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PERSONHOOD, DISCRIMINATION, AND THE NEW GENETICS*

Janet L. Dolgin[†]

INTRODUCTION

Revolutionary developments in molecular biology are altering social understandings of disease and the parameters of medical practice in ways that promise or threaten (depending on perspective) to alter the essential character of the social order. Among the most striking of these developments is the mapping of the human genome.

Decoding the human genome and identifying genetic sequences¹ may provide, among other things, for the production of individually tailored drugs,² for medicines without side effects,³ and perhaps eventually for gene therapy that will replace dysfunctional genes with genes that preclude or cure illness.⁴ But, the same developments threaten society with the potential for devastating biological accidents,⁵ with broad inva-

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¹ In June, 2000, the Human Genome Project (a public consortium, funded largely by the U.S. Government and including laboratories in the United States, Britain, Japan, Germany, France, and China) and private industry (the Celera Corporation) together announced the completion of a "first draft" of the human genome. Nicholas Wade, *Reading the Book of Life: Now, the Hard Part: Putting the Genome to Work*, N.Y. TIMES, June 27, 2000, at F1 [hereinafter *Now, the Hard Part*]; Nicholas Wade, *A Historic Quest: Double Landmarks for Watson: Helix and Genome*, N.Y. TIMES, June 27, 2000, at F5.

² *Life Story: A Survey of the Human Genome*, ECONOMIST, July 1-7, 2000, at 8 [hereinafter *Survey of the Human Genome*].

³ *Now, the Hard Part*, *supra* note 1, at F4.

⁴ *Survey of the Human Genome*, *supra* note 2, at 5.

⁵ *Id.* at 16.

sions of individual and communal privacy,⁶ and with "genetic" bigotry⁷ and the revival of eugenic policies.⁸

Behind the concrete promises and threats that attend the new genetics lies another sort of change—more subtle than those more usually, and more easily, described and assessed, but as important. In particular, developments in molecular biology will likely alter—and in certain contexts have already begun to alter—the ideological frame within which people define themselves and their actions.

This Article identifies and explores the ramifications of one such change. This change involves a fundamental shift in the locus of social value from the autonomous individual—long the central agent of thought and action in most domains of life⁹ in the post-Enlightenment West—to a larger whole, defined through the presumption of a shared genome. Among the consequences of this change are two evolving conceptions of a "genetic family" and a "genetic ethnic group." Each threatens to eviscerate a set of basic values related almost exclusively to the autonomous individual. Among those values are privacy, equality, and choice. This Article focuses on potential consequences of this shift in the locus of social value for familial and for ethnic and racial groups.¹⁰ The widespread availability of

⁶ Lawrence O. Gostin & James G. Hodge, Jr., *Genetic Privacy and the Law: An End to Genetics Exceptionalism*, 40 *JURIMETRICS* 21, 22 (1999) (summarizing likely benefits and concerns about proliferation of genetic information).

⁷ *Now, the Hard Part*, *supra* note 1, at F4.

⁸ *Survey of the Human Genome*, *supra* note 2, at 16.

⁹ For most of the last two and a half centuries, the person within familial settings has been defined in express contrast with the person in the marketplace. *See, e.g.*, JANET L. DOLGIN, *DEFINING THE FAMILY: LAW, TECHNOLOGY, AND REPRODUCTION IN AN UNEASY AGE* 1-6 (1997). So, for instance, society has understood the family as a hierarchical, holistic social unit, defined by enduring solidarity. *See, e.g.*, DAVID M. SCHNEIDER, *AMERICAN KINSHIP: A CULTURAL ACCOUNT* 51-52 (1968). In the last few decades of the twentieth century, new understandings of the domestic arena competed openly with old ones. Society and the law now often treat the person within family settings as an autonomous individual who has chosen to relate to others as family. *See generally* KATH WESTON, *FAMILIES WE CHOOSE: LESBIANS, GAYS, KINSHIP* (1991); *see also infra* notes 318-322 and accompanying text (distinguishing notion of traditional family from notion of family-by-choice).

¹⁰ As used in this Article, the difference between the terms "ethnic" and "racial" refers to a social, not a genetic, or other sort of biological, difference. In the United States, the difference between race and ethnicity lies in the consistency and force with which members of a group are excluded from mainstream society and its benefits. *See, e.g.*, JANET L. DOLGIN, *JEWISH IDENTITY AND THE JDL* 145

genetic information may create, and appear to validate, negative images of groups defined through reference to DNA and alter understandings of personhood that now prompt the law to protect privacy, and to prohibit ethnic and racial discrimination.

The implications of the new genetics for Ashkenazi Jews¹¹ shows the consequences of genetic information for those identified with groups long characterized through somatic traits.¹² The Jewish case is especially illuminating because of the disproportionate research attention that has, in recent years, been devoted to studying the genome of Ashkenazi Jews,¹³ the consequent identification of genetic alterations associated with Ashkenazi Jews, and the long history of stigmatization and discrimination that Jews have endured as a religious group, a racial group, an ethnic group, and a national group.¹⁴ The new genetics provides a new sort of data ("genetic information") and a new frame for interpreting such data that pose a series of interconnected dangers (of discrimination and stigmatization¹⁵) to Jewish communities, as well as to other communities that have been defined, or that can be defined, in "genetic" terms.

At least some of these dangers are especially disturbing because it is not likely that American law, as presently consti-

(1977) (considering difference between "race" and "ethnicity" in context of social scientists' use of scaled attributes to compare groups). In the American context, African-Americans have been treated as a "race" more consistently and more harshly than other groups.

This Article generally uses the term "ethnic" group, rather than the more cumbersome term "ethnic/racial" group. It is, however, important to remember that the dangers of social discrimination against a group by mainstream society are more likely to affect groups defined in racial, rather than ethnic, terms.

¹¹ The term Ashkenazi Jew refers to Jews from Europe and Russia. About eighty-two percent of the world's Jewish population is of Ashkenazi origin. Howard Markel, *Di Goldene Medina (the Golden Land): Historical Perspectives of Eugenics and the East European (Ashkenazi) Jewish-American Community, 1880-1925*, 7 HEALTH MATRIX 49, 50 (1997).

¹² Other cases could be described. See *infra* notes 182-190 (considering case of African-Americans).

¹³ See *infra* notes 203 & 212 and accompanying text (noting reasons for this attention to genetic information of Ashkenazi Jews).

¹⁴ See, e.g., LEONARD DINNERSTEIN, *ANTISEMITISM IN AMERICA* xix 58 (1994); see also *infra* notes 224-243 and accompanying text (describing stigmatization of Jewish communities in the West from middle ages to present).

¹⁵ See *infra* notes 94-96 and accompanying text (defining and differentiating between "discrimination" and "stigmatization").

tuted, will provide adequate protection against such dangers. Since the legal system has not been able to devise a consistent, comprehensive approach to genetic discrimination, it will probably prove unable to limit stigmatization against groups identified on the basis of genetic information.

This Article begins by reviewing developments in molecular biology that have resulted in the growing proliferation of genetic information. Part II describes an ideology of "genetic inheritance," developing as the social implications of the new genetics are digested and internalized by the society, and then reviews the responses of the law to discriminatory uses of genetic information. Finally, Part III presents and analyzes some potential consequences of an ideology of genetic inheritance for ethnic and racial groups in the United States. In part, the argument in this Part relies on evidence about the implications of the concept of the "genetic family" and on an analogy, long internalized within the culture, between familial and ethnic settings. Within both contexts, people have long defined "Self" and "Other" through the metaphors of blood. Further, Part III denotes and considers a remarkable assumption that underlies a recent state court decision and several law review commentaries—that in certain contexts autonomous individuals are being replaced by a larger, genetic whole. That process directly threatens many of the rights protected by the Bill of Rights insofar as those rights depend on, because they attach to, the individual person and not larger groups. Emerging visions of that larger whole displace the notion of the autonomous individual, and thus preclude, or at least limit, the very concept of choice as that concept has developed in the West since the Enlightenment.

I. THE "NEW GENETICS"

In molecular biology, the twentieth century became the age of information. Indeed, biology is fast becoming an "information" science.¹⁶ Geneticists now work *in silico*—on computers—as well as directly on living matter.¹⁷ Moreover, DNA,¹⁸

¹⁶ *Survey of the Human Genome*, *supra* note 2, at 6.

¹⁷ *Id.*

¹⁸ The full name for these molecules is deoxyribonucleic acid. In 1944, research-

the molecules on which genes are "written," is viewed as important insofar as it provides *information*—messages presented in a "code of chemicals."¹⁹ Many hypotheses are being formulated and a great deal of debate results as scientists attempt to discern the limits of that code for the physical and psychological state of humanity. In June, 2000, the federally-funded "Human Genome Project"²⁰ and private industry²¹ together announced the completion of a preliminary draft of the so-called "human genome."²² That draft provides a transcript of encoded DNA. The accomplishment is remarkable. However, comparatively little is yet known about the complicated implications of the genetic code.²³ Scientists have identified about ninety-seven percent of the bits of information on the DNA molecule, but the bits have not all been placed in order, and scientists do not know what most of the bits "say."²⁴

ers at the Rockefeller Institute realized that genes are made of DNA. The structure of the DNA molecule was discerned in 1953 by James D. Watson and Francis Crick, helped by the work of Rosalind Franklin and Maurice Willkins. *Reading the Book of Life: What Lies Ahead: Journey to the Genome*, N.Y. TIMES, June 27, 2000, at F4.

¹⁹ MATT RIDLEY, *GENOME: THE AUTOBIOGRAPHY OF A SPECIES IN 23 CHAPTERS* 13 (1999).

²⁰ See *supra* note 1 (defining Human Genome Project).

²¹ Dr. J. Craig Venter, President of Celera Genomics of Maryland, and Dr. Francis S. Collins, Director of the National Human Genome Research Institute, participated with President Clinton and Prime Minister Tony Blair (who participated by satellite) in announcing the completion of a preliminary draft of the human genome. Jeff Nesmith, *Genetic Code Map a Milestone: But Hurdles Remain to Conquer Disease*, ATLANTA J. & CONSTITUTION, June 27, 2000, at 1A, available at Lexis, News Library, Georgia New Sources File; Nicholas Wade, *Reading the Book of Life: The Overview: Genetic Code of Human Life is Cracked by Scientists*, N.Y. TIMES, June 27, 2000, at A1.

Results of the \$300 billion effort of the Human Genome Project have been posted on the Internet. Information is updated twice a day. Nesmith, *supra*, at 1A.

²² Molecular biologist Lee Silver defines the "human genome" as the genetic information contained on humans' twenty-three pairs of chromosomes. Lee M. Silver, *The Meaning of Genes and "Genetic Rights"*, 40 JURIMETRICS 9, 13 (1999). The human genome is a statistical construct that is said to reflect the DNA in human cells. *Survey of the Human Genome*, *supra* note 2, at 3. The people whose DNA was actually sequenced by the Human Genome Project and by Celera remain anonymous. Nicholas Wade, *Reading the Book of Life: Tools Already in Use: Whose DNA Is It? In a Way, Nobody's*, N.Y. TIMES, June 27, 2000, at F2.

²³ Now the Hard Part, *supra* note 1, at F4 ("Biologists face years of preparatory work in understanding the various levels of the genome's operation.").

²⁴ Nesmith, *supra* note 21, at 1A; *Human Genome: Scientists Celebrate 'Working Copy' of Map*, AMERICAN HEALTH LINE, June 27, 2000, available at Lexis, News Library, Georgia News Sources File [hereinafter *Scientists Celebrate*].

The task of deciphering the code's meaning is made difficult by, among other things, the absence of "punctuation" on DNA, which might indicate where one gene ends and another starts.²⁵ Moreover, genes compose a small part of any chromosome.²⁶ It is widely assumed that much of the rest of the DNA molecule is "junk."²⁷ The portions of DNA that are not genes may, however, prove essential to cell function.²⁸ Understanding the decoded genome depends on differentiating meaningful genes from other sequences that lie between the genes on the chromosome.²⁹

Even the number of genes that comprise the human genome remains in question; it is not yet known where all the genes begin and end because of the large areas on the DNA molecule that "interrupt" the coded genetic information.³⁰ Scientists now estimate that the human genome contains about 50,000 discrete genes.³¹ Any one gene may encode several proteins.³² Moreover, genes interact in complicated ways, so that

²⁵ *Now the Hard Part*, *supra* note 1, at F4.

