

Insuring Fairness: The Popular Creation of Genetic Antidiscrimination

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INTRODUCTION

In May 2008, President Bush signed into law the Genetic Information Nondiscrimination Act (GINA),¹ the product of a two-decade long debate over the civil rights implications of advanced genetic understanding. Since its inception in 1990, the Human Genome Project successfully has mapped almost the entirety of human genetic code, documenting over 2.85 billion nucleotide sequences and approximately 20,000 to 25,000 protein-producing genes.² Each variation may reveal personal and medical characteristics with unprecedented detail and accuracy. As scientists have learned various genes' significance in the overall schema of human health, anxiety about the use of genetic information has grown, leading to calls for legal protection.

By the 1990s, the term “genetic discrimination” had become common in discussions of the pitfalls of such abundant genetic information,³ even while the implications of that information have remained largely speculative. The mere potential of what genetic information could reveal raised the specter of disparate treatment in insurance, employment, and elsewhere. By 2008, the concept of genetic discrimination had so solidified in the public consciousness that GINA—outlawing particular forms of genetic discrimination—passed both houses of Congress with near unanimity. Genetics had become the basis for a new category protected from discrimination by statute. This Note critically examines what genetic discrimination is, what people believe it to be, whether it exists, and what the popular support for a ban reveals about social conceptions of fairness. It does not examine the political or policy implications of such a law or assess the desirability or unintended consequences of legal protections. Instead, it explores the social fairness ideas behind categorical protections for genetic information, and how closely the genetics-oriented antidiscrimination structure hews to such fairness ideas.

Part I discusses the popular understanding of genetic discrimination, the implications of the term itself, and the nature of the federal law designed to combat it. Framing the issue in the language of discrimination helps define a group rights approach based on the category of “genetics” and contributes significant associative power in pushing for legislative intervention. Part II asks whether the kind of genetic discrimination most commonly feared and prohibited by the new law exists or whether the fear of such discrimination is

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].

2. International Human Genome Sequencing Consortium, *Finishing the Euchromatic Sequence of the Human Genome*, 431 NATURE 931, 931 (2004), available at <http://www.nature.com/nature/journal/v431/n7011/full/nature03001.html>.

3. Although it is hard to pin down a first use of the term, “genetic discrimination” began to appear in scholarship on the topic as early as 1991. See, e.g., Larry Gostin, *Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers*, 17 AM. J.L. & MED. 109, 110 (1991) (citing P. Billings et al., Genetic Discrimination as a Consequence of Genetic Screening 6 (Oct. 24, 1990) (unpublished manuscript)).

speculative. Part III examines the economic rationality of genetic discrimination, and whether laws outlawing all forms of genetic discrimination have broader negative implications for the market. Although neither the existence of genetic discrimination nor its market implications can be resolved definitively, the uncertainty itself is revealing in light of the decisive action taken to halt genetic discrimination.

After considering the ambiguous evidence of actual discrimination and the potential threat of market malfunction, the primary question remains why GINA and other genetic antidiscrimination acts have been met with broad popularity rather than with skepticism and partisan division. What has motivated broad swaths of people and politicians to enact civil rights legislation related to genetics? Part IV examines this question using the main concepts of fairness found throughout the discourse on genetic discrimination, primarily sympathy for the immutable and involuntary nature of genetic conditions and the belief that genetics should be private. Part V examines whether these concepts of fairness apply broadly to the category implied by genetic antidiscrimination, or whether the favored amount of protection is more arbitrary and normative than the bright categorical lines of the civil rights framework suggest. Genetic antidiscrimination laws may be an effective means of achieving discrete outcomes, but the popular conception of the genetic remains tentative and incomplete. The simple, uncontroversial types of fairness that underpin other antidiscrimination regimes are complicated by the full context of that which is, or could be, genetic.

I. WHAT IS GENETIC DISCRIMINATION?

How genetics came to be the center of a new antidiscrimination regime is inextricably linked with how people understand the advancing science of genetics. The rise of genetics as a predictor of discrete medical conditions brought discussions of genetic information and genomic mapping to everyday medical concerns. The coinage of the term “genetic discrimination” shortly followed and, in turn, has framed and reinforced a particular notion of the genetic. This Part presents a short and unscientific history of this understanding of genetics, examines the significance of the “discrimination” label, and describes the state of genetic antidiscrimination laws.

A. THE POPULAR CONCEPTION

A key benefit to understanding the human genome is to find genetic variation that may indicate or even control disease.⁴ Along these lines, genetic information took a major step forward with the 1990 identification of chromosomal

4. U.S. Dep’t of Energy, Human Genome Project Information, Medicine and the New Genetics (Sept. 19, 2008), http://www.ornl.gov/sci/techresources/Human_Genome/medicine/medicine.shtml.

variations linked to breast cancer.⁵ This genetic code was named BRCA1 because of the link.⁶ Researchers found that carriers of a particular mutation of BRCA1 bore a substantial risk of developing breast cancer—anywhere from thirty to eighty percent, depending on other characteristics of the population studied.⁷ This discovery presented obvious benefits: better targeting meant better preventive treatment and earlier detection. Moreover, the identification of a so-called “breast cancer gene” suggested the promise of other genes with similarly revealing properties for similarly difficult health problems. This discovery joined the discovery of genetic links to Huntington’s disease and cystic fibrosis, and was followed by hundreds of other theoretical connections between health outcomes and genetic variation (with countless more to come).

The dangers of this information also were soon apparent, especially in terms of medical insurance. What would an industry based on actuarial risk-assessment do with this new ability to make even more precise calculations? How would people who might otherwise benefit from genetic analysis respond to the possibility that more knowledge could lead to higher premiums or lost coverage? A 1995 article in *Science* described the archetypal scenarios in which “people who are healthy themselves, but who have a gene that predisposes them or their children to a later illness” suffer on the insurance market as a result.⁸ For example, a healthy four-year-old child was denied coverage twice because doctors discovered, after his mother and maternal uncle died of sudden cardiac arrest, that he and his family carried a genetic pattern that increased susceptibility to heart conditions.⁹ Two sisters discovered BRCA1 mutations, with one sister in the early stages of breast cancer. Both took preventive measures but were “so fearful of losing their health insurance that they used assumed names when sharing their story.”¹⁰ These storylines are, anecdotally at least, typical of the public concern about genetic discrimination.¹¹

Although insurance dominates the discussion of genetic discrimination, the concern is neither self-contained nor the full extent of genetic discrimination

5. See Jeff M. Hall et al., *Linkage of Early-Onset Familial Breast Cancer to Chromosome 17q21*, 250 *SCIENCE* 1684, 1684 (1990).

6. National Cancer Institute, *Genetic Testing for BRCA1 and BRCA2: It’s Your Choice* (Feb. 6, 2002), <http://www.cancer.gov/cancertopics/factsheet/risk/brca> (“Inherited alterations in the genes called BRCA1 and BRCA2 (short for breast cancer 1 and breast cancer 2) are involved in many cases of hereditary breast and ovarian cancer.”).

7. Jeff Boyd, Editorial, *BRCA: The Breast, Ovarian, and Other Cancer Genes*, 80 *GYNCOLOGIC ONCOLOGY* 337, 337 (2001).

8. Kathy Hudson et al., *Genetic Discrimination and Health Insurance: An Urgent Need for Reform*, 270 *SCIENCE* 391, 391 (1995).

9. *Id.*

10. *Id.*

11. See, e.g., 154 *CONG. REC.* S3373 (daily ed. Apr. 24, 2008) (statement of Sen. Kennedy) (describing the experience of a woman whose employer pressured her to leave the health care plan after discovering the BRCA1 variation); Amy Harmon, *Fear of Insurance Trouble Leads Many to Shun or Hide DNA Tests*, *N.Y. TIMES*, Feb. 24, 2008, at A1 (discussing how “a \$300 genetic test for prostate cancer risk announced last month immediately drew callers to a public radio station in Washington that was discussing the test, voicing fears of insurance discrimination”).

worries. A major corresponding fear is that an employer providing group insurance will view a job candidate with a genetic predisposition to disease as a financial liability who could drive up that employer's costs, insurance or otherwise. All other factors being equal, the assumption goes, an employee with a genetic predisposition to disease is disfavored relative to one without such a predisposition.¹² Beyond fear of insurance or employment penalties come concerns about privacy and the social stigma associated with having what others might judge as abnormal or defective genes.

B. DIFFERENTIATION VS. DISCRIMINATION

In the strictest denotative sense, it is apparent why such differential treatment is called "discrimination." To discriminate is simply to distinguish between things—to recognize a difference and to use that difference in evaluation.¹³ Connotatively, however, genetic discrimination is far more loaded. In both common and legal parlance, the term "discrimination" offers distinctly negative implications, suggesting not merely distinction, but injustice. *Black's Law Dictionary*, for example, includes the colloquially accepted legal definition of discrimination as "differential treatment; esp., a failure to treat all persons equally when no reasonable distinction can be found between those favored and those not favored."¹⁴

This definition evolved in a particular historical context. Specifically, the current sense of the term became fixed in the public discourse on rights during the push for the Civil Rights Act of 1964. The Civil Rights Act, particularly Title VII, gave birth to the legal universe of "anti-discrimination" law.¹⁵ Discrimination came to refer to decisionmaking rooted in racism, sexism, and other negative categorical bias. With this definition in mind, advocates of group rights now commonly refer to the idea that "discrimination is always wrong."¹⁶ Prior

12. See, e.g., 154 CONG. REC. S3373 (daily ed. Apr. 24, 2008) (statement of Sen. Kennedy) (describing experiences of individuals who concealed genetic information for fear of discrimination); Henry T. Greely, *Banning Genetic Discrimination*, 353 NEW ENG. J. MED. 865, 866 (2005) ("Employers have an incentive to reduce their future health insurance costs by not hiring or by firing people who have predictably high health care expenses, for genetic or other reasons.").

13. E.g., MERRIAM-WEBSTER'S COLLEGIATE DICTIONARY 332 (10th ed. 1998) ("to distinguish by discerning or exposing differences; esp: to distinguish from another like object").

14. BLACK'S LAW DICTIONARY 500 (8th ed. 2004).

15. See Civil Rights Act of 1964 § 703, Pub. L. 88-352, 78 Stat. 241, 241-68 (1964) (making it an "unlawful employment practice for an employer to fail or refuse to hire or to discharge any individual, or otherwise to discriminate against any individual . . . because of such individual's race, color, religion, sex, or national origin") (codified at 42 U.S.C. § 2000e-2(e) (2006)).

16. This construction is prevalent among advocates of gay rights but is used in numerous other contexts as political shorthand for unfair categorical bias. See, e.g., Michael Levenson & Andrew Ryan, *Connecticut Supreme Court Legalizes Same-Sex Marriage*, BOSTON GLOBE, Oct. 10, 2008, http://www.boston.com/news/local/breaking_news/2008/10/connecticut_sup.html (quoting Connecticut State Senator Andrew McDonald as saying that the Connecticut Supreme Court has "firmly established that discrimination in any context and in any form is unacceptable and unconstitutional"); Press Release, Congressman Bobby Scott, Rep. Scott Prefers the Spirit of Christmas Over Lip Service (Dec. 13, 2007), http://www.house.gov/apps/list/press/va03_scott/pr_071213.html (quoting Rep. Scott as defend-

to the Civil Rights era, this statement might have suggested nonsensically that it was immoral to distinguish between things. Now, it instead suggests—somewhat circularly, perhaps—the immorality of unjust distinctions.

