination based on race and sex.

A. Genetic Information in the Workplace

If *Norman-Bloodsaw* were decided today, it appears that LBL's policy of testing employees for sickle cell trait would violate GINA, although testing for pregnancy, syphilis, and other non-genetic conditions would not. However, genetic testing and access to genetic information in the workplace is likely to continue even after GINA.

GINA generally prohibits an employer from acquiring or using an employee's genetic information. In particular, GINA closes the gap left by the ADA for post-offer, pre-placement medical testing. According to the EEOC, employers are no longer permitted to obtain any genetic information, including family medical history, from post-offer applicants.¹²³ However, if an employee submits to a medical examination and signs an authorization for the release of his or her medical records, the employer could incidentally acquire genetic information contained in the medical record, as currently there is no consistent, reliable method for segregating genetic information from

¹²² GeneTests.org, <http://genetests.org> (last visited May 20, 2010).

¹²³ Regulations Under the Genetic Information Nondiscrimination Act of 2008, 74 Fed. Reg. 9056, 9061 (proposed Mar. 2, 2009) (to be codified at 29 C.F.R. pt. 1635).

general medical information.¹²⁴

As noted above, there are exceptions to the prohibition against employer acquisition of genetic information. Notably, GINA permits “genetic monitoring” or periodic examination of employees for the purpose of monitoring the effects of exposure to workplace toxins.¹²⁵ This exception is subject to strict requirements, as genetic monitoring may occur only if:

(A) the employer provides written notice of the genetic monitoring to the employee;

(B) (i) the employee provides prior, knowing, voluntary and written authorization; or (ii) the genetic monitoring is required by Federal or State law;

(C) the employee is informed of individual monitoring results;

(D) the monitoring is in compliance with

(i) any Federal genetic monitoring regulations, including any such regulations that may be promulgated by the Secretary of Labor pursuant to the Occupational Safety and Health Act of 1970 (29 U.S.C. 651 et seq.), the Federal Mine Safety and Health Act of 1977 (30 U.S.C. 801 et seq.), or the Atomic Energy Act of 1954 (42 U.S.C. 2011 et seq.); or

(ii) State genetic monitoring regulations, in the case of a State that is implementing genetic monitoring regulations under the authority of the Occupational Safety and Health Act of 1970 (29 U.S.C. 651 et seq.); and

(E) the employer, including any licensed health care professional or board certified genetic counselor that is involved in the genetic monitoring program, received the results of the monitoring only in aggregate terms that do not disclose the identity of specific employees.¹²⁶

The record strongly suggests that the testing in *Norman-Bloodsaw* was without knowledge or consent, the tested employees were not

¹²⁴ See Mark Rothstein, *GINA, the ADA and Genetic Discrimination in Employment*, 36 J.L. MED. & ETHICS 837, 837-38 (2008).

¹²⁵ 42 U.S.C. § 2000ff-1(b)(5) (2008).

¹²⁶ *Id.*

provided with the results of testing, and the results were disclosed and maintained by the employer in a manner that identified the employees. However, at least some of the testing was done pursuant to DOE's mandatory occupational medical program, which was justified at least in part on safety grounds. According to the DOE, the occupational medical program required pre-placement examinations in order to determine "the health status and the physical fitness of the individual' for placement purposes, and to avoid placements which would present a 'health hazard or accident risk' to the individual, other employees, plant facilities, or the public."¹²⁷ There were also some suggestions by LBL that it conducted the testing for safety reasons, although these were less convincing.¹²⁸

The *Norman-Bloodsaw* experience suggests that we should be skeptical of safety justifications in general, including where required by state or federal authorities. It also suggests that genetic testing and the use of genetic information in the workplace must be scrutinized carefully despite the veneer of scientific objectivity. Scholars have made similar arguments with regard to other types of testing used to select and screen workers, including psychological testing, drug testing, and general medical testing.¹²⁹ We need to ask these questions again with respect to GINA's exceptions.

¹²⁷ Defendants-Appellees Brief, *supra* note 24, at 10.

¹²⁸ LBL spokesman Ron Kolb also reported to the press that the tests were "a service to employees and helped identify workers who could not be assigned to areas where radiation or other hazards were present." Claire Cooper, *Appeals Court Says Lab Workers Entitled to Trial on Secret Testing*, SCRIPPS HOWARD NEWS SERV., Feb. 4, 1998. In their brief, the LBL Defendants asserted that "[o]ver the years LBL has attempted to educate employees to the risk which radiation poses to reproduction and the specific risks which radiation poses to the fetus." Defendants-Appellees Brief, *supra* note 24, at 15.