²⁶ *Deconstructing a Chromosome*, N.Y. TIMES, June 27, 2000, at F6.

²⁷ *Scientists Celebrate*, *supra* note 24. Matt Ridley defines this "junk DNA" as "a jumble of repetitive or random sequences that [are] rarely or never transcribed." RIDLEY, *supra* note 19, at 9.

²⁸ MAXWELL J. MEHLMAN & JEFFREY R. BOTKIN, ACCESS TO THE GENOME: THE CHALLENGE TO EQUALITY 11 (1998). Mehlman and Botkin suggest that "junk" DNA may also or alternatively prove to have been important during the evolutionary process. *Id.*

²⁹ The parts of the chromosome between the genes, called introns, are not copied by the cell when it translates the gene's code to create a protein. *Deconstructing a Chromosome*, *supra* note 26, at F6.

³⁰ RIDLEY, *supra* note 19, at 6. The interruptions are called introns. *See supra* note 29.

³¹ David Baltimore, *Mapping Genes a Start, Not an End*, SEATTLE POST-INTELLIGENCER, June 27, 2000, at A13, available at Lexis, News Library, Washington News Sources File. Flies have about 14,000 genes and worms about 18,000. *Id.* In June, 2000, some researchers believed that the human genome may contain as few as 30,000 to 38,000 genes; others believe the number may be closer to 120,000, or even 150,000 genes. *Scientists Celebrate*, *supra* note 24; *Survey of the Human Genome*, *supra* note 2, at 6. By February, 2001, scientists at both Celera Genomics and at the public Human Genome Project had concluded that humans only have about 30,000 genes. Nicholas Wade, *Genome Analysis Shows Humans Survive on Low Number of Genes*, N.Y. TIMES, Feb. 11, 2001, at A1. Scientists at the Human Genome Project estimate the number to be between 30,000 and 35,000. *Id.* Scientists at Celera Genomics estimate that humans have 26,500 genes. Chris Adams, *Rival Genome Researchers Give Glimpse of Findings, Commend Parallel Effort*, WALL ST. J., Feb. 13, 2001, at B6.

³² Baltimore, *supra* note 31, at A13.

a particular illness or condition may result not simply from one or two genetic alterations, but from an interplay of a variety of genes and environmental factors.³³

Genetic information can be used, and has been used, to suggest that people are essentially homogeneous or to stress differences among them. Humans share 99.9 percent of their genetic information.³⁴ However, the differences among people—the so called genetic alterations—are the focus of a great deal of medical and scientific work.³⁵ People do not differ in the *genes* on their chromosomes; they do, however, differ in having alternative *forms* of genes (called alleles).³⁶ These allelic differences are at the heart of research aimed at establishing correlations between genes and illnesses (and other physical and psychological characteristics). Moreover, not all genetic alterations are inherited, but those that are occur in every cell of a person's body.³⁷

Certain genetic alterations (sometimes referred to as "mutations")³⁸ lead to, or predispose people to, illness. Human chromosomes, totaling forty-six in all, occur in pairs; half come from the egg, half from the sperm. Sometimes, illness associated with a genetic alteration will occur only if the alteration is inherited from both parents. Such illnesses, including, for instance, sickle-cell anemia, are termed "recessive."³⁹ Those with a recessive genetic alteration on only one arm, rather than on both arms, of a chromosome pair will not become ill but may pass the alteration on to offspring. Other hereditary conditions may become manifest if the relevant altered gene is inherited from only one parent. Huntington's disease, for instance, is such a dominantly inherited condition.

³³ Erica Goode, *Most Ills Are a Matter of More Than One Gene*, N.Y. TIMES, June 27, 2000, at F1, F6.

³⁴ Silver, *supra* note 22, at 13. Among the surprises of the Genome Project was discovering how closely related most animals and plants are to each other from a genetic perspective. *Survey of the Human Genome*, *supra* note 2, at 8.

³⁵ *Now the Hard Part*, *supra* note 1, at F4 (noting that biologists will now attempt "to track the major variants in DNA sequence found in the human population").

³⁶ Silver, *supra* note 22, at 13.

³⁷ MEHLMAN & BOTKIN, *supra* note 28, at 12 (stating that genes can be altered by errors in copying, by radiation, and by other external factors).

³⁸ *Id.* at 12.

³⁹ *Id.*

Certain diseases correlated with genetic alterations do not occur in the absence of the relevant genetic alteration. Examples include Huntington's disease and sickle-cell anemia. The etiology of other hereditary conditions is more complicated. For example, several genetic alterations that predispose people to breast cancer have been identified. If a woman tests positive for one of them—for instance, for the so-called BRCA1 gene—it is estimated that she has a fifty-six percent lifetime risk of becoming ill with breast cancer.⁴⁰ However, no guarantees can be provided to women who test negative for genetic alterations associated with breast cancer. Genetic alterations, not yet identified, may be associated with the illness. In addition, a wide set of non-genetic factors influences whether a woman becomes ill with breast cancer.⁴¹

Apparently more complicated, and far more murky, is the relation between genetic alterations and behavior.⁴² Even efforts that have focused on discrete psychiatric disorders have failed to locate genes associated with those conditions.⁴³ For example, researchers have announced the identification of genetic alterations associated with manic-depressive disorder or schizophrenia.⁴⁴ But subsequent evidence has undermined early claims.⁴⁵ Proposed correlations between genetic alterations and behavior,⁴⁶ or between the human genome and "human nature," are less certain still.⁴⁷

⁴⁰ Mark A. Rothstein & Sharona Hoffman, *Genetic Testing, Genetic Medicine, and Managed Care*, 34 WAKE FOREST L. REV. 849, 855 (1999). BRCA1 is located on chromosome 17. The second genetic alteration found to be associated with breast cancer is located on chromosome 13. RIDLEY, *supra* note 19, at 190.

⁴¹ Freya R. Schnabel, *Breast Cancer: What the History Can Tell You About Risk—and What You Can Tell Your Patient*, 38 CONSULTANT 2083, Sept. 1, 1998, available at Lexis, News Library, Allnews File (delineating major risk factors for breast cancer, which include age, gender, diet, exposure to environmental factors, and genetic factors).

⁴² *Survey of the Human Genome*, *supra* note 2, at 13.

⁴³ Goode, *supra* note 33, at F1. Alzheimer's is the only psychiatric disorder with which a genetic alteration has yet been associated. *Id.*

⁴⁴ *Id.*

⁴⁵ *Id.* For more information on genetic alterations, see generally RIDLEY, *supra* note 19.

⁴⁶ Goode, *supra* note 33, at F1.

⁴⁷ See *Survey of the Human Genome*, *supra* note 2, at 13.

II. SOCIAL IMPLICATIONS AND LEGAL RESPONSES

The decoding of the human genome has answered only a small number of the questions being asked about the specific role that genetics plays in causing disease and deformity, and even fewer of the questions being asked about the implications of genetics for behavior and social life. It has nonetheless empowered an ideology of genetic inheritance in terms of which people (it is hoped or feared) can be measured.⁴⁸ That ideology challenges familiar understandings of gender, race, history, relationships, illness, responsibility, blame,⁴⁹ and personhood.⁵⁰ Elements of that ideology have long been reflected in cultural understandings of the role of "nature" in determining physical and emotional states, and more specifically, in the eugenics movement that flourished in the United States and in Western Europe in the first half of the twentieth century.⁵¹ As interpretations of work in molecular biology begin to suggest links between specific genetic alterations on the one hand, and physical characteristics, spiritual and mental states, and particular diseases, on the other, an ideology premised on genetic inheritance again becomes significant in American culture. But the dynamic once presumed to explain human affairs, the balance between the forces of nature and nurture, has shifted.⁵²

⁴⁸ I am grateful to Kaja Finkler for the term "ideology of genetic inheritance" to describe the assumptions that attend the appropriation and elaboration of the new genetics within society. KAJA FINKLER, *EXPERIENCING THE NEW GENETICS: FAMILY AND KINSHIP ON THE MEDICAL FRONTIER IX* (2000) (introducing notion of ideology of genetic inheritance to describe people's "conceptualizations of familial inheritance of disease").

⁴⁹ DOROTHY NELKIN & SUSAN LINDEE, *THE DNA MYSTIQUE: THE GENE AS A CULTURAL ICON* 18, 127-48 (1995). Nelkin and Lindee suggest that if social problems, such as violence, are viewed as products of DNA, then society, and government in particular, are absolved of responsibility for such conditions. *Id.* at 129.

⁵⁰ See *infra* notes 254-259 and accompanying text (delineating implications of ideology of genetic inheritance for notions of personhood).

⁵¹ See, e.g., KENNETH M. LUDMERER, *GENETICS AND AMERICAN SOCIETY: A HISTORICAL APPRAISAL* 7-43 (1972) (summarizing history of American Eugenics Movements from 1905 to 1930).

⁵² See, e.g., Jeff Nesmith, *Human Gene Puzzle Solved: Scientists Say They've Decoded Mother*, AUSTIN AMERICAN-STATESMAN, June 27, 2000, at A1, available at Lexis, Current File (reporting first announcement of decoding of human genome in June 2000, and noting scientists' predictions of longer, healthier life; also quoting James Watson's comparison of decoding of genome to invention of printing press

Increasingly, society focuses on information about nature (and especially about genetics)⁵³ in understanding history, in explaining contemporary social patterns, and in predicting the future.⁵⁴ The apparent role of nurture, in balancing and molding nature, dims. Genetic information is venerated as a source of indubitable truths about people and about society.⁵⁵ Only a month after the announcement that geneticists had "mapped" the human genome,⁵⁶ an essay by Andrew Sullivan in the *New York Times Sunday Magazine* proclaimed that "genetic discrimination, however troubling, is both rational and inevitable. And the sooner we get over our handwringing, the better."⁵⁷ Indeed, genetic information is being used by doctors to diagnose disease, suggest treatment options, and assess prognoses. It is also being used by insurers, anxious to minimize

and proclaiming, "Now, let's print some books").

⁵³ Karen Rothenberg presents a definition of "genetic information" jointly developed by the National Action Plan on Breast Cancer and the National Institutes of Health Department of Energy. Those groups defined "genetic information" as "information about genes, gene products, or inherited characteristics that may derive from the individual or a family member." See Karen Rothenberg et al., *Genetic Information and the Workplace: Legislative Approaches and Policy Challenges*, 275 *SCIENCE* 1755, 1755, 1757 n.20 (1997). State statutes define "genetic information" variously. For instance, Texas prohibits discriminatory uses of genetic information, but the statute does not apply to information obtained through medical histories. *TEX. REV. CIV. STAT. ANN.* art. 9031 (Vernon 1999).

⁵⁴ Matt Ridley approvingly describes this new focus:

Rich Harris has systematically demolished the dogma that has lain unchallenged, beneath twentieth-century social science: the assumption that parents shape the personality and culture of their children. In Sigmund Freud's psychology, John Watson's behaviourism and Margaret Mead's anthropology, nurture-determinism by parents was never tested, only assumed. Yet the evidence from twin studies, from the children of immigrants and from adoption studies, is not staring us in the face: people get their personalities from their genes and from their peers, not from their parents.

RIDLEY, *supra* note 19, at 305-06 (citing RICH J. HARRIS, *THE NURTURE ASSUMPTION* (1998)).

Ridley, himself, claims that determinism is the product of nature and nurture; however, that claim is belied by the explanation Ridley provides. "Freedom," writes Ridley, "lies in expressing your own determinism, not somebody else's. It is not the determinism that makes a difference, but the ownership . . . Part of our revulsion at cloning originates in the fear that what is uniquely ours could be shared by another." *Id.* at 313.

⁵⁵ See, e.g., NELKIN & LINDEE, *supra* note 49, at 3.

⁵⁶ See *Survey of the Human Genome*, *supra* note 2, at 8.

⁵⁷ Andrew Sullivan, *Counter Culture: Promotion of the Fittest*, *N.Y. TIMES MAGAZINE*, July 23, 2000, at 16.

coverage risks; by employers, concerned about hiring someone likely to become ill in certain workplace environments or, in general, by social service agencies, deciding whether to approve or disapprove an adoption; by educators, placing students in various tracks and programs; and by prison boards, considering parole applications.⁵⁸ And genetic information can be used, and is being used, to stigmatize people and groups with which they are associated. Genetic information can not only facilitate what Sullivan calls "rational" discrimination, it can also encourage pernicious stigmatization.