The label of “genetic discrimination,” then, frames the above scenarios as unjust and, more significantly, as analogous to the race- and gender-based injustices outlawed through Title VII. Echoing this popular sentiment, President Bush in 2001 said that “[g]enetic discrimination is unfair to workers and their families.”¹⁷ He elaborated:

To deny employment or insurance to a healthy person based only on a predisposition violates our country’s belief in equal treatment and individual merit. In the past, other forms of discrimination have been used to withhold rights and opportunities that belong to all Americans. Just as we have addressed discrimination based on race, gender and age, we must now prevent discrimination based on genetic information.¹⁸

Genetic discrimination, as a term, at once suggests both the category and the argument for social and legal protection.

C. THE GENETIC INFORMATION NONDISCRIMINATION ACT

Legal protections to combat genetic discrimination appeared in nearly every state through the 1990s and 2000s, with at least forty-seven states enacting some form of statute identifying genetic information for explicit protection in health insurance contexts.¹⁹ Thirty-five states have employment discrimination prohibitions alongside the insurance provisions. These laws largely guard against the scenarios described above, varying in how they specifically and broadly define “genetics.”²⁰ The federal genetic antidiscrimination law, the Genetic Information Nondiscrimination Act (GINA),²¹ passed both houses of Congress with near unanimity, receiving only one negative vote in the House of Representatives.²² The law treats as “genetic information” any genetic tests by the

ing his vote against a bill by saying that “[d]iscrimination is wrong in any form”); No On 8, Final Statement from No on Prop 8 Campaign, (Nov. 6, 2008), <http://www.noonprop8.com/headlines/final-statement-from-no-on-prop-8-campaign/> (“And you made the case to the people of California and to the rest of the world that discrimination—in any form—is unfair and wrong.”).

17. President George W. Bush, *President’s Radio Address* (June 23, 2001), available at <http://www.whitehouse.gov/news/releases/2001/06/20010623.html>.

18. *Id.*

19. Kathy L. Hudson, *Prohibiting Genetic Discrimination*, 356 *NEW ENG. J. MED.* 2021, 2021 (2007).

20. For a full comparative chart of state genetic antidiscrimination laws, see National Conference of State Legislatures, *Genetics and Health Insurance: State Anti-Discrimination Laws* (Jan. 2008), <http://www.ncsl.org/programs/health/genetics/ndishlth.htm>.

21. GINA, Pub. L. No. 110-233, 122 Stat. 881, 881–921 (codified in scattered sections of 26, 29, and 42 U.S.C.).

22. United States House of Representatives, *Final Vote Results for Roll Call 234* (May 1, 2008), <http://clerk.house.gov/evs/2008/roll234.xml>; United States Senate, *Roll Call Vote of the 110th Cong.* 2d

individual or family members as well as the manifestation of a disease in family members.²³ It prohibits insurers from compelling or using genetic information in group²⁴ or individual insurance²⁵ and prohibits employers from considering such information in hiring, employment, or termination.²⁶ Functionally, genetic information is given full Title VII civil rights protection, alongside race, sex, religion, age, and disability.²⁷

II. DOES GENETIC DISCRIMINATION EXIST?

Given that genetic discrimination—or at least the anticipation of it—has prompted legal changes in nearly every state and on the federal level, one might expect genetic discrimination’s existence to be a settled matter. One would expect it to be widespread, or at least widely documented. As described above, genetic discrimination can take on several forms. This Part examines the evidence that genetic discrimination in insurance and employment contexts does and does not exist, and finds that the debate about the prevalence, severity, and existence of genetic discrimination remains live.

Genetic discrimination, in practice, appears to be an area marked by great public apprehension and little agreement as to the evidence. Although one can easily imagine the possibility of “social” genetic discrimination, including the “prejudicial attitudes and social stigma regarding people perceived to have ‘bad blood,’”²⁸ there has been far less scholarly examination of social phenomena.²⁹ Insurance- and employment-based discrimination should, in theory, be easier to study and quantify. The most commonly referenced and clearly documented instance of genetic discrimination goes back to the 1970s, when some insurance companies declined to cover carriers of sickle-cell anemia.³⁰ Several states responded by outlawing the consideration of sickle-cell anemia in evaluating

Session (Apr. 24, 2008), http://www.senate.gov/legislative/LIS/roll_call_lists/roll_call_vote_cfm.cfm?congress=110&session=2&vote=00113. The lone dissenter was Congressman Ron Paul (R-TX). Final Vote Results for Roll Call 234, *supra*.

23. GINA § 101(d), Pub. L. No. 110-233, 122 Stat. at 885.

24. *Id.* §102(a), Pub. L. No. 110-233, 122 Stat. at 888–92.

25. *Id.* §102(b), Pub. L. No. 110-233, 122 Stat. at 892–96.

26. *Id.* §§ 201–02, Pub. L. No. 110-233, 122 Stat. at 905–08.

27. “Title VII protection” is used as a shorthand throughout this Note for the specific kind of employment protection extended by Title VII of the Civil Rights Act. *See supra* note 15. Not all the protected categories derive from the Civil Rights Act; other titles in other acts grant some of the particular protections but have language that mirrors Title VII.

28. Sandra Taylor et al., *Investigating Genetic Discrimination in Australia: Perceptions and Experiences of Clinical Genetics Service Clients Regarding Coercion To Test, Insurance and Employment*, 5 AUSTRALIAN J. EMERGING TECH. & SOC’Y No. 2, at 65 (2007) (citation omitted).

29. This may be because social discrimination, such as outcast status or shunning by peers, does not lend itself as readily to legal remedy.

30. *See, e.g.*, Hudson et al., *supra* note 8, at 391; E. Virginia Lapham et al., *Genetic Discrimination: Perspectives of Consumers*, 274 SCIENCE 621, 621 (1996); Philip R. Reilly, *Efforts to Regulate the Collection and Use of Genetic Information*, 123 ARCHIVES OF PATHOLOGY & LABORATORY MED. 1066, 1066 (1999).

applications and setting rates.³¹

Despite references to sickle-cell–based discrimination as a forerunner to modern genetic discrimination, it is exceptionally hard to disentangle the racial component that may have been at work.³² That is, although present worries of genetic discrimination focus on insurers making problematic actuarial decisions, the sickle-cell example may have gone beyond risk-assessment (or beyond an assessment of the risk of sickle-cell in isolation). Contemporary assessments of genetic discrimination have no discriminatory incidents so definite or wide-spread to examine, producing an unresolved set of competing claims.

A. CONSUMER PERCEPTIONS OF DISCRIMINATION AND THE LIMITATIONS OF THE EVIDENCE

The literature on genetic discrimination contains scattered anecdotal examples of the discrimination recently outlawed by GINA,³³ but all such research appears limited to surveys of consumer perception. These are chronicled in widely-cited studies with names like “Genetic Discrimination: Perspectives of Consumers,”³⁴ “Perceptions of Genetic Discrimination Among At-Risk Relatives,”³⁵ and “Access to Health Insurance: Experiences and Attitudes.”³⁶ Advocates of greater protection cite these studies as actual evidence of ongoing genetic discrimination as opposed to the mere threat of it.³⁷ This section examines the literature on consumer perception, its findings and its inherent limitations.

A 1996 study of 332 members of genetic support groups found that twenty-two percent of respondents believed that genetic discrimination resulted in denial of insurance, and thirteen percent (potentially overlapping) believed it

31. ALA. CODE § 27-5-13 (LexisNexis 2007) (“[A]ny insurance company . . . is hereby prohibited from denying coverage to applicants because the applicant has been diagnosed as having sickle-cell anemia, and is hereby required to pay any valid claim made involving treatment or care of sickle-cell anemia . . .”); LA. REV. STAT. ANN. § 22:652.1(D) (2004) (“No insurance company shall charge unfair discriminatory premiums, policy fees or rates for, or refuse to provide any policy or contract of life insurance, life annuity, or policy containing disability coverage for a person solely because the applicant therefor has sickle cell trait.”).

32. Sickle-cell anemia in the United States is associated primarily with African-Americans. National Heart, Lung, & Blood Institute, *Sickle Cell Anemia, Who Is at Risk?*, http://www.nhlbi.nih.gov/health/dci/Diseases/Sca/SCA_WhoIsAtRisk.html (last visited May 25, 2009). Insurers that denied applicants on the basis of sickle-cell anemia may have used the disease as a proxy for race once it became illegal to engage in overtly racial discrimination.

33. Hudson et al., *supra* note 8.

34. Lapham et al., *supra* note 30.

35. Kira A. Apse et al., *Perceptions of Genetic Discrimination Among At-Risk Relatives of Colorectal Cancer Patients*, 6 GENETICS MED. 510 (2004).

36. Nancy E. Kass et al., *Access to Health Insurance: Experiences and Attitudes of Those with Genetic Versus Non-Genetic Medical Conditions*, 143A AM. J. MED. GENETICS 707 (2007).

37. Jon Beckwith & Joseph S. Alper, *Reconsidering Genetic Antidiscrimination Legislation*, 26 J.L. MED. & ETHICS 205, 206 (1998); Hudson et al., *supra* note 8, at 391; Genetics & Public Policy Center, *U.S. Public Opinion on Uses of Genetic Information and Genetic Discrimination 1* (Apr. 24, 2007), available at http://www.dnapolicy.org/resources/GINAPublic_Opinion_Genetic_Information_Discrimination.pdf.

caused denial of or dismissal from a job.³⁸ Although these numbers on their face might suggest an epidemic, any broad application of the data is hindered by two important factors: (1) the sample was constructed, not at random, but from volunteers within genetic-condition-based support groups responding to a study solicitation;³⁹ and (2) the data were limited to perceptions of discrimination.⁴⁰ Even if the participant solicitation did not specify that genetic discrimination would be the focus of the survey,⁴¹ one might reasonably conclude—as the study itself suggests—that those joining such a support group, let alone actively volunteering for surveys in its newsletter, might be those most inclined to have experienced or perceived genetic discrimination.⁴² Whether discrimination led the participants to join such a group or membership in the group heightened their sensitivity to their condition, a fairly large potential for bias exists within the sample. (This would be the case even relative to those with the same condition who have not chosen to join a support group.)