¹²⁹ See, e.g., ELAINE DRAPER, RISKY BUSINESS: GENETIC TESTING AND EXCLUSIONARY PRACTICES IN THE HAZARDOUS WORKPLACE 15-20 (1991) [hereinafter RISKY BUSINESS]; Elaine Draper, *The Screening of America: The Social and Legal Framework of Employer's Use of Genetic Information*, 20 BERKELEY J. EMP. & LAB. L. 286, 291 (1999) [hereinafter *The Screening of America*]; Sharona Hoffman, *Preplacement Examinations and Job-Relatedness: How to Enhance Privacy and Diminish Discrimination in the Workplace*, 49 U. KAN. L. REV. 517 (2001); Susan J. Stabile, *The Use of Personality Tests as a Hiring Tool: Is the Benefits Worth the Cost?*, 4 U. PA. J. LAB & EMP. L. 279 (2002).

B. Connections to Race and Sex Discrimination

The story behind *Norman-Bloodsaw* also illustrates that the acquisition and use of genetic information in the workplace is not neutral, and often reflects and reinforces long-standing patterns of stratification by race and sex. As suggested by one author, “[s]ocial stratification and discrimination are major problems with genetic information, in part because the layering of our society by race and ethnicity, gender, and social class affects the ways in which such information is used.”¹³⁰ In other words, the use of genetic information is not entirely separate from existing patterns of race and sex discrimination, rather these can be interlocking systems of classification and discrimination in the workplace.

Norman-Bloodsaw is often cited as a right to privacy case,¹³¹ which tends to obscure the race- and sex-based targeting of LBL’s testing. LBL singled out blacks for sickle cell testing, and blacks and Latinos for repeated syphilis testing. As explained by the plaintiffs:

the testing of all African-American employees for sickle cell trait and disease, and the disproportionate testing of African-American and Latino employees for syphilis label these employees as more likely to be carriers of sexually transmitted disease as well as genetic traits deemed undesirable, on the basis of race and national origin, and thus adversely affect the status of the plaintiffs.¹³²

The implication that some employees were more likely to be exposed to syphilis was not lost on the employees—as noted above one female employee, Vernon Ellis, said she felt “violated” by LBL’s conduct, which implied that “all black women are nasty and sleep around.”¹³³ The theme of sexual contagion was also suggested by another news report, noting that “[t]he workers say the repeated testing was not performed on the blood samples of white male employees, with one notable exception: a white man married to a

¹³⁰ *The Screening of America*, *supra* note 129, at 291.

¹³¹ See *supra* note 20 and accompanying text.

¹³² Plaintiffs-Appellants Brief, *supra* note 31, at 44.

¹³³ Hawkins, *supra* note 17, at 26.

black woman was repeatedly screened for syphilis.”¹³⁴

Women were also singled out for pregnancy testing, purportedly in connection with reproductive harms, although there was no indication that women were exposed to reproductive harms in the workplace, or that men were not similarly subject to any such harms.¹³⁵

The race- and gender-targeted testing at LBL suggests that we need to ask what types of workers get tested, for what conditions, and why. These questions are important, as GINA does not speak to the targeted nature of the testing in *Norman-Bloodsaw*, nor does it reach every place where discrimination occurs.¹³⁶

The story of *Norman-Bloodsaw* also connects to the well-known history of medical professionals exploiting communities of color, and the resulting distrust of medicine and medical testing within those communities.¹³⁷ The only genetic test conducted by LBL was for sickle cell trait. In their brief, the plaintiffs noted the history of stigmatization and discrimination against carriers of sickle cell trait, including “narrowing of economic opportunities, including exclusion from military aircrews.”¹³⁸ The history of stigma and discrimination

¹³⁴ *Id.*

¹³⁵ See RISKY BUSINESS, *supra* note 129, at 65 (discussing social construction of fetal protection policies and stratification by sex in the workplace). In addition, at least one news report noted the potential link between genetic information and gender discrimination. Marian Raab, *Genetic Shakeup*, WORKING WOMAN, Oct. 1998, at 14 (stating that “[w]omen are particularly vulnerable if employers begin to use the tests routinely because breast cancer runs in families.”).

¹³⁶ GINA applies only to employment and health insurance—it does not prohibit the use of genetic information on other forms of insurance, such as life, disability or long-term care insurance. See Wolf & Kahn, *supra* note 118, at 6; Billings et al., *supra* note 118, at 476. It also does not reach other contexts in which the use of genetic information has been problematic, including the military and professional sports. See Kaplan, *supra* note 118, at A1; Assael, *supra* note 118, at 1–2.

¹³⁷ See Vernillia R. Randall, *Slavery, Segregation and Racism: Trusting the Health Care System Ain't Always Easy! An African American Perspective on Bioethics*, 15 ST. LOUIS U. PUB. L. REV. 191, 191–92 (1996); Vence L. Bonham, et al., *Community-Based Dialogue: Engaging Communities of Color in the United States Genetics Policy Conversation*, 34 HEALTH POL. POL'Y & L. 325, 325–28 (2009).