All of these uses of genetic information raise concerns about protecting genetic privacy and precluding discrimination based on genetic information. Lawmakers and social critics have begun to respond to these concerns.⁵⁹ But the results of the law's response remain inconsistent and inadequate. And that is likely to remain the case, because it is unlikely that the legal system can respond effectively to the production of stigmatizing images aimed at particular people or groups—images that, once constructed, can be widely generalized in society.

⁵⁸ The American Medical Association has delineated twelve groups, outside the world of health care, who seek medical records. Such records may include genetic information. JEFFREY ROTHFEDER, *PRIVACY FOR SALE: HOW COMPUTERIZATION HAS MADE EVERYONE'S LIFE AN OPEN SECRET* 180 (1992).

⁵⁹ See, e.g., Dina Davis, *Groups, Communities and Contested Identities in Genetic Research*, 30 HAST. CENT. REP. 38 (2000); Jason Kaar, *Genetic Data, Privacy, and Discrimination*, 2000 INT'L LEG. PRACTITIONER 128 (2000); Aeikko Launis, *The Use of Genetic Test Information in Insurance: The Argument from Indistinguishability Reconsidered*, 6 SCI. & ENGINEERING ETHICS 299 (2000).

A. *The Ideology of Genetic Inheritance*⁶⁰

The notion that people *are* their genes predates the new genetics and the Human Genome Project. In Western culture, the notion has long been reflected, among other places, in social understandings of kinship⁶¹ and in popular claims about intelligence and criminality.⁶² It was institutionalized in the eugenics movements that developed in the United States, Germany, and Britain in the first few decades of the twentieth century.⁶³ Especially before World War I, a significant number of geneticists, and, ironically, social progressives,⁶⁴ participated enthusiastically in the eugenics movement.⁶⁵ However, institutionalized medicine largely ignored both eugenics and the science of genetics.⁶⁶ By the 1920s, as many eugenicists became expressly racist,⁶⁷ geneticists began

⁶⁰ See *supra* note 48 (summarizing Kaja Finkler's use of term "ideology of genetic inheritance"). As used in this Article, the term "ideology" refers to the underlying, often pervasive beliefs in terms of which people understand and act in the world. Janet L. Dolgin & JoAnn Magdoff, *The Invisible Event*, in *SYMBOLIC ANTHROPOLOGY: A READER IN THE STUDY OF SYMBOLS AND MEANINGS* 363 n.7 (Janet L. Dolgin et al. eds., 1977). The definition follows that of the French Indologist Louis Dumont. Dumont wrote:

Our definition of ideology thus rests on a distinction that is not a distinction of matter but one of point of view. We do not take as ideological what is left out when everything that is socially thought, believed, acted upon, on the assumption that it is a living whole, the interrelatedness and interdependence of whose parts would be blocked out by the a priori introduction of our current dichotomies.

LOUIS DUMONT, *FROM MANDEVILLE TO MARX: THE GENESIS AND TRIUMPH OF ECONOMIC IDEOLOGY* 22 (1977).

⁶¹ In 1968, the anthropologist David M. Schneider provided a cultural account of American kinship. See generally SCHNEIDER, *supra* note 9. For Americans, he explained, "[k]inship is the blood relationship, the fact of shared biogenetic substance." SCHNEIDER, *supra* note 9, at 107.

⁶² See LUDMERER, *supra* note 51, at 77 (describing development in the United States at turn of twentieth century of myth about the "menace of the feeble-minded"; the myth was supported through popularization of studies of "criminal" and "immoral" families).

⁶³ Gail Rodgers, Comment, *Yin and Yang: The Eugenic Policies of the United States and China: Is the Analysis that Black and White?*, 22 *HOUS. J. INT'L L.* 129, 133 (1999).

⁶⁴ Ironically, many eugenicists believed themselves progressive reformers. LUDMERER, *supra* note 51, at 16. Some of these urged, for instance, that the "power" of politicians would better be replaced by the "wisdom" of technologists. *Id.* at 17 (quoting ALBERT E. WIGGAM, *THE NEW DECALOGUE OF SCIENCE* 277 (1923)).

⁶⁵ *Id.* at 34-35.

⁶⁶ *Id.* at 63-73.

⁶⁷ Early on, a group of eugenicists, especially those associated with the Eugen-

to openly disclaim the movement.⁶⁸

In the decades immediately following World War II, American society began to favor explanations of behavior and of relationships among people based on cultural, rather than natural, factors—socialization, education, and *choice* over biological determinism.⁶⁹ Even Freudian psychology—which gained popular prominence in the 1950s and 1960s and which explains human thought and action as determined (indeed, as “over-determined”⁷⁰)—argues that human behavior is determined primarily by personal history and familial interactions.⁷¹

But by the last two decades of the twentieth century, social explanations of behavior and descriptions of personhood outside familial contexts began increasingly to be focused on biological (natural) phenomena.⁷² By this time, remarkable advances in molecular biology were being widely reported in professional journals and in the popular media.⁷³ Other scientists and social scientists quickly took note. So, for instance, psychologists began to suggest that genetic alterations may explain shyness, intelligence, religiosity, and character traits apparently more amorphous:

ics Record Office at Cold Spring Harbor, Long Island, supported legislation limiting immigration from southern and eastern Europe. These efforts played a part in the promulgation of the Immigration Restriction Act of 1924 (the Johnson Act), Ch. 190, 43 Stat. 153 (repealed 1952). LUDMERER, *supra* note 51, at 7, 25-27, 89.

⁶⁸ LUDMERER, *supra* note 51, at 121-34.

⁶⁹ R.C. Lewontin, Steven Rose, and Leon J. Kamin note that “the contrast between biological and cultural determinisms is a manifestation of the nature-nurture controversy that has plagued biology, psychology, and sociology since the early part of the nineteenth century. R.C. LEWONTIN ET AL., NOT IN OUR GENES: BIOLOGY, IDEOLOGY AND HUMAN NATURE 267 (1984). They argue that the dichotomy between nature and nurture should be abandoned. They suggest that “interactionism”—the notion that organisms are determined through an interaction between environment and genes—“is the beginning of wisdom.” *Id.* at 268.

⁷⁰ SIGMUND FREUD, THE INTERPRETATION OF DREAMS 340-44 (James Strackey trans. 1965, 8th ed. 1930).

⁷¹ The project of Freud’s great magnum opus, THE INTERPRETATION OF DREAMS, was to demonstrate the connection between the conscious and the unconscious dimensions of the mind and to locate the complicated, often apparently incoherent churning of the unconscious mind, in the events of early life. See generally FREUD, *supra* note 70.

⁷² FINKLER, *supra* note 48, at 14.

⁷³ *Id.* at 1.

The Minnesota Center for Twin and Adoption Research has provided percentage estimates of the extent to which certain personality traits are determined by heredity: extroversion, sixty-one percent; conformity, sixty percent; tendency to worry, fifty-five percent; creativity, fifty-five percent; aggressiveness, forty-eight percent. While human genome research has been promoted as a way to find disease genes, many within the scientific community believe that a map of the genome will also document the inheritance of these complex, socially important human traits.⁷⁴

Jeremy Rifkin reports other, similar examples. In 1996, one group of researchers claimed that they had evidence suggesting a "genetic basis for 'novelty seeking,' 'thrill seeking,' and 'excitability.'" ⁷⁵ Researchers at the National Institutes of Health reported evidence of a gene that predisposes people to worry.⁷⁶ And still other researchers, investigating genetic factors in relationships among family members, suggest that such factors affect the character of relationships between siblings and between parents and their children.⁷⁷

In 1984, Lewontin, Rose, and Kamin explained why social theories grounded in biological determinism were more compelling than approaches that focus on both the roles of nature and of nurture in personal and social life.⁷⁸ Rejecting "cultural determinism" along with "biological determinism,"⁷⁹ these authors viewed the "nature-nurture controversy" as having "plagued biology, psychology, and sociology since the early part of the nineteenth century."⁸⁰ Yet, they explained, biological determinism offers something that cultural determinism seems to lack:

We [neither biological determinists nor cultural determinists] are at a severe disadvantage. Unlike the biological determinists who have simple, even simplistic, views of the bases and forms of human existence, we do not pretend to know what is a correct description of all

⁷⁴ NELKIN & LINDEE, *supra* note 49, at 9 (citation omitted).

⁷⁵ JEREMY RIFKIN, *THE BIOTECH CENTURY* 150 (1998).

⁷⁶ *Id.*

⁷⁷ *Id.* at 152. Jeremy Rifkin notes that understanding relationships among kin through reference to genetic models transforms virtually all familiar understandings of the domestic arena. *Id.* at 152-53; *see also* DOLGIN, *supra* note 9, at 558-65 (describing construct of the "genetic family").

⁷⁸ LEWONTIN ET AL., *supra* note 69, at 265-70.

⁷⁹ *Id.* at 10-11.

⁸⁰ *Id.* at 267.

human societies, nor can we explain all criminal behavior, wars, family organization, and property relations as manifestations of one simple mechanism. Rather, our view is that the relation between gene, environment, organism, and society is complex⁸¹

For the moment at least, the pleas of Lewontin, Rose, Kamin, and others like them, are largely disregarded. We have entered what Kaja Finkler describes as the age of the "hegemony of the gene."⁸² At the center of the ideology of genetic inheritance, as it is developing in American culture, support intensifies for a vision of genetic essentialism that reduces personhood to DNA molecules. The ideological consequences are startling. Genetic data are amoral.⁸³ Genes are not, per se, good or bad. Alone, they suggest nothing about the proper scope of personhood or of social relationships. To the extent that people, and social relationships among people, are understood as the consequence of genetic data, neither those people nor their relationships can be guided by moral exhortation or judged through reference to a moral framework. Notions of responsibility become insignificant to a society committed broadly to an ideology of genetic inheritance.⁸⁴ Everything—relationships, judgments, religion, history—even time itself—is reduced to mapped sequences of DNA.⁸⁵

⁸¹ *Id.* at 266.

⁸² FINKLER, *supra* note 48, at 3.

⁸³ Genetic data are "a-moral," much as earthquakes or hurricanes lack a moral frame. Just as people are generally not considered responsible for the consequences of earthquakes or hurricanes, so they are not considered responsible for their behavior, their health, or their states of mind if these can be explained through reference to genetic information.

⁸⁴ See FINKLER, *supra* note 48, at 48. In a universe committed to an ideology of genetic inheritance, explains Finkler:

[E]verything about an organism's existence is predetermined and genetically programmed, including its variation, although geneticists recognize that the program may be affected by unknown and external factors in the environment, chance, or human manipulation. The sequence of our DNA reveals to us who and what we are; that is, what it means to be human. With DNA sequencing, some scientists have maintained that the riddle of life is close to being solved.

Id. (citations omitted).

⁸⁵ Ruth Hubbard and Elijah Wald described the Human Genome Project as "reductionism at its most extreme." RUTH HUBBARD & ELIJAH WALD, *EXPLODING THE GENE MYTH: HOW GENETIC INFORMATION IS PRODUCED AND MANIPULATED BY SCIENTISTS, PHYSICIANS, EMPLOYERS, INSURANCE COMPANIES, EDUCATORS AND LAW ENFORCERS* 3 (1993). "[G]enome scientists," they explain, "will be constructing a hypothetical sequence of submicroscopic pieces of DNA molecules, and will then

More specifically, an understanding of personhood that has long been assumed by Western culture is challenged by the construct of the "genome" that has attended the development of the Human Genome Project.⁸⁶ The notion of a "human genome," against which all people are assessed, displaces the central values (particularly liberty and equality) of the post-Enlightenment West—including, perhaps most importantly, the value of autonomous individuality.

An ideology based on the notion of a "human genome" replaces the individual, as the essential unit of social value, with that of the group. More accurately, from within such an ideology, genetic groups (families, ethnic groups, racial groups)⁸⁷ are viewed as replicating their units. Moreover, each unit is viewed as replicating every other unit. Neither the group nor the individual is ultimately privileged. Either can be identified⁸⁸ and defined through reference to the genome of the other.

The potential for genetic discrimination in the shift from individual to "genome" is clear and has been widely discussed and analyzed by lawmakers and by society generally.⁸⁹ For

declare that sequence to be the essence of humanity." *Id.*

⁸⁶ See *supra* Part I.

⁸⁷ For the most part, this Article uses one term—"ethnic"—in place of "ethnic/racial." Only when it seems especially important to stress the difference between "ethnic" and "racial" denominations of groups will the term "racial" be used. See *supra* note 10 (distinguishing between meaning of "ethnic" and "racial" in American context).