Perception data also are, regardless of sample, inherently limited as a proxy for the prevalence of an actual phenomenon. In surveys of more subjective discriminatory phenomena, we see the difficulty in extrapolating perception to reality.⁴³ Most of the data come from a simple “Yes/No” response to questions asking if the respondent had been, in one example, “[a]s a result of a genetic condition . . . refused health insurance.”⁴⁴ The anecdotes collected by the author suggest situations that may be anomalous or simply unverifiable. These include a man who was denied a job after a pre-employment physical exam revealed a genetic defect; the potential employer, knowing such discrimination was illegal, “told the applicant that he would deny the conversation in the future if asked.”⁴⁵ Ultimately, the survey provides limited insight into whether genetic discrimination, as commonly described, is the primary force behind the respondents’ difficulties and is at all widespread. The authors acknowledge the study’s limitations, calling for additional research to “confirm or deny the perceptions of consumers in this study.”⁴⁶

38. Lapham et al., *supra* note 30, at 622.

39. *Id.* at 621 (“Participants were recruited primarily through the national, regional, and local genetic support groups affiliated with the Alliance of Genetic Support Groups Random sampling was considered and ruled out because of time, cost, and the primarily educational focus of the project. Thus, the findings are applicable only to this group.”).

40. *See id.*

41. *Id.* (“The notices contained information about the study and requested volunteers . . . with one or more persons in the family with a genetic disorder who would be willing . . . to provide opinions on the ethical, legal, and social issues of the [Human Genome Project] as well as priority topics for education.”).

42. *Id.* at 623.

43. Cf. Edward C. Norton et al., *How Measures of Perception from Survey Data Lead to Inconsistent Regression Results: Evidence from Adolescent and Peer Substance Use*, 12 HEALTH ECON. 139 (2003) (discussing how human psychological factors make perception data a problematic substitute for direct measurement).

44. Lapham et al., *supra* note 30, at 622 tbl.1.

45. *Id.* at 623.

46. *Id.*

A more recent study claims stronger evidence that genetics are treated differently than other conditions, although this study, too, is limited to consumer perception. The 2007 study finds that:

While there are several recent editorials in the literature stating that genetic discrimination either does not exist or is a rare phenomenon, data from this empirical study suggest that a higher proportion of individuals with genetic conditions have experienced health insurance discrimination in the past compared to people with other types of chronic medical conditions—reinforcing the evidence that insurance companies have distinguished between genetic and other kinds of conditions in making coverage decisions. This study confirms the findings of other empirical studies that have found evidence that individuals with genetic conditions do experience health insurance discrimination.⁴⁷

Despite the definitive language of this conclusion, the 2007 study is similarly limited relative to the 1996 Lapham study it claims to validate. Most significantly, as discussed above, the basis for the conclusion of disparate treatment for genetic versus non-genetic conditions remains the self-reported understanding of the respondent.⁴⁸ Compared to the 1996 study, this effect is somewhat mitigated by the fact that better attempts were made to draw from a population less engaged in genetic advocacy.⁴⁹ Nonetheless, the difficulties of perception as a proxy for empirical incidence remain.

Also complicating the interpretation of results is the distinction between those “affected” by genetic conditions and those classified as “at-risk.” The separate consideration of asymptomatic or presymptomatic applicants (at-risk) and applicants with a manifested condition (affected) greatly alters the assessment of whether what has taken place is “genetic discrimination” in the common usage.⁵⁰ Assuming that pure genetic discrimination refers primarily to asymptomatic or presymptomatic individuals—people find less discriminatory an insurer’s unwillingness to underwrite a preexisting condition—the results change. Among those affected by breast cancer, thirty percent say that they have been “denied health insurance or offered it at a prohibitive rate”; among those at risk, roughly sixteen percent (seven respondents) answered in the affirmative.⁵¹ Twenty-three percent of those affected by breast cancer says that their health insurance companies have limited coverage, compared to ten percent of those at risk (five respondents).⁵²

47. Kass et al., *supra* note 36, at 716 (citations omitted).

48. *Id.* at 709 (“Data are reported here from [interview] items that focused specifically on respondents’ experiences and attitudes regarding health insurance.”).

49. Rather than recruit from genetic support groups exclusively, the Kass study drew participants from Maryland state disease registries and advertisements in Baltimore newspapers in addition to clinics and research studies at Johns Hopkins. *Id.* at 708.

50. See *supra* section I.B.

51. Kass et al., *supra* note 36, at 713.

52. *Id.*

These studies call into question the extent to which the aggregation of anecdotes and perceptions can reliably indicate an empirical phenomenon. The literature cannot disentangle how much of this perception may be discounted as misunderstanding versus how much indicates the conclusive presence of genetic discrimination. Some scholars have been willing to take the leap, citing perception studies for the claim that “[d]espite the limitations of the studies, it became clear that many instances arose in which genetic information was used to limit people’s life options.”⁵³ Even given such acceptance, it is not at all clear from a social-scientific standpoint, nor has it been resolved in the literature, how best to extrapolate the perception data.

B. CLAIMS FOR THE ABSENCE OF DISCRIMINATION

Other studies quite confidently assert the absence of genetic discrimination, and do so through a combination of methodological critique of the studies like those above and competing surveys in different respondent populations. A study by Mark Hall and Stephen Rich published in 2000 found that “[m]ultiple, independent sources refuted, or were unable to document, any substantial level of genetic discrimination by health insurers, either before or after the legal prohibitions were enacted, or in states with or without these laws.”⁵⁴ The survey respondents in some of the studies aggregated by Hall and Rich included consumers, medical geneticists, genetic counselors, and insurance companies themselves.⁵⁵ Hall and Rich reconciled their consumer survey data with the studies that reach the opposite conclusion by observing that “in the vast majority of cases, these most likely are either based more on existing symptoms than on genetic information itself, or they relate to other types of insurance besides health or are concerned with the payment for genetic services.”⁵⁶ Henry Greely, writing in the *New England Journal of Medicine*, likewise notes that “early reports often involved allegations of discrimination on the basis of disease, rather than a genetic predisposition to disease.”⁵⁷

Insurance representatives also maintain that the industry does not engage in such discrimination, nor does it wish to do so. In a response to an article on genetic discrimination, one representative insisted that “health insurers are not inclined to discriminate on the sole basis of a theoretical risk of future disease.”⁵⁸ Verifiability, of course, confounds the uncritical application of these insurers’ responses. Given the apparently strong social sentiment against genetic

53. Beckwith & Alper, *supra* note 37, at 206.

54. Mark A. Hall & Stephen S. Rich, *Laws Restricting Health Insurers’ Use of Genetic Information: Impact on Genetic Discrimination*, 66 AM. J. HUM. GENETICS 293, 302 (2000).

55. *Id.* at 294.

56. *Id.* at 302.

57. Greely, *supra* note 12, at 865.

58. William J. Nowlan, Letter to the Editor, *A Scarlet Letter or a Red Herring?*, 421 NATURE 313, 313 (2003).

discrimination,⁵⁹ it seems unlikely that a company would want to be seen, in so many words, as engaging in the practice. Still, to the extent such representatives can be reliable sources, none suggest that the practice is ongoing or even under consideration.

In stark contrast to the political debate over genetic discrimination—one distinguished by uncommon harmony—the academic debate over whether genetic discrimination exists appears deadlocked in competing surveys and anecdotes.⁶⁰

Table 1. Competing Claims About the Existence of Genetic Discrimination⁶¹

Study	Year	Method	Respondents	Evidence of Genetic Discrimination?
Lapham et al. ⁶²	1996	Survey	Members of genetic support groups	Yes. (“22 percent believed they were refused health insurance, and 13 percent believed they were denied or let go from a job.”)
Kass et al. ⁶³	2007	Survey	Adults or parents of children with various “genetic” and “non-genetic” disorders	Yes. (“[I]ndividuals with genetic conditions do experience health insurance discrimination.”)
Matloff ⁶⁴	1999	Survey	Active members of the National Society of Genetic Counselors	No. (“We know there’s a problem with maintaining insurance for people who [already] have a disease, . . . [b]ut we’ve not had a documented case of genetic discrimination.”)
Hall & Rich ⁶⁵	2000	Survey	Consumers, physicians, genetic counselors, and insurance companies	No. (“Multiple, independent sources refuted, or were unable to document, any substantial level of genetic discrimination by health insurers.”)

59. A 2007 survey of 1199 people by the Genetics & Public Policy Center found that more than ninety percent of respondents believe that employers and insurers should not “be able to use a person’s genetic test results about increased risk of future disease.” Genetics & Public Policy Center, *supra* note 37, at 3.

60. *See infra* tbl.1.

61. This is, of course, only a summary of the literature and, although it is by no means exhaustive, it is representative and includes commonly referenced evidence for and against the existence of genetic discrimination.

62. Lapham et al., *supra* note 30, at 621.

63. Kass et al., *supra* note 36, at 716.

64. Joan Stephenson, *Genetic Test Information Fears Unfounded*, 282 JAMA 2197, 2197 (1999) (quoting Ellen Matloff, director of cancer genetic counseling) (first alteration in original) (internal quotations omitted).

65. Hall & Rich, *supra* note 54, at 302.

III. IS GENETIC DISCRIMINATION DESIRABLE?

Implicit in the language (and often explicit in the literature) is that genetic discrimination is undesirable.⁶⁶ At its heart, however, genetic discrimination in an insurance context could be described as genetic risk assessment. This Part examines the consequences of a ban on genetic risk assessment (a prominent form of genetic discrimination). The proliferation of highly popular genetic antidiscrimination laws suggests unequivocally that genetic risk assessment is legally, politically, and socially disfavored.⁶⁷ There is a difference, however, between that which is undesirable because it is economically irrational and that which is undesirable because, despite its economic logic, it offends our common understanding of fairness. In the former case, the government simply acts to correct the market; in the latter, it accepts a deliberate market distortion in order to reinforce a moral stance. If genetic discrimination creates market inefficiencies, as some claim, the broad consensus for antidiscrimination laws is self-explanatory. But, as this Part discusses, a substantial body of literature also suggests that the GINA regime would be less efficient and potentially destabilizing, suggesting another empirically unresolved debate.

A. GENETICS AND THE ECONOMIC THEORY OF POOLED RISK

The health insurance market is based on pooled risk.⁶⁸ Everyone in the pool pays some amount for insurance, with some people collecting less than is paid in and others collecting more. The fundamental idea behind pooled insurance is that it is unknown, in advance, who will need how much payout.⁶⁹ In theory, both consumers and insurers try to gauge a consumer's expected loss. An "actuarially fair" plan is one that prices premiums equal to the consumer's expected loss.⁷⁰ In theory, a consumer will not want to spend more than her expected loss (otherwise she is expected to lose money), and a firm will not want to charge less (otherwise it is expected to lose money).⁷¹ In practice, firms know only very vaguely how to estimate an individual's expected loss and, generally, the consumer knows even less.

66. As discussed above, the common understanding of the term "discrimination" carries inherent moral judgment. See *supra* section I.B.

67. The 2007 Genetics & Public Policy Center survey discussed above, *supra* note 59, suggests that support for a federal law such as GINA at about seventy-six percent. As previously mentioned, more than ninety percent, regardless of how they felt about a law, believed that employers and insurers should not "be able to use a person's genetic test results about increased risk of future disease." Genetics & Public Policy Center, *supra* note 37, at 3.