¹³⁸ Plaintiffs-Appellants Reply, *supra* note 79, at 21–22 (citing Lori Andrews, Medical Genetics: A Legal Frontier 18–24 (ABA 1987); see also V.M. VOGLE, ET AL., *Sickle Cell Anemia Trait in the*

associated with sickle cell trait and disease also was specifically noted by Congress in GINA's findings:

discrimination was evident in the 1970s, which saw the advent of programs to screen and identify carriers of sickle cell anemia, a disease which afflicts African-Americans. Once again, State legislatures began to enact discriminatory laws in the area, and in the early 1970s began mandating genetic screening of all African Americans for sickle cell anemia, leading to discrimination and unnecessary fear. To alleviate some of this stigma, Congress in 1972 passed the National Sickle Cell Anemia Control Act, which withholds Federal funding from States unless sickle cell testing is voluntary.¹³⁹

Upon discovery of the testing, Marya Norman-Bloodsaw wondered if the tests "were part of a larger, secret [DOE] experiment."¹⁴⁰ It was undisputed that at the time of the appeal the testing results were still held at LBL, and there was some suggestion that the results were used for research. According to the plaintiffs, documents disclosed by LBL indicated that the U.S. Department of Energy regarded LBL employee medical files as "valuable epidemiologic research records."¹⁴¹ The connections to a shameful history of exploitation were not lost on the media, which referenced the history of sickle cell trait and disease as well as the infamous Tuskegee experiment.¹⁴² In the words of one of the named plaintiffs,

Military Aircrew Population: A Report from the Military Aviation Safety Subcommittee of the Aviation Safety Committee, ASMA, AVIATION, SPACE AND ENVIRON. MED. (1991).

¹³⁹ GINA, *supra* note 1; *see generally*, KEITH WAILOO & STEPHEN PEMBERTON, *THE TROUBLED DREAM OF GENETIC MEDICINE: ETHNICITY AND INNOVATION IN TAY-SACHS, CYSTIC FIBROSIS AND SICKLE CELL DISEASE* 116-60 (2006) (Ch. 3 describes the social history of testing and treatment for sickle cell trait and disease).

¹⁴⁰ Hawkins, *supra* note 17, at 27.

¹⁴¹ Plaintiffs-Appellants Brief, *supra* note 31, at 2. This was also reported in the press. Hawkins, *supra* note 17, at 27 ("According to a guidebook that the [DOE] gave to contractors like [LBL], testing for health problems is performed to determine the fitness of applicants and as part of a health maintenance program. The document also states that the medical records of employees are considered 'valuable epidemiological research records.' This sentence has led some workers to suspect that they were part of a study to track the disease patterns of minorities . . . This is the second time in recent years that the DOE has been accused of testing people without consent. During the cold war, UC-Berkeley scientists secretly injected mental patients and prisoners with plutonium to study human biology.").

¹⁴² *See also* Pugh, *supra* note 36, at A01; Tony Pugh, *Minorities Distrust Medical Test Concerns:*

Mark Covington, "It's disgusting It goes back to the time when blacks were treated like filthy animals, and they wanted to make sure we weren't contaminating their environment."¹⁴³

Fears may have been heightened by the fact that LBL was not an unsophisticated employer. LBL is the oldest DOE National Laboratory, and has been home to ten Nobel Laureates and the site of multiple scientific achievements, several of which are connected with genetic research. It was named one of two DOE centers for the mapping and sequencing of the Human Genome and played roles in the identification of a heart disease gene, the first view of DNA double-helix, and the development of sickle cell and down-syndrome transgenic mice.¹⁴⁴ In addition, DOE funded research into the misuse of genetic testing in the 1990s. As noted by Professor Mark Rothstein at the time of the *Norman-Bloodsaw* case, "Lawrence Berkeley should have known better To have one of their labs on the wrong end of a suit like this has to be embarrassing."¹⁴⁵

CONCLUSION

Recovering the story behind the *Norman-Bloodsaw* case highlights important points about the use of genetic information at work. It reminds us that the genetic testing work does occur, and thinking about how the case would be decided today illustrates the limits of GINA's protections. Indeed, in the context of workplace discrimination, it may be helpful to think of GINA as a new layer in the scheme of overlapping protections provided by existing antidiscrimination laws, including Title VII and the ADA, an idea I plan to develop in future writings. The story behind *Norman-Bloodsaw*

Wariness of Health-Care Establishment Remains a Real Problem with Serious Health Consequences, CONTRA COSTA TIMES, Aug. 6, 1998, at 13A ("Incidents like the Berkeley lab case only further the suspicion"); Tony Pugh, *Blacks Remain Uneasy About Health Care System*, FORT WORTH STAR-TELEGRAM, Aug 10, 1998, at 1; Greengard, *supra* note 32, at 38 (referring to the case as a "public relations nightmare" and tying to the history of discrimination against people with sickle-cell trait).

¹⁴³ Hawkins, *supra* note 17, at 27.

¹⁴⁴ LBL webpage, <http://www.lbl.gov/Publications/75th/>.

¹⁴⁵ Bob Holmes, *Gene Invasion*, NEW SCIENTIST, Feb. 14, 1998, at 1010.

also reminds us that genetic testing of workers can reflect and reinforce pre-existing patterns of discrimination and stigmatization. As genetic information will likely continue to be available to employers through GINA's exceptions, we need to remember the lessons of *Norman-Bloodsaw* to avoid making the same mistakes in the future.