⁸⁸ Karen Lebacqz refers to one practical consequence. In 1989, during Senate hearings, Senator Pressler asked Francis Watson, the first head of the Human Genome Project, "If one wanted to determine the parentage of welfare children or something of that sort in certain instances, how accurate is DNA to determine a father of a child?" Watson replied, "Totally accurate." Karen Lebacqz, *Genetic Privacy: No Deal for the Poor*, in *GENETICS: ISSUES OF SOCIAL JUSTICE* 247 (Ted Peters ed., 1998) (citing *Hearing before the Subcomm. on Science, Technology and Space of the Comm. on Commerce, Science, and Transportation*, 101st Cong. 51 (1998) (statements of Senator Pressler and Francis Watson)).

⁸⁹ See generally Paul R. Billings et al., *Discrimination as a Consequence of Genetic Testing*, 50 AM. J. HUM. GENET. 476 (1992); Lawrence O. Gostin, *Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers*, 17 AM. J.L. & MED. 109 (1991); Eric Mills Holmes, *Solving the Insurance/Genetic Fair/Unfair Discrimination Dilemma in Light of the Human Genome Project* 85 KY. L.J. 503 (1997); Tara L. Rachinsky, *Genetic Testing: Toward a Comprehensive Policy to Prevent Genetic Discrimination in the Workplace*, 2 U. PA. J. LAB. & EMPLOYMENT L. 575 (2000); Michael S. Yesley, *Protecting Genetic Difference*, 13 BERKELY TECH. L.J. 653 (1998); Richard A.

instance, an individual belonging, or assumed to belong, to a particular familial or ethnic group may be identified as being at risk for a particular disease because the mapped genome of the group with which the individual is associated includes a gene linked with the disease in question. Conversely, members of a "genetic group" may all be identified as being at risk for a disease because individuals belonging to the group are known to suffer from the disease in question. The potential for genetic stigmatization—for the creation of negative images not expressly connected with practical ends, such as those of employers or insurers—is equally clear, but has been studied less widely.⁹⁰

B. Genetic Discrimination and Stigmatization

Larry Gostin has defined "genetic discrimination" as "the denial of rights, privileges or opportunities on the basis of information obtained from genetically-based diagnostic and prognostic tests."⁹¹ This Article defines the term to include, as well, such denials on the basis of assumptions stemming from family histories (whether elicited in health care or in other contexts) as well as from ethnic group identification. In this regard, genetic discrimination merges with genetic stigmatization. This second concept involves the construction of derogatory images about a group through reference to genetic information associated with the group. In practice, genetic discrimination and genetic stigmatization merge. Historically, discrimination has been one consequence of stigmatization.⁹² Groups

Bornstein, Note & Comment, *Genetic Discrimination, Insurability and Legislation: A Closing of the Legal Loopholes*, 4 J.L. & POL'Y 551 (1996); Jeremy A. Colby, Note & Comment, *An Analysis of Genetic Discrimination Legislation Proposed by the 105th Congress*, 24 AM. J.L. & MED. 443 (1998). These are a small sample of the articles published only in law reviews or in law-related journals since the early 1990s.

⁹⁰ But see generally *The Fifth Legal Health Law Symposium: Communities of Color and Genetic Testing*, 27 SETON HALL L. REV. 887 (1997) (including articles by, among others, Lori B. Andrews, James E. Bowman, Lisa C. Ikemoto, and Carol Lee).

⁹¹ Gostin, *supra* note 89, at 110.

⁹² Margaret Lock, *Genetic Diversity and the Politics of Difference*, 75 CHI-KENT L. REV. 83, 85-86 (1999) (citation omitted) (noting origin of concept of "race" in eighteenth century and possible use of concept of race in association with "the development of the capitalist economy and global expansion by entrepreneurs,

stigmatized through dehumanizing images, and thus viewed as physically and mentally marginal, have often been subjected to discrimination in a variety of social contexts, and have thus been precluded from participating in mainstream society. Moreover, mainstream society has often created stigmatizing images of groups and used them to institutionalize discrimination. In theory, stigmatizing images and derogatory speech can be distinguished from discriminatory acts that preclude those targeted from enjoying society's social and economic benefits. In fact, stigmatization and discrimination are intertwined, cause and effect merge, and it is difficult to distinguish absolutely prejudicial images from discriminatory acts.

Genetic information can be employed in the service of both discrimination and stigmatization. People may, for instance, be rejected for jobs or for insurance coverage because they have tested positive for a harmful genetic alteration, and are thus thought to pose an unacceptable financial burden for an employer or insurer.⁹³ And, people, individually and in groups, may be imagined as physically or mentally flawed on the basis of genetic information, whether or not they are, in fact, deprived of social benefits as a result.⁹⁴ The differences between discrimination and stigmatization, as here differentiated, are particularly important in considering the ability of the law to control or limit inappropriate uses of genetic information. For the most part, American law is more effective at, and more concerned with, prohibiting express acts of discrimination than instances of stigmatization.⁹⁵ And thus, in contexts involving

particularly with the slave trade and the arrival of a substantial number of Europeans in North Africa, followed by the subjugation of the indigenous peoples").

⁹³ The case of Terri Seargent is illustrative. Ms. Seargent was dismissed from her job because of the expenses associated with her medical condition (a genetic defect resulting in an enzymatic deficiency that causes difficulty breathing). See Kaar, *supra* note 60, at 131.

⁹⁴ See *infra* notes 209-220 and accompanying text.

⁹⁵ See David A.J. Richards, *Constitutional Legitimacy, the Principle of Free Speech, and the Politics of Identity*, 74 CHI.-KENT L. REV. 779, 803 (1999) (referring to group libel laws—"[l]aws making it a criminal or civil wrong to engage in defamation of racial, ethnic, or religious groups"—as "constitutionally suspect"). Richards notes that constitutional rulings "suggest that group libel statutes directed against the expression of false racial or religious stereotypes, as such, would be . . . similarly unconstitutional." He refers, for support, to *Brandenburg v. Ohio*, 395 U.S. 444 (1969) (holding unconstitutional subversive advocacy statutes "applied to speech fomenting racial and religious hatred and bigotry") and *R.A.V. v. City of*

genetic information, the law has begun to respond to the threat of discrimination. It has remained, and perhaps should remain, largely silent with regard to genetic stigmatization. So, for instance, Professor David Richards argues in a somewhat different context that the stigmatizing evils of prejudicial speech and image-making can be combated more effectively by political action, including what Richards calls "cultural politics," than by laws that expressly prohibit speech that stigmatizes social groups.⁹⁶

Thus, the discussion in this Section of the law's responses to the use of genetic information focuses on instances and potential instances of genetic discrimination, especially in employment and insurance contexts. However, many of the cases of discrimination considered here stem from, and can lead to, stigmatizing images of the people or groups involved. The use of genetic information to construct such prejudicial, stigmatizing images is considered in Part III.

In the United States, most reported instances of genetic discrimination have involved insurers or employers.⁹⁷ But such discrimination has occurred or might occur in a variety of

St. Paul, 505 U.S. 377 (1992) (holding unconstitutional a city ordinance that banned public display of symbols that suggested bias against religious, racial, or gender groups), among other cases. *Id.* at 803, n.84.

⁹⁶ See Richards, *supra* note 95, at 811 (connecting group libel laws with creation of "a kind of orthodoxy of appropriate tribalization in the terms of public discourse"). Professor Richards thus defends the position that laws prohibiting group libel should not survive the constitutional protections of free speech. Richards concludes:

American free speech law undoubtedly has its grave critical defects, but its view of group libel offers a plausible alternative interpretation of the principle of free speech to the common view elsewhere about group libel. American interpretive experience suggests that a sound argument of principle not only protects such anti-constitutional speech . . . but, properly understood, renders such protection a more effective instrument of ultimate public education in enduring constitutional values, in particular, the place of the basic human rights of conscience and speech in a free and democratic society of equal citizens. In American circumstances, the principle of free speech—extended to blatantly racist and anti-Semitic advocates like the KKK—has remarkably energized and empowered the battle for racial justice and religious toleration under the rule of law

Id. at 820-21 (citations omitted).

⁹⁷ See generally Anita L. Schill, *Genetic Information in the Workplace: Implications for Occupational Health Surveillance*, 48 AAOHN J. 80 (2000); Billings et al., *supra* note 89.

other contexts. Social service agencies have rejected applications submitted by prospective adopting parents on the basis of negative genetic information.⁹⁸ Genetic information influences decisions about parental rights, children's custody, criminal sentencing, and prisoners' parole status.⁹⁹ Within health care contexts, the potential for genetic discrimination is enormous. People may be treated as ill, for instance, and may therefore think of themselves as ill, though they are not ill, and are almost certain not to become ill.¹⁰⁰ Alternatively, care may be withheld or not vigorously administered because of the presumption that genes determine fate.¹⁰¹

Studies confirm the existence of genetic discrimination by, among others, employers, insurers, adoption agencies, blood banks, and schools.¹⁰² Forty percent of those responding to a

⁹⁸ Sheryl Stolberg, *Insurance Falls Prey to Genetic Bias*, L.A. TIMES, Mar. 27, 1994, at A1.

⁹⁹ See, e.g., *Kelly v. Cataldo*, 488 N.W.2d 822 (Minn. Ct. App. 1992) (involving a father seeking paternity of his married lover's child on the basis of genetic testing); Ilene Sherwyn Cooper, *Advances in DNA Techniques Present Opportunity to Amend EPTL to Permit Paternity Testing*, 71 N.Y.S. BAR. J. 34, 34-35 (1999) (describing relevance of genetic testing to asserting right of nonmarital child to inherit from biological parent); Rochelle Cooper Dreyfuss & Dorothy Nelkin, *The Jurisprudence of Genetics*, 45 VAND. L. REV. 313, 328-29 (1992) (describing the use of genetic tests to establish diminished responsibility and suggesting that genetic essentialism could provide for the law's relying on "a genetic predisposition to criminality" as a "full defense"); Deborah A. Ellingboe, Note, *Sex, Lies, and Genetic Tests*, 78 MINN. L. REV. 1013, 1013-14 (1994) (describing *Kelly v. Cataldo*).

¹⁰⁰ Practical consequences include the use of genetic information by health insurers to define preexisting conditions and thereby to deny coverage. This possibility is considered in *Katskee v. Blue Cross/Blue Shield of Nebraska*, 515 N.W.2d 645 (1994). *Katskee*, itself, concerned a related issue—the obligation of a health insurer to cover prophylactic treatment for a hereditary condition from which the insured did not (yet) suffer. See *id.* at 648-50; see also *infra* notes 112-113 and accompanying text (concerning case of insured who tested positive for hereditary form of high cholesterol).

¹⁰¹ NELKIN & LINDEE, *supra* note 49, at 100-01 (describing the notion of genetic predisposition as encouraging a passive acceptance of negative facts about people and society).

¹⁰² See generally Lisa N. Geller, *Individual, Family, and Societal Dimensions of Genetic Discrimination: A Case Study Analysis*, 2 SCIENCE & ENGINEERING ETHICS 71 (1996); Billings et al., *supra* note 89; see also Ami S. Jaeger & William F. Mulholland II, *Impact of Genetic Privacy Legislation on Insurer Behavior*, 4 GENETIC TESTING 31 (2000). A 1992 survey of the U.S. Congressional Office of Technology Assessment reported that genetic information was important to insurers in determining eligibility for insurance. *Id.* at 37 (citing OTA, *Genetic Tests and Health Insurance: Results of a Survey*, OTA-BP-BA-98, U.S. Government Printing Office (1992)).

1996 survey of members of genetic support groups reported having been asked to provide information about genetic diseases on insurance application forms.¹⁰³ Almost half of those required to provide such information were denied coverage.¹⁰⁴ Analysis of a questionnaire sent to thousands of people at risk for genetic disorders indicated that about half of those responding reported having experienced genetic discrimination.¹⁰⁵

Anecdotal confirmation of such discrimination is plentiful. Members of one New Hampshire family were denied health insurance after the family's health insurer learned, from a doctor's notation on an insurance form, that the family's six year-old son had Fragile X Syndrome, a genetic condition that interferes with mental development.¹⁰⁶ The insurer denied coverage to the boy's three sisters and parents, though none of them had been diagnosed with the condition.¹⁰⁷

Another case involved a thirty-one year old woman with a familial history of Huntington's disease; the woman had not been tested, and thus did not know whether she carried the genetic alteration associated with Huntington's.¹⁰⁸ She and her husband decided to adopt rather than risk having a child who might inherit the condition.¹⁰⁹ In the middle of the adoption process, the adoption agency asked the couple to withdraw their application because of the woman's familial medical history.¹¹⁰ Another woman, also at risk for Huntington's disease,

¹⁰³ Jaeger & Mulholland, *supra* note 102, at 37.