68. For a more complete overview of the economic concepts discussed in this subsection, including examples of pooling and rating practices, see RICHARD J. BUTLER, *THE ECONOMICS OF SOCIAL INSURANCE AND EMPLOYEE BENEFITS* 104–18 (1999); AMERICAN ACAD. OF ACTUARIES, *WADING THROUGH MEDICAL INSURANCE POOLS: A PRIMER* (2006), http://www.actuary.org/pdf/health/pools_sep06.pdf.

69. BUTLER, *supra* note 68, at 104.

70. *Id.* at 109.

71. See Patrick L. Brockett et al., *Genetic Testing, Insurance Economics, and Societal Responsibility*, 3 N. AM. ACTUARIAL J. 1, 10 (1999).

If we assume both the insurer and the consumer to be loss-minimizing, profit-maximizing actors, we see an incentive for insurers to determine as precisely as possible every risk-increasing factor a consumer might possess, erring on the side of overstating a patient's risk. The consumer, on the other hand, will want to minimize or even conceal risk factors in order to pay a premium at or below her expected loss. These competing impulses create the information battle at stake in the genetic discrimination debate.⁷² If a patient is more likely to develop cystic fibrosis, Huntington's disease, or cancer, that patient has—all other factors held constant—a higher expected loss. In this framework, some amount of genetic discrimination is both rational and expected—not unlike the common practice of increasing premiums based on tobacco use or cholesterol level.⁷³ As one group of actuarial scholars explains:

Insurers generally hold that a *statistical* justification provides a sufficient defense for using a classification scheme; that is, the use of a particular variable by a company in a rate-making structure does not constitute “unfair” discrimination provided individuals with differing levels of the variable have statistically and significantly different prospectively projected costs. Indeed, if two people having different levels of the variable do have different expected loss costs, then it could be argued that it would constitute unfair discrimination against the lower-risk person *not* to use that information in classification.⁷⁴

Employer-based insurance plans are based on the group market: premiums are set by group, and, thus, the actuarial implications of any individual's health status are distributed across the group pool. On the individual market, insurers make individual determinations (except where prohibited by law).⁷⁵ If an insurer can gain additional information about a person applying for individual insurance, be it genetic or otherwise, the economic incentive is for the insurer to

72. *See id.* at 11.

73. *See* Hall & Rich, *supra* note 54, at 303.

74. Brockett et al., *supra* note 71, at 6 (emphasis in original).

75. This applies to the approximately nine percent of the population covered by directly purchased insurance and, potentially, the fifteen percent of the population without health insurance coverage. *Id.* Representatives of the insurance industry have recently suggested that if health insurance were made mandatory, they might give up the current and longstanding model of individual pricing based on individual risk assessment. Laura Meckler & Vanessa Fuhrmans, *Insurers Offer To End Prices Tied to Illness*, WALL ST. J., March 25, 2009, at A4. That the industry would make such an offer, especially in light of its own recent opposition to “community rating” and “guaranteed issue” on the individual market, does not directly alter the theoretical conclusions of this Note. *See, e.g.*, LEIGH WACHENHEIM & HANS LEIDA, *THE IMPACT OF GUARANTEED ISSUE AND COMMUNITY RATING REFORMS ON INDIVIDUAL INSURANCE MARKETS 2* (2007), <http://www.ahip.org/content/fileviewer.aspx?docid=20794&linkid=179392> (report commissioned and released by America's Health Insurance Plans, predicting unintended consequences and negative effects from community rating and guaranteed issue). Instead, it suggests that health insurance in the United States may be moving towards a rights-based model, rather than its current individual approach modified by antidiscrimination exceptions. *See infra* notes 97–98 and accompanying text.

pursue that information.

B. THREATS TO THE MARKET

At first glance, genetic antidiscrimination and privacy laws might appear merely to preserve the status quo. If genetic discrimination is not currently taking place or is not widespread, the laws would extend that state of affairs. What changes, however, is the balance of information. If neither the consumer nor the insurer knows about genetic test results, people likely will insure against it at approximately the same level, distributing the risk throughout the population. In theory, if all parties involved—consumer and insurer—share information about the genetic test results, then genetic status is accounted for in costs like any other medical condition.

Theoretical problems arise under a regime protecting asymmetry of information, in which consumers know of their elevated or decreased risk and insurers do not. In this theoretical model, consumers with genetic predisposition to disease would purchase insurance priced below their expected loss. When the time comes to claim payment at higher-than-expected levels, insurers will be induced to raise premiums universally to compensate for the losses. This increase will raise the prices above the expected losses of the healthiest consumers, inducing them to leave the market. The average expected loss of the pool now having increased, the process feeds on itself, in a cycle known as “adverse selection.”⁷⁶

Accordingly, some scholars have predicted serious consequences for the legal enforcement of asymmetrical information (albeit modeled more robustly than the theoretical sketch above). One predictive model simulated the health care marketplace under various distributions of genetic information.⁷⁷ The scholars running the model suggested that a market with full and equal information could improve efficiency in the current market while an antidiscrimination regime could severely undermine it.⁷⁸ They concluded that “[i]f information is symmetrically distributed, then, in contrast to standard models, the screening of insurance applicants for illness risks can enhance efficiency.”⁷⁹ By contrast, “if the information is private, it will be demonstrated that in case of treatment costs higher than willingness-to-pay, asymmetry in information . . . could cause the whole market to break down.”⁸⁰

A model examining insurance patterns among a group of women tested for

76. For a similar and more complete description of adverse selection in the context of genetic information and life insurance, see Ken R. Smith et al., *Genetic Testing and Adverse Selection in the Market for Life Insurance*, in *GENETIC INFORMATION: ACQUISITION, ACCESS, AND CONTROL* 58–59 (Alison K. Thompson & Ruth F. Chadwick eds., 1999).

77. R. Strohmeier & A. Wambach, *Adverse Selection and Categorical Discrimination in the Health Insurance Markets: The Effects of Genetic Tests*, 19 *J. HEALTH ECON.* 197, 200 (2000).

78. “Efficiency” in the model employed by Strohmeier & Wambach refers to the economic definition of the term, in which rational actors maximize their expected utility. *Id.* at 201.

79. *Id.* at 200.

80. *Id.*

BRCA1 challenged this conclusion.⁸¹ The BRCA1 model examined the insurance-purchasing behavior of those who do and do not find that they have the genetic variation. The study found that women in possession of the information chose not to leverage their asymmetrical advantage on the insurance market. If the provision of such information does not substantially alter purchasing behaviors, the implication is that no adverse selection would follow.⁸² Extrapolating this study proved difficult, however, as the authors' model dealt with the life insurance market. The authors provided a number of plausible explanations for why the women studied did not choose to take up new life insurance policies once asymmetrically armed with their genetic information. The reasons a person may have for choosing or not choosing to purchase life insurance, however, are potentially quite dissimilar from the forces at work in the health insurance market. On that basis, adverse selection in the health insurance market remains an open question, with the authors noting the study as evidence that not all actors in the world of genetic information behave as economic theory would predict.

Another economic study of genetic discrimination considered ostensibly comparable changes in health insurance laws that removed the ability of insurers to make particular risk assessments.⁸³ The first, and arguably most extreme, example evaluated the effects of Washington State's "guaranteed issue" provision, in which any applicant must be found eligible for some reasonable offer of coverage.⁸⁴ The inability of insurers to deny coverage and the stricter pricing requirements were a "disaster for numerous insurers."⁸⁵ The same article discussed the spiraling price increases following a New Jersey health insurance reform law that prompted the rapid enrollment of tens of thousands of previously uninsured citizens, many with serious conditions.⁸⁶ The applicability of these scenarios to GINA is obviously questionable, but the suggestion nonetheless is clear that at some point, asymmetric information coupled with reduced provider flexibility could distort the market.

C. IS THE MARKET WITHOUT THESE LAWS NECESSARILY EFFICIENT?

That genetic discrimination laws could alter the condition of the market for insurance is not necessarily to suggest that the *current* market is free of distortions related to genetic information.⁸⁷ The difficulties with the anecdotal and survey data on genetic discrimination have been discussed above, but

81. Smith et al., *supra* note 76.

82. *Id.* at 67–68.

83. Brockett et al., *supra* note 71.

84. *Id.* at 11.

85. *Id.*

86. *Id.*

87. There are other known distortions in the market, some of which we deliberately accept. Despite its actuarial value, for example, insurers are prohibited from discriminating according to race. See Brockett et al., *supra* note 71, at 7 ("While certain potential classification variables such as race or ethnic origin are not legal to use in rate making . . . it is, in fact, debatable as to who gains and who

taking the studies at face value, there remains the suggestion that the level of discrimination they describe may be market-irrational. One study finds that “in a significant number of cases, applications for insurance policies were rejected for reasons that reflect serious misunderstandings of genetic disease. For example, a carrier of a mutant gene for a recessive condition who would, of course, never develop the disease, was denied a policy.”⁸⁸ This outcome would suggest that the insurer has either forgone a risk assessment, the basis for rational discrimination in health insurance, or simply made the assessment incorrectly.

On that basis, one could suggest that the market is currently irrational, prone to genetic panic, and that antidiscrimination legislation may improve efficiency. But this issue may be more about technology than about discrimination. The insurer may not be reacting to some inchoate terror inherent in genetic test results, but rather to the limited manner in which medical science allows us to interpret such test data. The predispositions revealed by certain types of genetic testing do not always provide the kind of actuarial precision that allows for a fully rational analysis of expected loss.⁸⁹ In a world of imperfect knowledge—where both applicant and insurer recognize some indeterminate amount of increased risk—insurers may err on the side of rejecting a potential customer rather than taking on someone who could significantly and to an unknown degree affect the stability of the insurance pool. This is a variety of irrational behavior, to be sure, but one that might reasonably lessen over time as insurance companies and the medical profession arrive at more precise understandings of genetic test results and the associated propensity to disease. Decisions based on misunderstanding would naturally decline as insurers find ways to profitably offer packages to otherwise healthy people.

Some pre-GINA state laws attempt to account for the distinction between rational genetic discrimination, as advocated by the economists who fear the effects of asymmetric information, and irrational discrimination, based on hasty decisions and fundamental misunderstanding. Vermont law, for example, prohibits

loses in the wealth transfer inherent in a mandated suppression of information.”). *See also infra* note 104 and accompanying text (discussing the actuarial implications of race).

88. Beckwith & Alper, *supra* note 37, at 206.

89. Despite the tantalizing promise of great precision, many common genetic tests, like those for BRCA genes, sometimes offer such ambiguous results as to make the risk determination only barely more precise—if at all—than without such testing. *See, e.g.,* Deborah Franklin, *Family Struggles with Ambiguity of Genetic Testing*, ALL THINGS CONSIDERED (National Public Radio, broadcast, Dec. 30, 2008), transcript available at <http://www.npr.org/templates/story/story.php?storyId=98818197>; Nicholas Wade, *Genes Show Limited Value in Predicting Diseases*, N.Y. TIMES, Apr. 15, 2009, at A1; *see also* Trudo Lemmens, *Selective Justice, Genetic Discrimination, and Insurance: Should We Single Out Genes in Our Laws?*, 45 MCGILL L.J. 347, 371 (2000) (“The predictive value of genetic tests varies widely. Moreover, the prophetic character of genetic testing is often overstated in the early phases of research . . .”).

Making or permitting any unfair discrimination against any individual by conditioning insurance rates, the provision or renewal of insurance coverage, or other conditions of insurance based on medical information, including the results of genetic testing, *where there is not a relationship between the medical information and the cost of the insurance risk that the insurer would assume by insuring the proposed insured*. In demonstrating the relationship, the insurer can rely on actual or reasonably anticipated experience.⁹⁰

The effect of such a rule is to validate genetic discrimination so long as it serves market efficiency.

IV. ENFORCING FAIRNESS THROUGH GENETIC ANTIDISCRIMINATION

How, then, did GINA come to be, and what does a category based on genetic information mean? We cannot say with any great certainty that genetic discrimination is rampant or that it is illusory.⁹¹ At least some credible market theories suggest a greater possibility of market distortion under an antidiscrimination regime than under one of symmetric information.⁹² Such conflicts are the kind most likely to devolve into arguments over first principles, breaking down along partisan lines between Democrats who favor government intervention and Republicans who oppose it. Consider, for example, some conservative politicians' position that the science on climate change is too indeterminate to warrant regulatory action,⁹³ or the Bush Administration's requirement that agencies undertaking significant regulatory action specify, in writing, the market failure to be corrected.⁹⁴ One might have expected the Democratic majority to believe that market efficiency was subordinate to the inherent right to affordable health care, and the Republican minority and president to fear government-oriented tinkering and the predicted havoc it might play with the market. Instead, the bill passed unanimously in the Senate, nearly unanimously in the House, and was immediately signed into law.⁹⁵

90. VT. STAT. ANN. tit. 8, § 4724(7)(D) (2005) (emphasis added); *see also* ARIZ. REV. STAT. ANN. § 20-448(E) (2002) (“[U]nless the applicant’s medical condition and history and either claims experience or actuarial projections establish that substantial differences in claims are likely to result from the genetic condition . . .”).

91. *See supra* Part II.

92. *See supra* Part III.

93. For example, Sen. James Inhofe (R-OK), then-Chairman of the Environment and Public Works Committee, argued that “[m]uch of the debate over global warming is predicated on fear, rather than science.” Senator James Inhofe, *The Science of Climate Change*, Senate Floor Statement (July 28, 2003), <http://inhofe.senate.gov/pressreleases/climate.htm>.

94. Exec. Order No. 13,422, 72 Fed. Reg. 2763 (Jan. 23, 2007) (“Each agency shall identify in writing the specific market failure (such as externalities, market power, lack of information) or other specific problem that it intends to address (including, where applicable, the failures of public institutions) that warrant new agency action . . .”). This executive order was reversed by the Obama Administration. Exec. Order No. 13,497, 74 Fed. Reg. 6113 (Jan. 30, 2009).

95. The bill had been introduced several times in the past over the course of several sessions, twice passing the Senate by similarly wide margins, but never reaching the House floor for a vote. In the 109th Congress: S. 306, 109th Cong. (2005) (passing the Senate, 98–0); H.R. 1227, 109th Cong. (2005)

Why the stampede to fix a debatably real problem with uncertain market effects? Why the broad public support for such an action? The answer lies in the social concept of “fairness.” Even if racial discrimination were economically beneficial, for example, we can assume that it would remain prohibited as offensive to our fundamental understanding of justice. This legal enforcement of social fairness is the very essence of antidiscrimination legislation, and it explains why, despite the uncertainty about genetic discrimination, GINA and similar laws have received near unanimous approval. This Part examines the different conceptions of fairness that underlie GINA’s categorical antidiscrimination approach and its strong popularity.

A. GENETIC ANTIDISCRIMINATION IS ABOUT GENETICS

Key to understanding the conceptions of fairness at work is separating which impulses are universally directed versus which are specific to the discrete category of genetic information. Is GINA about genetics, or is it merely an incremental step in the universal application of such protection? The fairness impulses at work in the passage of GINA or similar state laws are, for many of its supporters, distinct from a belief in universal application. This is a given in the context of GINA’s *employment* protections, which depend wholly on the targeting of discrete categories. There is not, for example, a common political sentiment that an employer should have to prove that *every* personnel decision was based on a bona fide occupational qualification⁹⁶ rather than on personality and managerial discretion. Although there is not much data to this effect, it seems reasonable to believe that most people are comfortable with more impressionistic hiring decisions so long as they do not target discrete categories that people feel merit protection.

In the health care context, on the other hand, there may be reason to believe that GINA’s supporters are less concerned with genetic discrimination in particular than with advancing universal availability of health coverage. Indeed, of the countries grappling with genetic protections, the United States is somewhat unique in its market-based approach to health insurance, especially individual

(never leaving subcommittee). In the 108th Congress: S. 1053, 108th Cong. (2003) (passing the Senate, 95–0); H.R. 3636, 108th Cong. (2003) (never leaving subcommittee). In the 107th Congress: S. 318, 107th Cong. (2002) (never leaving committee); H.R. 602, 107th Cong. (2002) (never leaving subcommittee).

96. That a particular job skill or characteristic is a “bona fide occupational qualification” is a legally valid defense for discriminating between job candidates on the basis of a statutorily protected category (that is, age or gender). Civil Rights Act, 42 U.S.C. § 2000e-2(e) (2006) (“[I]t shall not be an unlawful employment practice for an employer to hire and employ employees . . . on the basis of his religion, sex, or national origin in those certain instances where religion, sex, or national origin is a *bona fide occupational qualification* reasonably necessary to the normal operation of that particular business or enterprise[.]” (emphasis added)).

health insurance.⁹⁷ Especially among political liberals and within the Democratic Party, health insurance is often discussed as a right that should not be denied either outright or through prohibitively high cost.⁹⁸ No doubt, many voters and legislators would support a bill prohibiting health insurance discrimination on the basis of genetics, income, personality, or willingness to pay until the system resembled one of guaranteed issue and full community (rather than individual or small-group) rating of risk. This would short-circuit any specific examination of what genetic antidiscrimination laws mean because they would not be about genetics at all.

The distribution of state laws before GINA instead suggests that universal rights-based conceptions of health care were not nearly broad enough to account for GINA's unanimous support. As of 2008, forty-eight states individually barred some form of genetic discrimination in the context of health insurance.⁹⁹ Of these states, however, only fifteen had any form of individual-market guaranteed issue law—normally with a number of exceptions and qualifications—and only thirty-two states had some form of high-risk insurance pool available to medically eligible individuals.¹⁰⁰ This means that the vast majority of states enacting genetic antidiscrimination laws did not enact guaranteed issue,¹⁰¹ and nearly a third of such states did not have a mechanism for high-risk individuals on the individual market.

B. IMMUTABILITY, BLAMELESSNESS, AND THE DISABILITY MODEL

The structure of GINA most immediately calls to mind the antidiscrimination regimes based on race, gender, and disability. Indeed, some of GINA's most significant operative language uses the same wording found in the Civil Rights

97. See Lemmens, *supra* note 89, at 382 (discussing how the United States' market-based insurance approach complicates questions of responding to genetic discrimination relative to other countries with state-run systems).

98. Compare, for example, the rights-based language on then-presidential candidate Barack Obama's health insurance website, Obama for America, Health Care, <http://www.barackobama.com/issues/healthcare/index.php> (last visited Apr. 22, 2009) ("Require insurance companies to cover pre-existing conditions so all Americans regardless of their health status or history can get comprehensive benefits at fair and stable premiums."), with the more market-oriented language used by Republican candidate John McCain, McCain-Palin 2008, Straight Talk on Health System Reform, <http://www.johnmccain.com/content/default.aspx?guid=8475c713-a541-4b97-a2aa-800e35da37bb> (last visited Apr. 22, 2009) ("One approach would establish a nonprofit corporation that would contract with insurers to cover patients who have been denied insurance and could join with other state plans to enlarge pools and lower overhead costs.").

99. Only Mississippi and Pennsylvania do not have genetics-related protection related to health insurance. See Nat'l Conference of State Legislatures, *supra* note 20.

100. The Henry J. Kaiser Family Found., Individual Market Guaranteed Issue, 2008, <http://www.statehealthfacts.org/comparetable.jsp?cat=7&ind=353> (last visited May 25, 2009).

101. Even without data on how many guaranteed-issue bills actually were proposed in the states lacking such a law, it seems reasonable to assume that the concept was at least known to their relevant legislators and to some subset of voters.

Act of 1964 and the Americans with Disabilities Act of 1990.¹⁰² Given the apparently shared motivations behind such legislation, it seems sensible to consider the concepts of fairness underpinning civil rights and disability legislation, and the areas where these fairness constructs apply to genetics.¹⁰³

In the insurance and employment contexts (as employment relates to insurance), each of these categories—race, gender, genetic predisposition—carries a statistical relationship to expected costs that could be actuarially useful.¹⁰⁴ Barring discrimination on the basis of race in employment and insurance speaks not to a concern about market economics but to a normative judgment on how the tension between actuarial fairness and social fairness must be resolved. In the insurance context, “[s]ocial fairness says that certain types of risk classification unfairly penalize people for factors they cannot control or for which they should not be held responsible.”¹⁰⁵ Genetic characteristics, in this regard, would resemble the other protected categories. In the employment context, as well, public opinion shows a desire to accommodate those with fixed, physical

102. Compare Americans with Disabilities Act § 102, Pub. L. No. 101-336, 104 Stat. 332 (codified at 42 U.S.C. § 12112 (2006)) and Civil Rights Act of 1964 § 703(a), Pub. L. No. 88-352, 78 Stat. 255 (codified at 42 U.S.C. § 2000d (2006)), with GINA § 202(a), Pub. L. No. 110-233, 122 Stat. 907. Each section of these three laws employs identical language, with the only significant change being the categories to whom the protection is being assigned.

103. Sen. Carl Levin (D-MI), among other legislators, made the direct comparison between the laws in a floor statement supporting GINA:

Our history has shown us that some employers have discriminated on the basis of a range of impermissible categories. As a result, Congress has passed laws such as the Civil Rights Act, CRA, the Americans with Disabilities Act, ADA, and the Age Discrimination in Employment Act, ADEA. These laws have made significant steps in reducing discrimination in employment, but problems remain and Congress continues to work to pass additional antidiscrimination legislation to expand those protections.

154 CONG. REC. S3372 (daily ed. Apr. 24, 2008) (statement of Sen. Levin).

104. In several analyses, race itself has been found to be a factor with significant implications for predicted health outcomes. In particular, African American health outcomes are predicted to be, on average, significantly poorer than outcomes for other racial groups. See, e.g., Linda A. Clayton & Michael W. Byrd, *Race: A Major Health Status and Outcome Variable 1980–1999*, 93 J. NAT’L MED. ASS’N 35S (2001); Vickie M. Mays et al., *Race, Race-Based Discrimination, and Health Outcomes Among African-Americans*, 58 ANN. REV. PSYCHOL. 201 (2007), available at <http://arjournals.annualreviews.org/doi/abs/10.1146/annurev.psych.57.102904.190212>; U.S. Dep’t of Health & Human Servs., Centers for Disease Control & Prevention, *Health Disparities Experienced by Black or African Americans*, MORBIDITY & MORTALITY WKLY. REP. 1, Jan. 14, 2005, at 1, <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5401a1.htm>. But see Francis S. Collins, *What We Do and Don’t Know About ‘Race,’ ‘Ethnicity,’ Genetics, and Health at the Dawn of the Genome Era*, 36 NATURE GENETICS SUPPLEMENT 513, 513 (2004), available at <http://www.genome.gov/Pages/News/Documents/RaceandGeneticsCommentary.pdf> (arguing that, despite the conventional wisdom, race is a meaningless predictor of health outcomes insofar as race itself is an indeterminate classification).