¹⁰⁴ Jaeger & Mulholland, *supra* note 102, at 37.

¹⁰⁵ Geller, *supra* note 102, at 75. Geller and her colleagues sent questionnaires to 27,790 people at risk for four genetic disorders (Huntington's disease, phenylketonuria, hemochromatosis, and mucopolysaccharidoses). Nine-hundred-seventeen questionnaires were returned. Four-hundred-fifty-five respondents indicated having experienced genetic discrimination. Geller, *supra* note 102, at 75.

The National Human Genome Research Institute also reports that a survey of genetic counselors, primary care doctors, and patients, conducted in the late 1990s, "identified 550 people who had been denied employment or insurance based on their genetic predisposition to an illness." National Human Genome Research Institute, *Genetic Information and the Workplace*, at http://www.nhgri.nih.gov/HGP/Reports/genetics_workplace.html (last visited May 23, 2000).

¹⁰⁶ Bornstein, *supra* note 89, at 566-67; Stolberg, *supra* note 98, at A1.

¹⁰⁷ Bornstein, *supra* note 89, at 566-67; Stolberg, *supra* note 98, at A1.

¹⁰⁸ Billings et al., *supra* note 89, at 480.

¹⁰⁹ Billings et al., *supra* note 89, at 480.

¹¹⁰ Billings et al., *supra* note 89, at 480. Billings and his colleagues solicited information about people who had experienced genetic discrimination by advertising in newsletters and professional journals and by writing to professionals in rele-

and also anxious to adopt a child, made public a letter she had received from an adoption agency. The letter explained, "We have decided, in your situation, not to proceed with your application because there is a fifty-fifty chance of your getting Huntington's Disease."¹¹¹

In other cases, genetic discrimination has followed directly from genetic testing, rather than from conclusions based on familial history or ethnic membership. For example, the insurer of a heart attack patient in Boston refused to cover future care for cardiovascular disease after the man tested positive for a hereditary form of high cholesterol.¹¹² The insurer contended that the man suffered from a "pre-existing condition" and was therefore not entitled to insurance for any symptoms connected with high cholesterol.¹¹³

Employers and insurers anxious to obtain genetic information have also relied on reports of family histories and on correlations between various illnesses and ethnic group identities to exclude applicants presumed to be at risk for genetic disease.¹¹⁴ The predictive value of such information is uncertain. Even the results of direct genetic testing¹¹⁵ cannot be relied upon to predict health with certainty.¹¹⁶ Predictions based on information about family history or ethnic identification are even less likely to be accurate.¹¹⁷

vant fields. Billings et al., *supra* note 89, at 477; see also Geller, *supra* note 102, at 77 (describing 25-year old woman precluded from adopting through agency because of family history for Huntington's Disease).

¹¹¹ Billings et al., *supra* note 89, at 480.

¹¹² Bornstein, *supra* note 89, at 566 (citing Susan Ince, *Predictive Testing; A Bite of the Apple*, HARV. HEALTH LETTER (Harvard Medical School Health Publications Group, Boston, MA), June, 1995, at 3, 4).

¹¹³ Bornstein, *supra* note 89, at 566.

¹¹⁴ Bornstein, *supra* note 89, at 568-69.

¹¹⁵ There are two broad categories of tests for genetic conditions. The first analyzes biochemical substances that may suggest the presence of genetic alterations. DAVID SUZUKI & PETER KNUDTSON, *GENETICS: THE CLASH BETWEEN THE NEW GENETICS AND HUMAN VALUES* 146 (1990). The second sort of test analyzes DNA directly, either to detect chromosomal abnormalities such as that responsible for Down's syndrome or to detect differences in allele sequences, such as that responsible for sickle-cell anemia. *Id.*

¹¹⁶ See *infra* notes 128-130 and accompanying text.

¹¹⁷ Insurers justify reliance on genetic information in making insurance decisions as an extension of reliance on medical information, more generally. Bornstein, *supra* note 89, at 569. Bornstein notes the difference between relying on information showing that a person is ill and relying on information that a person is at

Mandated genetic testing or reported cases of genetic discrimination by employers, insurers, and others have not been common, and have primarily affected people known (through medical and family histories) to be at risk for genetic disorders.¹¹⁸ However, as genetic tests for an increasingly wide assortment of diseases are developed,¹¹⁹ and as the cost of such testing decreases,¹²⁰ employers, insurers, and others may well require that the people they serve or employ submit to genetic testing. Indeed, some commentators predict that genetic testing will become universal.¹²¹

Mandated genetic testing has concrete advantages for insurers and employers.¹²² In particular, such testing promises to reduce institutional costs.¹²³ Genetic testing could also be advantageous, in certain regards, to those compelled by insurers or employers to submit to it. For instance, genetic tests may identify people particularly susceptible to harm in hazardous workplace environments; presumably, many such

increased risk of becoming ill at some undetermined time in the future. Bornstein, *supra* note 89, at 569.

¹¹⁸ See Robert H. Jerry, II, *Health Insurers' Use of Genetic Information: A Missouri Perspective on a Changing Regulatory Landscape*, 64 MO. L. REV. 759, 761-62 (1999) (noting that as of 1999, genetic discrimination was a "largely nonexistent business practice" but noting as well the potential for more widespread genetic discrimination).

Francis Collins, Director of the U.S. National Human Genome Research Institute at the National Institutes of Health, noted that genetic tests are now available "for very rare diseases in families plagued by certain illnesses" but that "more routine testing of now-healthy people to predict their future risks of cancer or other killers is poised to explode." *Id.* at 771 n.30 (citing *Genetic Tests Remain Unregulated and Inaccurate*, 6 AM. POL. NETWORK-AM. HEALTH LINE 14).

In 1991, Larry Gostin predicted, "One day, employers and insurers will be able to obtain a genetic profile from the blood drawn from a small finger prick." Gostin, *supra* note 89, at 110. As the Human Genome Project nears completion, it is possible to test directly for more and more genetic alterations.

¹¹⁹ See, e.g., Nesmith, *supra* note 52, at A1 (predicting availability of genetic tests for dozens of "major causes of illnesses and death" within ten years).

¹²⁰ Genetic tests now cost between several hundred and several thousands dollars. Colby, *supra* note 89, at 449.

¹²¹ Colby, *supra* note 89, at 450.

¹²² See, e.g., Andrew Sullivan, *Counter Culture: Promotion of the Fittest*, N.Y. TIMES MAGAZINE, July 23, 2000, at 16.

¹²³ See, e.g., The National Human Genome Research Institute, *Genetic Information and the Workplace*, at http://www.nhgri.nih.gov/HGP/Reports/genetics_workplace.html (last visited May 23, 2000) (reporting that some employers may use results of genetic tests to discriminate against even asymptomatic workers "because the employers fear the cost consequences").

people could be protected by alternative assignments.¹²⁴ For the most part, however, genetic testing in employment and insurance contexts is less likely to benefit those tested than those requiring that such testing be conducted.¹²⁵

Thus, mandated genetic testing, and the potentially discriminatory uses of genetic test results, raise broad social concerns. Discriminating against people on the basis of genetic traits over which they have no control, and which may or may not result in illness, may be deeply unjust.¹²⁶ Such discrimination may reinforce and strengthen existing social prejudice against groups defined in genetic terms.¹²⁷ Moreover, discriminatory uses of genetic information may occur even in cases in which test results cannot be interpreted with certainty. As a practical matter, genetic test results generally do not identify everyone at risk for particular genetic diseases,¹²⁸ conversely, such tests may result in false positive results. Furthermore, it is typically difficult to make accurate predictions about health and illness, even from accurate test results for autosomal dominant genes. "For most genetic diseases," Larry Gostin explains, "the onset date, severity of symptoms, and efficacy of treatment and management are highly variable."¹²⁹ Predictions are particularly uncertain in the case of diseases associated with multiple genetic and environmental factors, among many others, breast cancer, colon cancer, and heart disease.¹³⁰

Ironically, genetic discrimination, if widely institutionalized, may ultimately prove less and less useful to insurers and

¹²⁴ Gostin, *supra* note 89, at 111.

¹²⁵ In the future, genetic therapy may be widely available. At present, such therapy is largely unavailable or, where available, ineffective. Should genetic therapy become a reality for people predisposed to, or suffering from, genetic diseases, the benefits of genetic testing for those tested will increase enormously.

In April 2000, the first unequivocal success with gene therapy was reported. All of the patients involved were infants who suffered from severe combined immune deficiency, a condition viewed as "especially suited for treatment" with genetic therapy. Gina Kolata, *Scientists Report the First Success of Gene Therapy*, N.Y. TIMES, Apr. 28, 2000, at A1.

¹²⁶ Gostin, *supra* note 89, at 112 (describing genetic discrimination as "violat[ing] basic tenets of individual justice" and as "detrimental to public health").

¹²⁷ See *infra* Part II.B.

¹²⁸ Gostin, *supra* note 89, at 113-14.

¹²⁹ Gostin, *supra* note 89, at 113.

¹³⁰ Gostin, *supra* note 89, at 114.

employers. Billings and his colleagues refer to "the myth of genetic perfection."¹³¹ The myth assumes a " 'perfect' family with a disease-free genome."¹³² No such family exists.¹³³ "Unfortunately," they explain, "all families are at risk."¹³⁴ Geneticists estimate that the average person is affected by between five and fifty harmful genetic alleles.¹³⁵ As Mansoura and Collins assert:

Genetic disease should not be thought of as the unfortunate fate of relatively few individuals who have been affected by rare inherited disorders. With our rapidly expanding understanding of the role of genes in common disorders such as many forms of cancer, heart disease, diabetes, and mental illness, it seems more likely that in the future virtually all of our lives will be touched by the genetic revolution.¹³⁶

Perhaps, when that time arrives, genetic discrimination, even if not broadly prohibited by law, will no longer serve institutional interests.

In the meantime, however, genetic discrimination may prove harmful to many. Among those at particular and unusual risk for such discrimination are members of ethnic groups defined long before the decoding of the human genome through biological correlates (e.g., facial features, hair color and texture, skin color). People identified with such groups may be excluded from financial and social opportunities because they are assumed to be at risk for genetic conditions associated with their ethnicity. In addition, and even more insidiously, prejudice against members of such groups by those with control over insurance, employment, and other matters could be justified through reference to genetic test results. In short, the results of mandated genetic testing could be misused to reaffirm the biological marginality—and thus to justify the social and eco-

¹³¹ Billings et al., *supra* note 89, at 480 (noting that "the chance of developing a genetic condition is perceived differently from a similar probability of contracting an illness not produced primarily by a gene").

¹³² Billings et al., *supra* note 89, at 480.

¹³³ This presumes a universe in which genetic engineering is not widespread.

¹³⁴ Billings et al., *supra* note 89, at 480.

¹³⁵ See Monique K. Mansoura & Francis S. Collins, *Medical Implications for the Genetic Revolution*, 1 J. HEALTH CARE L. & POL'Y 329, 334 (1998); see also Lisa Seachrist, *Jewish Groups Worry Genetic Studies Foster Discrimination*, BIOWORLD TODAY, Apr. 23, 1998, available at LEXIS, News Library.

¹³⁶ Mansoura & Collins, *supra* note 135, at 334.

conomic marginality—of individuals identified with various ethnic groups.¹³⁷

C. Genetic Discrimination: Limits of the Law's Response

The law's response to the dangers of genetic discrimination has been inconsistent and inadequate. Only one federal statute expressly regulates the use and regulation of genetic information.¹³⁸ Relevant state laws, though numerous, differ widely from state to state and fail, as a whole, to provide comprehensive protection. Moreover, constitutional law provides only a circumscribed right to informational privacy.¹³⁹ Any such right is limited to situations involving government action and cannot be invoked as protection against private parties, including researchers, insurance companies, employers, or biomedical data banks.¹⁴⁰

Almost four-fifths of the states have laws that limit genetic discrimination in at least some regard.¹⁴¹ However, many of these laws provide little practical protection.¹⁴² A few are more comprehensive, but even these have limited applicability.

¹³⁷ SUZUKI & KNUDTSON, *supra* note 115, at 156. Suzuki and Knudtson wrote: Especially in societies such as ours, characterized by long histories of prejudice against particular minorities, it is not difficult to imagine how occupational genetic screening could lend an air of scientific legitimacy to attempts, conscious or unconscious, to exclude certain categories of workers from jobs or to restrict their access to more rewarding ones.

Despite their limited medical value, the genetic dossiers arising from mass genetic screening of workers could, just like a factory worker's hereditary skin color, be used to segregate genetically 'desirable' job applicants from genetically 'undesirable' ones. History demonstrates that the most powerful groups in a society often attempt to justify their status by proclaiming the innate superiority of their race, class or ethnic group.

Id.

¹³⁸ Health Insurance Portability and Accountability Act, Pub. L. No. 104-191, 110 Stat. 1936 (1995) (codified in scattered sections of 29, 42, 26, and 18 U.S.C.).

¹³⁹ Gostin & Hodge, Jr., *supra* note 6, at 42 (noting *Whalen v. Roe*, 429 U.S. 589 (1977), in which the Court noted in dicta "the threat to privacy implicit in the accumulation of vast amounts of personal information in computerized data banks or other massive government files").

¹⁴⁰ *Id.* at 22; see also *Shelley v. Kraemer*, 334 U.S. 1, 13 (1948).

¹⁴¹ See Colby, *supra* note 89, at 464 (reporting existence of "some form of genetic discrimination legislation" in thirty-nine states); see also Jerry, II, *supra* note 118, at 772.

¹⁴² See *infra* notes 143-154 and accompanying text.

ty.¹⁴³ Many state laws that regulate discriminatory uses of genetic information cover only employers or insurers (especially health insurers).¹⁴⁴ As a result, in such states, life insurers, adoption agencies, prisons, and schools, among other groups and institutions, are not precluded by the law from discriminating on the basis of genetic information. Most relevant state statutes have a variety of other limitations. A few, reflecting the form of the earliest statutes aimed at regulating genetic information,¹⁴⁵ prohibit genetic discrimination with regard only to specific diseases.¹⁴⁶ Other state statutes provide broader protection, but permit various forms of genetic discrimination or allow invasions of genetic privacy. In New York, for instance, employers may require genetic testing for conditions indicating "increased risk of disease as a result of working in [the employment] environment."¹⁴⁷ Employers are not permitted to deny employment on the basis of genetic test results, but the employee's genetic privacy is unprotected. Moreover, New York allows insurers to rely on the results of genetic testing in underwriting.¹⁴⁸ A number of states, including Illinois and Indiana, permit consumers to provide genetic information to insurers.¹⁴⁹ In those states, insurers are able to offer premium reductions to those submitting test results indicating the absence of various genetic conditions.¹⁵⁰ In consequence, insurance will be increasingly costly for those who refrain from being tested or from submitting test results, or who test positive for genetic alterations associated with ill-

¹⁴³ See *supra* notes 137-140 and accompanying text.

¹⁴⁴ See COL. REV. STAT. ANN. § 10-3-1104.7 (West 1999); GA. CODE ANN. §§ 33-54-1, -8 (1996); MD. CODE ANN., INS. § 27-909 (Supp. 1999); see also Natalie Anne Stepanuk, Comment, *Genetic Information and Third Party Access to Information: New Jersey's Pioneering Legislation as a Model for Federal Privacy Protection of Genetic Information*, 47 CATH. U.L. REV. 1105, 1123-24 (1998).

¹⁴⁵ The first statute dealing with genetic discrimination was passed in North Carolina in 1975. The law prohibited employment discrimination against people exhibiting traits for sickle cell or hemoglobin C. Rothenberg et al., *supra* note 53, at 1755.

¹⁴⁶ See, e.g., LA. REV. STAT. ANN. § 22:652.1 (West 1995); TENN CODE ANN. § 56-7-207 (Supp. 1997).

¹⁴⁷ N.Y. EXEC. LAW § 296(19)(b) (McKinney Supp. 1997).

¹⁴⁸ N.Y. INS. LAW § 2612 (McKinney Supp. 1997).

¹⁴⁹ 410 ILL. COMP. STAT. ANN. 513/20 (West 1997); IND. CODE ANN. § 27-8-26-9 (Michie 1994 & Supp. 1999).

¹⁵⁰ *Id.*

ness.¹⁵¹ In still other states, laws regulating the use of genetic information do not include information from medical histories within the scope of "genetic information" and thus fail to protect against discrimination based on family histories.¹⁵²

A few states have relatively inclusive statutes that limit genetic discrimination and protect genetic privacy. For instance, the New Jersey Genetic Privacy Act¹⁵³ widely protects privacy with regard to genetic information. The Act was intended to protect those with genetic diseases or predisposed to such diseases from societal discrimination generally, not only in insurance and employment contexts.¹⁵⁴

However, even broad statutes, such as New Jersey's, provide only limited protection because their reach is significantly limited by the terms of the Employee Retirement Income Security Act of 1974 ("ERISA").¹⁵⁵ Under ERISA, federal law pre-empts state law with regard to employers' self-funded health insurance plans.¹⁵⁶ Most people not receiving health care through the government are covered by such self-funded plans.¹⁵⁷ Therefore, even in states with apparently comprehensive statutes, many people are not protected from genetic discrimination by health insurers.

At present, only one federal statute, the Health Insurance Portability and Accountability Act of 1996 ("HIPAA"),¹⁵⁸ provides an express federal statutory response to genetic discrimination and the invasion of genetic privacy.¹⁵⁹ HIPAA prohib-

¹⁵¹ See Jerry, II, *supra* note 118, at 770 (noting that if insured are able to volunteer results of genetic testing and insurers are able to rely on those results, higher premiums will be paid by people with "no tests or poor results").

¹⁵² See, e.g., FLA. STAT. ANN. § 627.4301 (West Supp. 1999); MD. CODE ANN., INS. § 27-909 (Supp. 1999).

¹⁵³ N.J. STAT. ANN. § 17B:30-12 (West Supp. 2000).

¹⁵⁴ Stepanuk, *supra* note 144, at 1124 n.88, 1127 n.108 (citing Senate Health Committee Statement to Senate Committee Substitute for Senate, Nos. 695 and 854, 207th Legis. Reg. Sess. 1 (N.J. 1996)).

¹⁵⁵ Employee Retirement Income Security Act of 1974, Pub. L. No. 93-406, 88 Stat. 829 (1974).

¹⁵⁶ 29 U.S.C. § 1144(a) (2000).

¹⁵⁷ Kourtney L. Pickens, Comment, *Don't Judge Me By My Genes: A Survey of Federal Genetic Discrimination Legislation*, 34 TULSA L.J. 161, 172 (1998).

¹⁵⁸ Health Insurance Portability and Accountability Act of 1996, Pub. L. No. 104-191, 110 Stat. 1936 (1996) (codified in scattered sections of 29, 42, 26, and 18 U.S.C.).

¹⁵⁹ In addition to this congressional response, an Executive Order, issued by President Clinton in early 2000, prohibits federal agencies from discriminating

its insurance companies (including self-funded employer plans) from relying on genetic information to establish eligibility for health insurance coverage¹⁶⁰ and thus from classifying genetic predispositions as pre-existing conditions.¹⁶¹ However, the statute provides no definition of the term "genetic information," and thus it fails clearly to prohibit discriminatory reliance on information obtained from medical histories.¹⁶² Moreover, the statute does not prevent plans from raising rates or excluding coverage altogether for particular medical conditions.¹⁶³

Other federal laws,¹⁶⁴ including Title VII of the Civil Rights Act of 1963¹⁶⁵ and Title I of the Americans with Disabilities Act of 1990 (the "ADA"),¹⁶⁶ provide protection against genetic discrimination in certain contexts. But both statutes were promulgated before genetic testing was a serious practical concern; thus, neither was intended specifically to address the dangers of genetic discrimination.¹⁶⁷

against employees and applicants for employment on the basis of "genetic information." Executive Order 13145, 65 Fed. Reg. 6877 (Feb. 10, 2000). The Order defines genetic information to include information obtained from genetic testing of an individual or of an individual's family member or from family histories indicating the presence of a genetic disease or disorder within the family. The Executive Order provides exceptions. An employer may ask someone who has been given a conditional offer of employment about the occurrence of a disease or a medical condition or disorder in family members "if the request or requirement is consistent with the Rehabilitation Act and other applicable law." *Id.*

¹⁶⁰ 29 U.S.C. § 1182(9)(1) (2000).

¹⁶¹ Health Insurance and Portability and Accountability Act of 1996, 104 P.L. No. 104-191, § 701(b)(1)(B), 110 Stat. 1936, 1940 (1996).

¹⁶² Jerry II, *supra* note 118, at 775-76 (noting that the structure of HIPAA suggests that the term "genetic information" "should be given a reading that does not include medical history").

¹⁶³ 26 U.S.C. § 9802(a)(2)(B) (2000); 29 U.S.C. § 1182(a)(2)(B) (Supp. III 1997); see also Pickens, *supra* note 157, at 173-74; Rothenberg et al., *supra* note 53, at 1756; Stepanuk, *supra* note 144, at 1110, n.14.

¹⁶⁴ In addition to Title VII of the Civil Rights Act of 1990 and Title I of the Americans with Disabilities Act, both of which are considered at *infra* text accompanying notes 165-172, the Privacy Act of 1974, 5 U.S.C. § 552 (2000), requires federal agencies to abide by fair information practices with regard to the collection and use of records. See Gostin & Hodge, Jr., *supra* note 6, at 43-44; see also *id.* at 54-56 (delineating fair information practices).

¹⁶⁵ 42 U.S.C. §§ 1971, 2000a-2000h-6 (2000).

¹⁶⁶ 42 U.S.C. §§ 12101-12213 (2000).

¹⁶⁷ In 1995, the Equal Employment Opportunity Commission (the "EEOC"), the agency responsible for enforcing the ADA, issued guidelines that asserted that an employer who discriminates against an individual on the basis of "genetic informa-

More specifically, Title VII prohibits employers from discriminating on the basis of "race, color, religion, sex, or national origin."¹⁶⁸ Thus, the requirement that members of a protected group submit to genetic testing in an employment context,¹⁶⁹ as well as genetic discrimination by an employer or prospective employer against members of a protected group, might be illegal under Title VII.¹⁷⁰ Although Title VII would seem to be relevant to cases involving genetic conditions that disproportionately affect a relevant class under the Act, almost no case law exists that involves the use of genetic information in the workplace. One Ninth Circuit decision allowed a Title VII claim involving genetic discrimination to go forward.¹⁷¹ But even if other courts follow the Ninth Circuit model, Title VII is clearly limited in preventing discrimination in employment contexts because it only prohibits genetic discrimination linked with a group protected under the Act. In addition, an employer may respond to a showing that reliance on genetic information had a "disparate impact" on a protected group by demonstrating that the treatment alleged to violate the statute was justified because it was "job related" or a "business necessity."¹⁷²

tion relating to illness, disease, or other disorders" would be viewed as having violated the ADA. 1 EEOC COMPL. MAN. (BNA) 902-45 (1995). The practical effect of the EEOC guidance remains unclear. National Human Genome Research Institute, *Genetic Information and the Workplace*, Jan. 20, 1998, at http://www.nhgri.nih.gov/HGP/Reports/genetics_workplace.html (last visited May 23, 2000).

¹⁶⁸ 42 U.S.C. § 2000e-2(a).

¹⁶⁹ The Act applies to private employers with at least fifteen employees, governmental employers, laboratory organizations, and employment agencies. *See id.* § 2000g(e).

¹⁷⁰ *See Norman-Bloodsaw v. Lawrence Berkeley Laboratory*, 135 F.3d 1260, 1272 (9th Cir. 1998) (concluding that employer's singling out female and black employees for "non-consensual testing" falls "neatly into a Title VII framework").

¹⁷¹ *Id.* at 1264. The Ninth Circuit also concluded that the U.S. Constitution protects the right to genetic privacy. This claim was relevant in that the defendant, Lawrence Berkeley Laboratory, was a government employer. The claims against Lawrence-Berkeley Laboratory centered around its having tested African-American employees for the sickle-cell trait and female employees for pregnancy.