105. Hall & Rich, *supra* note 54, at 305; see also Godfrey B. Tangwa, *Genetic Information: Questions and Worries from an African Background*, in GENETIC INFORMATION: ACQUISITION, ACCESS, AND CONTROL, *supra* note 76, at 280 (“[T]he main ethical objection to the use of genetic information in insurance is that it does not seem morally right or even ordinarily fair to discriminate for or against, to reward or punish, people on the basis of involuntary and ineradicable biodata.”).

impairments that appear to be outside their control.¹⁰⁶

Put otherwise, the defining conception of fairness at work is one that shields people from penalty for immutable characteristics for which the bearers are blameless—essentially a disability model.¹⁰⁷ At one end of the spectrum would be an impairment like blindness, with nearly universal recognition as a genuine disability and widespread support for accommodation and protections.¹⁰⁸ People generally believe that the blind have neither caused their condition nor are in a position to change it.¹⁰⁹ At the other end would be conditions like drug addiction¹¹⁰ and obesity,¹¹¹ broadly considered not to be a disability in the classic sense that invokes the need for legal protection. Compared to blindness, drug addiction appears mutable and, correspondingly, within the addicted person's control. In the popular conception, it is neither immutable nor is the sufferer blameless.¹¹² In the case of obesity, studies show that the common perception of control accompanies negative biases.¹¹³ Highlighting the ambiguities inherent along such a spectrum is a characteristic such as homosexuality, where support for legislative protection hews closely to one's perceptions of sexual orientation as immutable characteristic versus choice.¹¹⁴

Reinforcing the disability model's natural relationship to genetics is the manner in which genetic characteristics had already, prior to GINA, found inclusion in the EEOC's interpretation of the ADA.¹¹⁵ An Executive Order by President Clinton expressed the intention of his Administration to include genetic conditions within the scope of the ADA and the EEOC's protection.¹¹⁶ President Clinton, in signing the Order, stated that “no employer should ever

106. See Paula M. Popovich et al., *The Assessment of Attitudes Toward Individuals with Disabilities in the Workplace*, 137 J. PSYCHOL. 163, 168 (2003) (“[P]articipants considered more of the physical or sensory-motor conditions to be disabilities than the psychological conditions.”).

107. This was made explicit by Sen. Carl Levin (D-MI): “We do not determine our own DNA. We are born with it. We cannot allow discrimination on the basis of such a fundamental aspect of life and one in which we had no choice.” 154 CONG. REC. S3372 (daily ed. Apr. 24, 2008) (statement of Sen. Levin).

108. See Popovich, *supra* note 106, at 168 tbl.1, 171 tbl.3.

109. Correspondingly, the most broadly recognized disabilities are physical conditions. See *id.* at 168.

110. See *id.* at 168 tbl.1, 171 tbl.3.

111. See Rebecca Puhl & Kelly D. Brownell, *Bias, Discrimination, and Obesity*, 9 OBESITY RES. 788, 799–800 (2001) (“Courts have generally viewed overweight as voluntary and mutable and, therefore, have disqualified it as a disability.”).

112. E.g., Petula Dvorak, *Something in the Air: When a Smoker Gets Lung Cancer, Sympathy Is Stained with Blame*, WASH. POST, Dec. 16, 2008, at F5.

113. See Puhl & Brownell, *supra* note 111, at 796.

114. See William Saletan, *Original Skin: Blacks, Gays and Immutability*, SLATE, Nov. 13, 2008, <http://www.slate.com/id/2204534/index.html> (discussing the differences between perceptions of race and sexual orientation turning on immutability). The immutability implications of sexual orientation are discussed in greater detail, *infra* section V.B.

115. EQUAL EMPLOYMENT OPPORTUNITY COMM’N, NOTICE NO. 915.002, POLICY GUIDANCE ON EXECUTIVE ORDER 13145: TO PROHIBIT DISCRIMINATION IN FEDERAL EMPLOYMENT BASED ON GENETIC INFORMATION (2000), available at <http://www.eeoc.gov/policy/docs/guidance-genetic.html>.

116. Exec. Order No. 13,145, 65 Fed. Reg. 6877 (Feb. 8, 2000).

review your genetic records along with your resume.”¹¹⁷ Thus, the fairness guarantees of the ADA—and presumably the fairness principles that justify disability law—applied to genetics. In the disability model, society is willing to bear some amount of cost-sharing and market distortion in order to protect an afflicted class it views as blameless and helpless, and it now appears willing to extend that categorization to genetics.¹¹⁸

C. THE PRIVACY MODEL

Concerns about privacy offer an additional model for the type of fairness promoted by genetic antidiscrimination legislation.¹¹⁹ This relates to the social sentiment that some information—especially some medical information—is fundamentally personal and that to require disclosure is impermissibly invasive. The impulse, then, is that one should not be judged by or forced to divulge that which is fundamentally private. Privacy fairness extends beyond the disability model in that it may include factors that are neither involuntary nor immutable. For example, most would consider it fair to offer some level of protection for information about whether a person has sought out psychotherapy or terminated a pregnancy despite the fact that this information would be the result of a person’s ostensibly voluntary actions and decisions. Even in the face of market distortions, concerns for privacy suggest it would be unfair in many contexts to require disclosure.

Medical concepts defending fairness through privacy have been codified in related contexts, in common law and statute. The deeply rooted professional and common law tradition of doctor-patient confidentiality¹²⁰ suggests the longstanding social importance of guarding the privacy of personal medical information. In statute, variations of this sentiment were expressed in the Health Insurance

117. President William Jefferson Clinton, Remarks at the Signing of Executive Order 13,145 (Feb. 8, 2000), *available at* <http://www.genome.gov/10002346>.

118. Beckwith & Alper, *supra* note 37, at 208 (“[I]t is often argued that it would be unfair to penalize people for developing genetic diseases that are beyond their control.”).

119. As with the concerns about punishing people for immutable conditions, concerns for privacy fairness pervaded the Congressional discussion about genetic discrimination and GINA:

A person’s unique genetic code contains the most personal aspects of their identity. As we begin to decipher this information, Americans have legitimate fears about how this deeply private information will be used. Surveys show that people are already declining to take medically valuable tests out of fear that they will face discrimination or invasion of their personal privacy.

154 CONG. REC. S3363 (daily ed. Apr. 24, 2008) (statement of Sen. Kennedy).

120. *See* AM. MED. ASS’N, CODE OF ETHICS OF THE AMERICAN MEDICAL ASSOCIATION 8 (1848) (“Secrecy and delicacy, when required by peculiar circumstances, should be strictly observed The force and necessity of this obligation are indeed so great, that professional men have, under certain circumstances, been protected in their observance of secrecy, by courts of justice.”); National Library of Medicine, The Hippocratic Oath, http://www.nlm.nih.gov/hmd/greek/greek_oath.html (last visited Apr. 23, 2009) (“Whatever I see or hear in the lives of my patients, whether in connection with my professional practice or not, which ought not to be spoken of outside, I will keep secret, as considering all such things to be private.”).

Portability and Accountability Act of 1996 (HIPAA).¹²¹ One of HIPAA's major components directs the Secretary of Health and Human Services (HHS) to promulgate regulations protecting "the privacy of *individually identifiable* health information."¹²² The word "genetics" is not a part of the statute or the HHS regulations that followed.¹²³ Nonetheless, HHS states on its website that genetic information is covered under HIPAA so long as it is "individually identifiable and maintained by a covered health care provider, health plan, or health care clearinghouse."¹²⁴ As such, prior to GINA, HIPAA was considered the only federal genetic antidiscrimination law, albeit one in which genetics was part of a much broader category.

Why, then, should genetic information have been singled out for additional, post-HIPAA protection through GINA? Put otherwise, what makes genetics inherently more private than other individually identifiable medical information? In the words of satirist and talk-show host Stephen Colbert, questioning a guest's decision to publish his genome online, genetic information is like "the social security number that God gave you."¹²⁵ This impulse to heightened genetic privacy derives from some of what is known about genetic information and much of what remains unknown. Genetics, the theory goes, contain a wealth of individualized information about which more is continually discovered.

The challenge this presents is highlighted by concerns over the privacy implications of DNA collection schemes involving convicted felons. In these plans, law enforcement officers collect DNA for identification purposes, drawing what was originally believed to be "junk DNA" in order to avoid gathering any information that would reveal more than a person's identity.¹²⁶ Since the initiation of these schemes, more revealing information has been found embedded in the so-called junk DNA.¹²⁷ This has raised not only privacy concerns for those convicted, but it suggests that access to any genetic information—even

121. Health Insurance Portability and Accountability Act of 1996, Pub. L. No. 104-191, 110 Stat. 1936 (codified at 42 U.S.C. § 1320d-2).

122. *Id.* § 264(a) (emphasis added).

123. See 45 C.F.R. §§ 160.103, 164.501 (2008).

124. U.S. Dep't of Health & Human Services, Does the HIPAA Privacy Rule Protect Genetic Information?, <http://www.hhs.gov/hipaafaq/about/354.html> (last visited Apr. 23, 2009).

125. *The Colbert Report* (Comedy Central television program Feb. 11, 2009) (interview with Dr. Steven Pinker), available at <http://www.colbertnation.com/the-colbert-report-videos/218577/february-11-2009/steven-pinker>. Colbert's remark was preceded by the additionally telling rhetorical question, "Are you crazy?" expressing, levity aside, the broad social squeamishness about making such information so public. *Id.*

126. See Rick Weiss, *Vast DNA Bank Pits Policing Vs. Privacy*, WASH. POST, June 3, 2006, at A1 ("The U.S. profiling system focuses on just 13 small regions of the DNA molecule—regions that do not code for any known biological or behavioral traits but vary enough to give everyone who is not an identical twin a unique 52-digit number.").

127. See, e.g., Alvin Powell, *Evolution Caught Playing with the Genetic On-Off Switch: Opossum Genome Shows "Junk" DNA Source of Genetic Information*, HARV. U. GAZETTE ONLINE, May 9, 2007, <http://www.news.harvard.edu/gazette/2007/05.10/99-junkdna.html>; Weiss, *supra* note 126 ("Still, the blood, semen or cheek-swab specimen that yields that DNA, and which authorities almost always save,

junk—is potential access to a vast repository of personal medical information.