¹⁷² Plaintiffs alleging genetic discrimination under Title VII would have to show that genetic information was used disproportionately to effect groups protected under the statute. *See Griggs v. Duke Power Co.*, 401 U.S. 424, 432 (1971) (delineating requirements for "disparate impact" claim). If plaintiffs succeed in this task, the burden shifts to the employer who can justify the treatment in question by showing that it is "job-related" or a "business necessity." *See* 42 U.S.C. § 2000e-2(k)(1)(A); *see also Griggs*, 401 U.S. at 432.

The ADA may be more generally applicable to genetic discrimination in the workplace than Title VII of the Civil Rights Act of 1964, but potential reliance on the ADA to protect against genetic discrimination is limited in other ways. The statute, which applies only to employers with fifteen or more employees,¹⁷³ expressly prohibits discrimination against employees or potential employees because of a disability, and has been interpreted by the Equal Employment Opportunity Commission (the "EEOC") to protect people against employers who "discriminate . . . on the basis of . . . genetic information."¹⁷⁴ Moreover, some (though not all)¹⁷⁵ have interpreted the decision of the Supreme Court in *Bragdon v. Abbott*¹⁷⁶ to define disability broadly under the ADA.¹⁷⁷

However, even if the ADA does apply to genetic discrimination, it does not prevent employers from requiring preplacement medical examinations that include genetic testing. Furthermore, the EEOC has concluded that employers may exclude people who pose a risk to the health or safety of others or of self.¹⁷⁸ This standard may be especially hard to

No Title VII plaintiff alleging that an employer's use of genetic information had a "disparate impact" on a covered group has ever been successful. See Elizabeth Reiter, Comment, *The Department of Defense DNA Repository: Practical Analysis of the Government's Interest and the Potential for Genetic Discrimination*, 47 BUFF. L. REV. 975, 1010 (1999).

¹⁷³ 42 U.S.C. § 12111(5)(A) (2000).

¹⁷⁴ 1 EEOC COMPL. MAN. (BNA) 902, at 902-45 (1995). EEOC rules are not binding on courts. See Laura F. Rothstein, *Genetic Discrimination: Why Bragdon Does Not Ensure Protection*, 3 J. HEALTH CARE L. & POLY 330, 335 (2000) (citing Mark S. Dichter & Sarah E. Sutor, *The New Genetic Age: Do Our Genes Make Us Disabled Individuals Under the Americans With Disabilities Act?*, 42 VILL. L. REV. 613, 620 n.23 (1997)).

¹⁷⁵ Rothstein, *supra* note 174, at 335.

¹⁷⁶ 524 U.S. 624 (1998).

¹⁷⁷ George J. Annas, *Protecting Patients from Discrimination—The Americans with Disabilities Act and HIV Infection*, 339 NEW ENG. J. MED. 1255, 1257 (1998).

¹⁷⁸ The ADA provides that an employer may exclude an individual who poses "a direct threat to the health or safety of other individuals in the workplace," 42 U.S.C. § 12113(b), and defines "direct threat" as a "significant risk to the health or safety of others that cannot be eliminated by reasonable accommodation," 42 U.S.C. § 12111(3). The EEOC interpreted the statute to allow exclusions in cases involving "a significant risk of substantial harm to the health or safety of the individual or others." 29 C.F.R. 1630.2(r) (2001) (emphasis added). See Amanda J. Wong, Comment, *Distinguishing Speculative and Substantial Risk in the Presymptomatic Job Applicant: Interpreting the Interpretation of the Americans with Disabilities Act Direct Threat Defense*, 47 UCLA L. REV. 1135, 1139 (2000) (arguing that EEOC interpretation was not justified by ADA and allows for discrimina-

apply fairly in the context of presymptomatic genetic conditions.¹⁷⁹ In addition, although the statute prohibits genetic discrimination, it may be difficult for an individual to prove that failure to obtain employment or a promotion resulted from genetic discrimination.¹⁸⁰ Finally, the virtual absence of relevant case law makes it difficult to assess the extent to which the ADA may be useful in protecting against genetic discrimination in the workplace.

Thus, to date, neither state nor federal law has responded effectively to the risks of genetic discrimination and of invasions of genetic privacy by employers, insurers, health care workers, and others. In consequence, as the human genome is mapped and interpreted, genetic privacy is inadequately protected, and no uniform defense exists against genetic discrimination. These threats are especially ominous for groups historically defined through metaphors of "blood," since genetic information can be interpreted to reaffirm the social marginality of such groups and to justify prejudice against them. To such groups we now turn.

III. GENETIC DISCRIMINATION AND STIGMATIZATION: AN ETHNIC EXAMPLE

Virtually no one is immune from genetic discrimination. But people identified with ethnic groups may be particularly vulnerable to genetic discrimination within institutional contexts and to genetic stigmatization¹⁸¹ within the society broadly.¹⁸² Employers, insurers, and others may arrive at as-

tion the ADA was intended to prevent).

¹⁷⁹ See Wong, *supra* note 178, at 1160-65 (arguing that predispositions are difficult to analyze fairly under the individualized analysis demanded by the ADA).

¹⁸⁰ Rothenberg et al., *supra* note 53, at 1756.

¹⁸¹ See *supra* text accompanying notes 90-95 (considering distinction between discrimination and stigmatization).

¹⁸² This Article focuses on a Jewish example. Other groups are also vulnerable to genetic discrimination. Within the American context, African-Americans are especially likely to suffer from discriminatory uses of genetic testing and research. For centuries, science, reflecting society, has described African-Americans derogatorily in terms of heredity. Anita Allen quotes an illustrative 1926 article on the "Negro," published in the *ENCYCLOPAEDIA BRITANNICA*. Anita LaFrance Allen, *Genetic Testing, Nature, and Trust*, 27 *SETON HALL L. REV.* 887, 890 (1997) (quoting and citing 19 *ENCYCLOPAEDIA BRITANNICA* 344 (13th ed. 1926). Allen quotes and describes that article:

sumptions about an individual's genome from information regarding the genome of the individual's ethnic group.¹⁸³ Such discrimination may be especially harmful when aimed at individuals belonging to groups that have historically been singled out for racist treatment on the basis of somatic characteristics.¹⁸⁴

Moreover, information about genetic alterations regarding members of groups historically subject to racism can provide a pretext for further discrimination, both within and beyond institutional settings. Even more, within society, generally racist assumptions may direct social interpretations of genetic

Citing learned authorities the article asserted that: "Mentally the Negro is inferior to the white." The Negro is subject to "indolence" and "lethargy" perhaps due to "premature closing of the cranial sutures and lateral pressure of the frontal bone" or because, "after puberty sexual matters take the first place in the Negro's life." Negroes "far surpass white men in acuteness of vision, hearing, direction and topography." But the Negro is like "a child, normally good-natured and cheerful, but subject to sudden fits of emotion and passion during which he is capable of performing acts of singular atrocity" When it comes to hair, the Negro is like neither the white man nor the higher ape; for those two have true hair, whereas the Negro head is capped by a kind of wool, a "woolly" or "frizzly" pile capable of being felted. Finally, "the recognized leaders of the [Negro] race are almost invariably persons of mixed blood, and the qualities which have made them leaders are derived certainly in part and perhaps mainly from their white ancestry."

Id. (citations omitted; all citations are from pp. 344-46 of the ENCYCLOPAEDIA BRITANNICA article). More recently, a study in the journal *Pediatrics* reported on the relationship between sickle-cell anemia and intelligence. M. McCormack et al., *A Comparison of the Physical and Intellectual Development of Black Children With and Without Sickle-Cell Trait*, 56 PEDIATRICS 1021 (1975). Anita Allen comments that still "there are people on the lookout for evidence that Blacks are genetically inferior to whites in intellect and that Blacks have criminal proclivities fixed in their genetic make-ups." Allen, *supra*, at 890 (citation omitted). The history of the treatment African-Americans have received in research and medical contexts in the United States is not comforting to those concerned about potential discriminatory uses of genetic information. The most well-known, and perhaps most startling (though hardly the only), example is that of the Tuskegee Syphilis Study, conducted during a period of forty years by the United States Public Health Service. The subjects, poor African-American men, were not offered, and were discouraged from seeking, treatment for the condition so that the government could study the "natural history" of the disease. BARRY R. FURROW ET AL., *BIOETHICS: HEALTH CARE LAW AND ETHICS* 381 (3d ed. 1997).

¹⁸³ Similarly, genetic discrimination can result from assumptions about an individual's predisposition to disease because the individual is kin to others who suffer from, or who are known to be at risk for, a genetic illness.

¹⁸⁴ See *supra* notes 168-172 and accompanying text (delineating limitations of Title VII of Civil Rights Act of 1964 in responding to such cases).

information about such groups and about individuals associated with them. In short, discriminatory use of genetic information by employers, insurers, and others can debar members of ethnic groups from social benefits, including employment opportunities and insurance coverage. Moreover, genetic information can be used within institutional settings and more generally to spread unappealing images of particular groups. These images can then motivate further discrimination, which can be "justified" on "rational," *genetic* grounds.

The discourse that surrounds the new genetics can accommodate prejudicial impulses that have encouraged society to define certain groups of people as physically marginal or inferior. Professors Nelkin and Lindee locate racist images in the language of the new genetics during the early 1990s:

[A] physical anthropologist . . . at the University of California at Berkeley lectured to hundreds of undergraduates on the genetic basis of racial differences. [A professor at] City College in New York . . . has asserted that differences in average test scores (which unquestionably exist) are self-evident proof of genetic differences—as though the SAT provided direct access to DNA.¹⁸⁵

Apparently neutral genetic screening programs can threaten similar results. Several decades ago, African-Americans expressed serious concern about the danger to their community created by widescale screening for sickle-cell anemia. In the early 1970s, Congress passed a law that financed and encouraged voluntary screening of African-Americans for the sickle-cell trait.¹⁸⁶ Before passage of that law, over a dozen states, mostly in the South, made marriage licenses and admission to primary school for African-Americans dependent on sickle-cell screening.¹⁸⁷ Such screening was eventually abandoned, but

¹⁸⁵ NELKIN & LINDEE, *supra* note 49, at 116-17.

¹⁸⁶ National Sickle Cell Anemia Control Act, Pub. L. No. 92-294, 86 Stat. 136 (1972) (codified as amended at 42 U.S.C. §§ 300(b)(1) et seq.). The Sickle Cell Act was passed in 1972, as an amendment to the Public Health Service Act, ch. 373, tit. I, § 2, 58 Stat. 682 (1944) (codified as amended at 42 U.S.C. §§ 201 et seq.); see also Tom Dworetzky, *No Deltas Need Apply; Genetic Screening*, 15 OMNI 5, 16 (1993), available at LEXIS, News Group File, All. In 1981, the Act was amended in part and repealed in part, Omnibus Budget Reconciliation Act, 95 Stat. 827 (1981).

¹⁸⁷ Mark A. Erhart, *Science Seeks Advances, Not Racism*, CHICAGO TRIB., Feb. 16, 1998, available at LEXIS News Library, CHTRIB File; Tony Pugh, KnightRidder News Service, *Blacks Remain Uneasy About Health Care System*, FT.

members of the targeted community were left feeling that they had been betrayed.¹⁸⁸ Some concluded that the screening programs constituted an attempt at racial genocide.¹⁸⁹ African-Americans have since hesitated to submit voluntarily to genetic screening projects.¹⁹⁰

In contrast, Jews have participated enthusiastically in a wide variety of genetic screening and research programs.¹⁹¹ They were encouraged to do so by researchers seeking subjects from communities presumed to be more homogenous genetically than the population as a whole,¹⁹² and perhaps also—as several commentators have suggested—by their own traditional interest in science and research.¹⁹³ More recently, however,

WORTH STAR-TELEGRAM, Aug. 10, 1998, available at LEXIS, News Library, FWSTEL File.

¹⁸⁸ Black organizations lobbied Congress to pass the National Sickle-Cell Anemia Control Act of 1972. Pugh, *supra* note 187.

¹⁸⁹ Pugh, *supra* note 187; Rosamond Rhodes, *Autonomy, Respect, and Genetic Information Policy: A Reply to Tuija Takala and Matti Hayry*, 25 J. MED. & PHIL. 114, 117 (2000).

Hannah Bradby described the screening programs for the sickle-cell trait as a "benchmark for failure." *Genetics and Racism*, in THE TROUBLED HELEX: SOCIAL AND PSYCHOLOGICAL IMPLICATIONS OF THE NEW HUMAN GENETICS 295, 303 (Theresa Marteau & Martin Richards eds., 1996). Bradby explained:

Although initially welcomed as an initiative to meet the long-neglected health needs of African Americans, and a means by which they could take control of their own lives, the U.S. sickle cell disease programme was subsequently described as racist, as a form of anti-black eugenics and even a step towards genocide.