Airline security suggests an analogous scenario for understanding when more information becomes, suddenly, a difference in kind. Airport screening involving baggage examinations and metal detector walk-throughs have been long-established parts of air travel. The details of privacy concerns in this area had reached an equilibrium, and the addition of procedures like shoe removal or segregation of liquids were slid into the existing framework without much cause for revising consent or privacy procedures. Even pat-downs largely were considered another tool from the same kit. The introduction of x-ray scanning that could create an image of the would-be passenger unclothed, however, was seen as a difference in kind. Despite this method's efficiency, the amount of personal information it reveals compared to a metal-detector scan or a pat-down has met with both public concern¹²⁸ and legal challenge.¹²⁹ Similarly, the essential nakedness of one's personal medical details contained in genetic information raises concerns dormant in similar areas and demands the formulation of a new legal regime to protect privacy fairness.¹³⁰

V. THE PROBLEMS OF CATEGORIZING "GENETICS"

At the core of antidiscrimination law is the category to be protected: people of a given race, national origin, gender, or religion.¹³¹ The concept of social fairness that provides the moral foundation for antidiscrimination laws is rooted in a common understanding of the contours, boundaries, and implications of that category. Racial antidiscrimination protection, for example, depends on an identifiable category of "race," and on that category's characteristics being immutable. Our attitude towards racial antidiscrimination legislation necessarily would be altered if we believed race were fluid, or if we could no longer tell if a characteristic were "racial."¹³² The fairness models described above depend on

contains additional genetic information that is sensitive, including disease susceptibilities that could affect employment and health insurance prospects . . .").

128. See *Europe Delays Airport X-Ray Eye*, BBC NEWS, Oct. 23, 2008, <http://news.bbc.co.uk/2/hi/europe/7687126.stm>; *New Airport X-Ray Too Revealing?* (CBS Evening News television broadcast July 17, 2003), transcript available at <http://www.cbsnews.com/stories/2003/07/17/eveningnews/main563797.shtml>.

129. See, e.g., *Zboralski v. Monahan*, 616 F. Supp. 2d 792 (N.D. Ill. 2008).

130. Cf. Mark A. Rothstein, *Keeping Your Genes Private*, SCI. AM., Sept. 2008, at 64, 64. Rothstein argues, with language particularly apt to the concepts of privacy and a figurative nakedness, that protective legislation is needed beyond HIPAA because the revelation of "an individual's genetic endowment could also readily cause embarrassment or stigma." *Id.*

131. See *supra* section I.B, discussing the centrality of categorization to the concept of discrimination.

132. Over time, of course, that very question—of what is and is not "race"—has indeed been a subject of considerable controversy. See IAN HANEY LÓPEZ, *WHITE BY LAW: THE LEGAL CONSTRUCTION OF RACE* 78–109 (2006) (arguing that legal structures created race as a coherent category); Jared Diamond, *Race Without Color*, DISCOVER, Nov. 1994, at 83 (discussing the infinite and possibly meaningless ways of categorizing "races").

Rather than undermine the point in the genetics context, however, the debate over race reinforces the

similar assumptions in order for GINA and other genetic-specific antidiscrimination measures to have a bounded and internally consistent purpose.

This Part explores the factors that undermine the existence of a discrete and wholly rational category for genetics and genetic information. The purpose is not to suggest that the law or its goals are somehow normatively invalid, nor to suggest that unintended consequences may follow its implementation. Instead, this Part seeks to highlight the law's categorical incoherence, elaborating some of the complications that flow from delineating a protected class out of a concept as broad, embryonic, and vaguely defined as "genetic information."

A. THE DIFFICULTIES OF "GENETIC EXCEPTIONALISM"

Genetic information is fundamentally medical information, albeit medical information obtained through a particular method. The thinness of this distinction relative to the bold lines created by antidiscrimination legislation has led some to criticize the phenomenon of "genetic exceptionalism"—the idea that genetics and the information it provides are somehow different in kind from comparable non-genetic medical information.¹³³ Critics of a genetics-oriented approach to legal protection charge that the distinction is fundamentally arbitrary and elevates the method of acquiring information (genetics) above the content of that information (diseases and predispositions).¹³⁴ The difficulty is that genetics may be, simultaneously, everything and nothing. That is, if genetic information contains the building blocks for our entire medical makeup, then all manifestations, however observed, are fundamentally genetic.¹³⁵ And, by extension, the observation of genes stands to become another observation of symptoms.¹³⁶

The possibly illusory nature of the boundary between genetic and non-genetic is highlighted by the difference between what is and is not considered permissible under GINA and under the various genetic antidiscrimination regimes preceding it. Some state laws bar consideration of genetic test results but allow consideration of family history that, without any specific "genetic testing,"

idea that when these categorical lines become problematic, the category-based laws that depend on them become more complex and, in one sense, arbitrary.

133. For a fuller discussion of the term "genetic exceptionalism" and its possible history, see Lemmens, *supra* note 89, at 369–76.

134. Lawrence O. Gostin & James G. Hodge, Jr., *Genetic Privacy and the Law: An End to Genetics Exceptionalism*, 40 JURIMETRICS 21, 23 (1999) (arguing that "genetic exceptionalism creates significant legal protection for some information but denies it for other information").

135. Even the notion of free will itself is implicated by the idea that so much of genetics is revelatory of one's personal biological and even, by extension, psychological destiny. See Emilio Mordini, *Linear Destiny and Geometric Fate*, in GENETIC INFORMATION: ACQUISITION, ACCESS, AND CONTROL, *supra* note 76, at 309; Sandra Aamodt & Sam Wang, *Mugged By Our Genes?*, NYTIMES.COM: THE WILD SIDE, <http://judson.blogs.nytimes.com/2009/03/24/guest-column-mugged-by-our-genes/> (suggesting that "the genes you get from your parents partly determine your risk of being mugged").

136. See Reilly, *supra* note 30, at 1067 (describing the consistent failure of attempts to sort out the genetic from the non-genetic).

would suggest genetic predispositions.¹³⁷ Thus, intuiting the presence of a BRCA variation by family history would be permissible, whereas a *genetic* test for the very same information would be impermissible. Texas's genetic antidiscrimination law specifically delineates that the former would not count as genetic testing, and thus would be permissible. Acceptable (and presumably non-genetic) information includes the following:

a blood test, cholesterol test, urine test, or other physical test used for a purpose other than determining a genetic or chromosomal variation, composition, or alteration in a specific individual; a routine physical examination or a routine test performed as part of a physical examination; a test to determine drug use; or a test to determine the presence of the human immunodeficiency virus.¹³⁸

Investigating a greater likelihood of heart disease through a combination of heart rhythm, cholesterol, and blood pressure measurements is permissible and reasonably common, possibly even in an individual insurance context. Determining a greater likelihood of heart disease by detecting a chromosomal variation is impermissible.¹³⁹ Moreover, as new genetic links are found, more potential conditions would become "genetic" and, thus, their use would become legally problematic.¹⁴⁰ This distinction is the heart of the genetic exceptionalism critique, which charges that irrational fear about the unknowns of genetics rather than any coherent concept of fairness fuels a rush to genetic antidiscrimination laws.¹⁴¹

B. THE MALLEABLE NATURE OF IMMUTABILITY

Reflexively, the impulse is to sympathize with the bearer of a disadvantageous genetic predisposition. The person with the predisposition to cystic fibrosis, especially the person who has manifested cystic fibrosis, has drawn a card that many feel, under other circumstances, they themselves could have drawn. These are the clean examples of genetics as disability with obvious and pleasing divisions. As the understanding of the human genome expands, how-

137. See Beckwith & Alper, *supra* note 37, at 207–08; Hall & Rich, *supra* note 54, at 293 (“[M]any states still allow insurers to consider family history of disease, and they allow insurers to underwrite on the basis of observed clinical signs and symptoms . . .”).

138. TEX. INS. CODE ANN. § 546.001 (Vernon 2009).

139. See Anna Helgadottir et al., *A Common Variant on Chromosome 9p21 Affects the Risk of Myocardial Infarction*, 316 SCIENCE 1491 (2007), available at <http://www.sciencemag.org/cgi/reprint/316/5830/1491.pdf> (identifying a genetic variant related to a significant increase in the risk of heart disease).

140. Trudo Lemmens, *Private Parties, Public Duties? The Shifting Role of Insurance Companies in the Genetics Era*, in GENETIC INFORMATION: ACQUISITION, ACCESS, AND CONTROL, *supra* note 76, at 33 (“Protection would then depend on the level of research into specific diseases. As soon as a genetic component would be found, protection would be granted.”).

141. See Beckwith & Alper, *supra* note 37, at 208 (arguing that “genetic essentialism” is a fallacy based on incomplete understanding that is becoming “increasingly untenable” as we learn more about how genes function).

ever, these basic characteristics currently associated with genetic predispositions call into question how applicable the characteristics of immutability and blamelessness are to the field of genetic predispositions as a whole, or which genetic predispositions people would be comfortable protecting.

The fixed and unchanging nature of genetic variations may be more flexible than is generally discussed. The first sense in which this is true is the increasing likelihood of literally altering one's genetic makeup through the burgeoning practice of gene therapy.¹⁴² Early research suggests a number of potential techniques for modifying, correcting, or blending specific genes.¹⁴³ Given the rapid development of genetic medicine, it stands to reason that practical medical application of such technology, already occurring in rodent-based trials, could emerge in the near future.¹⁴⁴ Such direct control over genetics would cast new light on the questions that currently characterize the genetic discrimination debate. If genetic therapy could correct for genetic variations, would it be appropriate for an insurer who covers such therapy to charge more to patients who choose not to get it? Would it be appropriate for employers to recommend such treatment?

More complex questions along the same lines also arise regarding the ability to affect one's predisposition to a disease even if unable to affect the genes underlying that predisposition. Non-genetic therapy ranging from environmental changes¹⁴⁵ to medicinal treatment to surgery all can reduce the likelihood that a person predisposed to a disease will ever actually suffer it. For example, a woman with the BRCA gene variations predisposing her to breast and ovarian cancer can functionally eliminate the increased risk of either disease through hysterectomy or preventive mastectomy. Although it hardly satisfies a sense of social justice to condition affordable medical care on a willingness to undergo such an invasive and personally difficult procedure, some might think it wholly appropriate for insurers to be able to judge on that basis if a pill-based treatment could achieve the same effect. The introduction of such possibilities creates a sliding scale along which to view the evaluation of genetic information: If a procedure were effective and non-invasive, would it be worth creating a market distortion and collectively bearing added risk in order to protect someone's ability to refuse that procedure? What if the procedure were moderately invasive? GINA does not consider the ability of a person to mitigate their risks in prohibiting the actuarial consideration of genetic information. Still, once the condition appears to be within a person's control, the fair outcome even under a disability model becomes less certain.

Even accepting genetic conditions to be immutable, the discovery of genetic bases for conditions generally considered behavioral calls into question what

142. See generally LEROY WALTERS & JULIE GAGE PALMER, *THE ETHICS OF HUMAN GENE THERAPY* (1997) (exploring different techniques for and ethical implications of modifying genes).

143. *Id.*

144. *Id.* at 99.

145. See Gostin & Hodge, *supra* note 134, at 34.

blamelessness means in the context of an immutable predisposition.¹⁴⁶ Genetic research has produced in the popular press such tantalizing headlines as “Can’t Quit Smoking? Blame Your Genes,” suggesting that the voluntary behaviors underlying addictions may be more voluntary for some than for others as a result of involuntary, immutable genetics.¹⁴⁷ This calls into question what it means for a person suffering the effects of one genetic condition (for example, breast cancer) to be blameless while a person suffering another (for example, drug addiction) shoulders responsibility. We never can quantify whether it is harder for a person with a predisposition to drug use to abstain throughout their lives than for a person with a predisposition to cancer to undergo preventive surgery. Genetic predispositions to ostensibly behavioral conditions reveal our inability to truly separate the involuntary from the voluntary and the immutable from the malleable.

Homosexuality presents another interesting dilemma as a characteristic that may have a strongly genetic component.¹⁴⁸ Unlike genetics, sexual orientation has no federal Title VII protection,¹⁴⁹ and yet we would not necessarily expect the possible genetic origins of homosexuality to place that characteristic under GINA’s protection. Nor would we expect Title VII protections to have the kind of unanimity that characterizes GINA’s passage. Studies have shown that the belief that homosexuality is an inborn genetic trait is highly correlated with a willingness to provide additional rights and protections based on sexual orientation.¹⁵⁰ Although this seems to track the immutability model of fairness (believing that the immutable merits protection), the correlation may occur in the other direction (favoring protection, and therefore predisposed to believe that the characteristic is immutable). Indeed, groups morally opposed to the expansion

146. See Tangwa, *supra* note 105, at 275–76 (“The only possible danger here may be that of *reductionism to genetics* whereby personal behaviour and particular orientations or habits such as alcoholism, smoking, homosexuality, paedophilia, etc., may be attributed to or blamed on the genes, with or without any leading evidence.”). Tangwa seems by his language to typify this difficulty, suggesting that a problem with genetics is that we may lose our ability to distinguish the voluntary disfavored characteristics from the involuntary. I might suggest, on the other hand, that the possibility of losing this distinction suggests a problem with attempting to distinguish voluntariness along such clear lines.

147. Associated Press, *Can’t Quit Smoking? Blame Your Genes: New Studies Show ‘Double Whammy’ Link to Addiction and Cancer*, MSNBC.COM, Apr. 2, 2008, <http://www.msnbc.msn.com/id/23919596/>.

148. See Dean Hamer et al., *A Linkage Between DNA Markers on the X Chromosome and Male Sexual Orientation*, 261 SCIENCE 321 (1993); Stella Hu et al., *Linkage Between Sexual Orientation and Chromosome Xq28 in Males but Not in Females*, 11 NATURE GENETICS 248 (1995); see also Chandler Burr, *Homosexuality and Biology*, THE ATLANTIC MONTHLY, March 1993, at 47, 62–65.

149. See *supra* note 27. Although no federal protection exists, twenty states, and numerous cities, have laws prohibiting employment discrimination based on sexual orientation, similar to Title VII protections. Human Rights Campaign, *Statewide Employment Laws & Policies* (Aug. 21, 2008), http://www.hrc.org/documents/Employment_Laws_and_Policies.pdf. The distribution of such policies—clustered in the Northeast, upper Midwest, and West Coast—highlights the often politicized and culturally divided manner in which the debate has taken place. This stands in marked contrast to the near-unanimity with which identical provisions have been enacted based on genetics.

150. See Saletan, *supra* note 114.

of gay rights reject claims of a genetic basis for sexual orientation;¹⁵¹ this suggests that in addition to favoring protections for that which we recognize as immutable, we may choose to see as immutable that which we feel is deserving of protection.

C. THE DISCLOSURE CONCERNS OF PRIVATE GENETICS

If genetic antidiscrimination is driven by the sentiment that a person's genetics are a private concern, the application of the idea may be more limited than it seems. The private is, by its very definition, the sphere walled off from the public.¹⁵² Genetic variation in this model is a thing with private implications to be carried individually. Lest one be marked as having bad blood, a person should have the freedom to guard that information. Disfavored genetic variations, though, are not merely personal handicaps devoid of social implication. The communicability of genetics, the genetic bases of social behavior, and the possibility of genuine employment concerns all suggest that the privacy approach to genetics as a whole category—rather than an à la carte grouping of favored and disfavored sufferers—may be untenable.

The first complication in a broader application of privacy for genetics is that genetic conditions are communicable, at least from parent to child. In familial and reproductive contexts, genetic conditions have implications that extend beyond any particular individual. Although the implications are less dire than those for a sexually transmitted disease, the logic for contextual disclosure is applied similarly. In 1996, the New Jersey courts likened certain genetic predispositions to infectious diseases. The opinion in *Safer v. Estate of Pack* held that physicians had a common-law duty to warn not only their patients about such conditions, but the patient's family members as well. The opinion noted the "physician's duty to warn those known to be at risk of avoidable harm from a genetically transmittable condition."¹⁵³ The physician's duty to warn extrapolates easily to a personal duty to disclose one's conditions to family members, reproductive partners, and others who may be invested.¹⁵⁴ In such a scenario, genetic privacy is not a categorical right but a contextually balanced preference with countervailing interests.¹⁵⁵

151. See, e.g., JAMES C. DOBSON, BRINGING UP BOYS 116–17 (2001) (arguing that "there is no evidence to indicate that homosexuality is inherited" and that "if homosexuality were genetically transmitted, it would be inevitable, immutable, irresistible, and untreatable"); Robert Knight, *Born or Bred? Science Does Not Support the Claim that Homosexuality Is Genetic*, CONCERNED WOMEN FOR AMERICA (2004), <http://www.cwfa.org/images/content/bornorbred.pdf>.

152. See, e.g., BLACK'S LAW DICTIONARY 1233 (8th ed. 2004) (defining "private" as "[r]elating to an individual, as opposed to the public").

153. *Safer v. Estate of Pack*, 677 A.2d 1188, 1192 (N.J. 1996).

154. NEIL F. SHARPE & RONALD F. CARTER, GENETIC TESTING: CARE, CONSENT, AND LIABILITY 422–23 (2006) (discussing a genetic screener's duty to protect third parties under several legal models dealing with contagious diseases or the potential to cause harm to others).

155. Elisabeth Hildt, *Influences of Genetic Testing on a Person's Freedom*, in GENETIC INFORMATION: ACQUISITION, ACCESS, AND CONTROL, *supra* note 76, at 241 ("[W]hat is of particular importance is

This prevents the unlimited application of privacy justifications to genetic information but still fits within the GINA framework. After all, there are other examples of conditions with a legal or moral duty to disclose in some contexts and an expectation of privacy in others. A sexual partner, for example, should be able to inquire about sexually transmitted diseases; in most circumstances, we expect that an employer should not. But other genetic characteristics may have broader disclosure implications that complicate the desirability of GINA's restrictions.

The contours of a bona fide occupational qualification defense¹⁵⁶ have not yet been tested in a genetic context but are potentially quite murky. In 2001, the Burlington Northern Santa Fe Railroad Corporation settled a lawsuit filed after the company, without the consent of its employees, subjected employee blood samples to genetic testing.¹⁵⁷ Burlington Northern was attempting to locate a predisposition to carpal-tunnel syndrome as a way to avoid disability payments to workers who developed the condition.¹⁵⁸ These actions are derided, perhaps rightly, as somewhat villainous, but a different set of facts might have recast the question.

Suppose Burlington Northern is aware that some of its positions present a greater risk of carpal-tunnel syndrome, and it informs applicants of this fact. Can the corporation disqualify applicants especially prone to carpal-tunnel as a bona fide occupational qualification? Can it merely request that applicants get tested and—should someone with a strong predisposition choose to take the job—disclaim liability for the condition's subsequent manifestation? Or, is the privacy of this information so paramount that Burlington Northern must consider all applicants as being equally predisposed to carpal tunnel? GINA currently allows an exception for jobs involving toxic chemicals, presumably for situations like this one, in which a predisposition could render an otherwise safe job dangerous. The logic of this exemption may suggest that genetic privacy even in the employment context, rather than an absolute, must be balanced like other health information against occupational realities.

CONCLUSION

Seven months after GINA's passage, the *New York Times* reported on a limited trend of parents who tested their infant and toddler children for genetic

whether the person who has undergone genetic testing is able to control who will know the results. It is very difficult to achieve such a strict control, however, especially because there is a clear conflict between individual and public interests here.”).

156. See *supra* note 96 and accompanying text.

157. Press Release, Equal Employment Opportunity Commission, EEOC Settles Suit Against BNSF for Genetic Bias (Apr. 18, 2001), <http://www.eeoc.gov/press/4-18-01.html>.

158. Rip Watson, *Burlington Northern Settles Suit over Genetic Tests*, L.A. TIMES, Apr. 11, 2001, at C3.

modifications that might allow the children to excel at particular sports.¹⁵⁹ These parents did not try to shield children from genetic fate or to see that their lives remain unaffected by immutable genetic constraints. Quite the contrary. We can envision a scenario in which the story's eager parents promote their children's genetic predispositions to potential trainers, even to the detriment of children born comparably "deficient." We are, in short, only beginning to learn what our genetics (and those of our children) mean. We are conflicted over what to do with the information, and how it may change our understanding of our fates, our free will, and our obligations to one another.

From the construction of the term "genetic discrimination" to the legal protections enacted through GINA, the approach to safeguarding against negative consequences from genetic testing has thus far been a categorical one, focused on group rights. Just as a person can be of a particular race (or races), so too can a person be of a particular genetic status and, correspondingly, can suffer discrimination as a result. This approach provides a convenient way to create a statutory framework confronting the challenges of genetic information. When discussing categorical discrimination, we are comfortable having social fairness trump even economically rational discrimination.

The creation of categorical protections rendered the largely unresolved—and perhaps problematically subjective—debate over the nature and extent of genetic discrimination to some extent irrelevant. Claims that genetic discrimination does not exist and predictions that protective legislation would have market consequences had little apparent effect on public opinion or the unanimity of congressional action to prevent such discrimination.

The moral impetus behind such categorical protections is the desire to shield from harm the blameless, helpless victims of genetic fate, and to protect their privacy. A fuller examination of genetics and their implications suggests that such notions of fairness do not support the entire category of the genetic very well. Instead, the logic behind these constructs may be more circular and ad hoc. There is widespread, instinctual recognition of social unfairness in the woman who cannot secure health care because of a BRCA gene mutation; the difficulty is grappling with the arbitrary relationship of genetics, as a category, to that impulse. Genetics, and the predispositions that accompany them, may not prove immutable in the future. To the extent that genetics are immutable, that immutability may suggest a different approach to sexual orientation, addiction, obesity, athletic inclination, and even personality. If genetics should be private, that privacy is only absolute insofar as we can cordon off genetics without public implications. Although genetic antidiscrimination suggests broad categorical protections, its realization may favor a narrower, more normatively determined segment of the genetic.

159. Juliet Macur, *Born to Run? Little Ones Get Test for Sports Gene*, N.Y. TIMES, Nov. 29, 2008, at A1.