Id. at 304 (citations omitted).

¹⁹⁰ Madeleine J. Goodman & Lenn E. Goodman, *Overselling of Genetic Anxiety*, 12 HAST. CENT. RPT. 20, 20 (1982) (noting criticism of mass screening for sickle-cell trait and discontinuance of programs "on grounds that it stigmatized the black population"); see also Mark Levin, *Screening Jews and Gentiles: A Consideration of the Ethics of Genetic Screening Within the Jewish Community: Challenges and Responses*, 3 GENETIC TESTING 207, 207 (1999).

¹⁹¹ See generally Nancy J. Nelson, *Ashkenazi Community is Not Unwilling to Participate in Genetic Research*, 90 J. NAT'L CANCER INST. 884 (1998).

¹⁹² *Genetics: U.S. Jews Urged to Help Testing*, GENE THERAPY WEEKLY, May 4, 1998, available at LEXIS, News Group File, All (citing Francis Collins, Director of the National Human Genome Research Institute, urging Jews, and others, to participate in genetic trials).

¹⁹³ Seachrist, *supra* note 135; Sally Lehrman, *Jewish Leaders Seek Genetic Guidelines*, 389 NATURE 322, 322 (Sept. 25, 1997); *Genetics: U.S. Jews Urged to Help Testing*, *supra* note 192. But see Nancy Press et al., *How are Jewish Women Different From All Other Women?: Anthropological Perspectives on Genetic Susceptibility Testing for Breast Cancer*, 7 HEALTH MATRIX 135, 138-39 (1997) (asserting that although "Jewish culture places particular value on science and medicine" and although "in Jewish culture scientific knowledge is always thought to be useful,"

leaders of Jewish organizations, as well as Jewish scientists and researchers,¹⁹⁴ have begun to question whether the disadvantages of communal participation in such research and screening projects may be greater than the advantages.¹⁹⁵ Jewish participation in genetic screening and research efforts has resulted in more genetic information about Jews than about other groups. And that information may entail a series of interconnected dangers for Jewish communities.

Examination of the present and potential dangers that genetic information poses for Jews reveals some of the broader dangers inherent in a social ideology that seems increasingly to view people's thoughts and actions as the inevitable consequence of natural ("genetic") facts. Thus, such dangers illustrate concretely the implications for American culture of shifting understandings of individuals and of groups that develop from an ideology of genetic inheritance.

A. *Genetic Alterations Associated with Ashkenazi Jews*

A disproportionate number of harmful genetic alterations have been identified with Ashkenazi Jews. Among them are alterations that predispose people to Tay-Sachs disease,¹⁹⁶ breast cancer,¹⁹⁷ ovarian cancer,¹⁹⁸ Bloom Syndrome,¹⁹⁹ and colon cancer.²⁰⁰ Publicity attending these findings has resulted in the widespread, though erroneous, belief that Jews are more prone to genetic disorders than other people.²⁰¹

Jewish women may not "react differently from other women with regard to interest in genetic testing for breast cancer").

¹⁹⁴ Lehrman, *supra* note 193, at 322.

¹⁹⁵ Lehrman, *supra* note 193, at 322.

¹⁹⁶ Levin, *supra* note 190, at 208.

¹⁹⁷ Karen H. Rothenberg, *Breast Cancer, The Genetic 'Quick Fix,' and the Jewish Community*, 7 HEALTH MATRIX 97, 98 (1997).

¹⁹⁸ *Id.*

¹⁹⁹ Benjamin B. Roa et al., *Ashkenazi Jewish Population Frequency of the Bloom Syndrome Gene 2281^6ins7 Mutation*, 3 GENETIC TESTING 219 (1999).

²⁰⁰ Nelson, *supra* note 191, at 884.

²⁰¹ Marlene E. Post, *Curb Bias Against Mutant-Gene Carriers*, NEWSDAY, Aug. 27, 1997, available at LEXIS, Current File (referring in headline to Jews as "mutant gene-carriers").

Even doctors and scientists believe that Jews are more likely to suffer from genetic diseases than others. One sperm bank in Boston advises patients not to use "Jewish sperm," explaining that Jewish donors are particularly likely to transmit genetic diseases to their offspring. Interview with Anonymous (a sperm bank

There is no evidence that Jews are more likely than anyone else to carry genetic alterations predisposing them to disease.²⁰² A disproportionate number of genetic alterations have been identified with Ashkenazi Jews because the population has submitted willingly to genetic testing and has been more systematically studied than most other groups.²⁰³ In fact, all people appear to have a significant number of genetic alterations that predispose them to serious diseases. Francis Collins, director of the National Human Genome Research Institute, estimates the number, on average, to be somewhere between five and fifty.²⁰⁴ "There is no evidence," asserts Collins, "that the burden of genetic flaws is greater for one population than another."²⁰⁵

In addition, it is comparatively easy to identify genetic alterations associated with groups, such as Ashkenazi Jews, that have interbred for significant periods of time.²⁰⁶ Particular genetic alterations are likely to appear with greater frequency among comparatively isolated populations.²⁰⁷ Indeed, genetic alterations have been identified with several groups that have been relatively isolated from other populations or that have tended not to intermarry with surrounding populations.²⁰⁸ Among such groups are Finns, Norwegians, Amish, and Icelanders.²⁰⁹ As a sociological matter, however, Jews differ from these groups in having been subject to discrimination for centuries, often justified through reference to prejudicial images of Jews' deformed, marginal physicality.²¹⁰

patient/donee), May 2000 (on file with author).

²⁰² Beta Prince-Gibson, *Put to the Test*, JERUSALEM POST, Sept. 4, 1998, available at LEXIS, News Library (noting absence of evidence that any population carries more "genetic flaws" than any other).

²⁰³ *Id.* (noting commercial companies' interest in promoting genetic testing and referring to representatives of one such company, Myriad Genetics, whose representatives advised doctors that Jewishness was one among a set of criteria that indicated a need for genetic testing).

²⁰⁴ Nelson, *supra* note 191, at 885.

²⁰⁵ *Id.*

²⁰⁶ Seachrist, *supra* note 135 (referring to so-called "founder effect" as one of the causes of correlation between genetic alterations and comparatively isolated populations).

²⁰⁷ See *supra* note 206 (referring to "founder effect").

²⁰⁸ The Jews of Eastern Europe and Russia tended to live in isolation from surrounding populations. They spoke their own language (Yiddish) and lived in their own villages (*shtetls*). See Markel, *supra* note 11, at 52-53.

²⁰⁹ Nelson, *supra* note 191, at 884.

²¹⁰ *Genetics: U.S. Jews Urged to Help Testing*, GENE THERAPY WEEKLY, May 4,

In fact, so-called "genetic markers," associated with comparatively isolated groups of people, do not indicate "real" racial differences:

Despite the existence of such genetic markers for particular groups, though, the genes carry a wider, paradoxical lesson about "racial" differences—which is that, in the main, there aren't any Over the years [Dr. Cavalli-Sforza] has examined a wide range of genes in a wide range of populations. These populations do differ genetically, but the pattern of differences in well-known genes such as those for blood groups and the HLA proteins of the immune system rarely conform to the conventional racial picture.

In fact, it is remarkable how homogenous humanity is. Around 85% of the genetic variability measured by Dr. Cavalli-Sforza is variation between individuals within a given group. Another 6% is variation between groups within a single continent, and 9% is variation between continents²¹¹

Unfortunately, such information will not necessarily obliterate the use of genetic information, including reliance on genetic markers, to validate racist images. Thus, the identification of genetic alterations with Jews (and other groups whose social marginality has been justified and reinforced through reference to somatic characteristics) may have social implications not relevant to the decoding of genetic alterations within the population as a whole.

1998, available at LEXIS, Current File (quoting Karen Rothenberg of the University of Maryland as having said, "Those other groups [i.e., the Amish, Mormons, Finns, Icelanders], none of them are stigmatized The one thing that everyone Jewish shares is a concern for anti-Semitism").

²¹¹ *Survey of the Human Genome*, supra note 2, at 12.

Jews first volunteered for mass genetic screening programs in the 1970s as part of an effort to identify carriers of Tay-Sachs disease, a neurological condition that occurs primarily in descendants of Jews from Eastern Europe.²¹² The disease is inherited recessively, and thus occurs only when both parents are carriers; carriers themselves are unaffected by the disorder.²¹³ During the first decade of Tay-Sachs screening, over 100,000 people were screened in the United States.²¹⁴ About four percent were identified as Tay-Sachs carriers.²¹⁵ Internationally, over one million adults were tested by 1992, and over 1,000 couples were identified as at risk for having children who would suffer from the disease.²¹⁶

The apparent success of Tay-Sachs screening programs at identifying carriers and affected fetuses²¹⁷ was compromised by a number of unsettling consequences. Some of those identi-

²¹² Paul J. Edelson, *The Tay-Sachs Disease Screening Program in the U. S. as a Model for the Control of Genetic Disease: An Historical View*, 7 HEALTH MATRIX 125, 126 (1997); Levin, *supra* note 190, at 207.

Tay-Sachs is a central nervous system disorder. It affects children in the first year of life, leading to blindness, seizures, and retardation. The condition is inevitably fatal, generally in early childhood. Edelson, *supra*, at 125. An assay for disease—in particular, for the Tay-Sachs enzyme (Hexosaminidase A)—was developed in 1971. *Id.* at 127.

The condition occurs only in those homozygous for the gene. Carrier parents are unaffected and their children are unaffected if the other parent is not also a carrier. *Id.* Two carrier parents have a twenty-five percent chance of having an affected child.

²¹³ Goodman & Goodman, *supra* note 191, at 21; Regina Kennen & Robert M. Schmidt, *Stigmatization of Carrier Status: Social Implications of Heterozygote Genetic Screening Programs*, 68 AM. J. PUB. HEALTH 1116, 1118 (1978).

²¹⁴ Edelson, *supra* note 212, at 129.

²¹⁵ Edelson, *supra* note 212, at 129. Some have concluded that the screening was more successful among Orthodox Jews than among other groups. Hannah Bradby, *Genetics and Racism*, in THE TROUBLED HELIX: SOCIAL AND PSYCHOLOGICAL IMPLICATIONS OF THE NEW HUMAN GENETICS 307 (Theresa Marteau & Martin Richards eds., 1996) (noting testing of only fifteen percent of "at-risk persons per community").

²¹⁶ Levin, *supra* note 190, at 208. Through amniocentesis or chorionic villae sampling, 469 fetuses affected with Tay-Sachs were identified. The vast majority of these were aborted. Abortions were performed on 451 of the 469 affected fetuses. Levin, *supra* note 190, at 208.

²¹⁷ Screening programs were less successful outside the U.S. In Britain, for instance, only 400 of the 400,000 members of the British Jewish community were tested. Edelson, *supra* note 212, at 130 (citing Charles R. Scriver & Reynold J. M. Gold, *Tay-Sachs Heterozygote Screening: Specificity and Sensitivity*, in TAY-SACHS DISEASE: SCREENING AND PREVENTION 139-43 (Michael M. Kaback et al. eds., 1977)).

fied as Tay-Sachs carriers suffered serious psychological harm, perhaps because they did not adequately understand the implications of "carrier status"²¹⁸ or perhaps, more generally, because the notion of genetic alterations suggests physical, and thus social, deformity or, at least, marginality. In any event, a few couples, learning that one was a carrier for Tay-Sachs, canceled their plans to marry, even though neither the "carrier" nor any child produced through the union would ever have suffered from the disease.²¹⁹ More broadly, those identified as carriers of the Tay-Sachs gene experienced significant anxiety and depression.²²⁰

In recent years, members of the American Jewish community have become concerned about genetic screening and research programs that threaten to mark Jews as more likely than non-Jews to be genetically flawed. At least one journalist has asserted that blood samples from Jews tested in Tay-Sachs screening programs have remained on file at various medical facilities and have been used in research projects, though the subjects never consented to such use.²²¹ These projects are further reported to have resulted in some of the early findings about additional genetic alterations associated with Ashkenazi Jews.²²²

B. *Reviving Anti-Semitic Images*

Such findings can resuscitate a disconcerting canard that Jews are diseased and physically marginal. Some public responses to the results of genetic screening programs and research projects among Jews reflect such canards. For instance, several journalists have described the identification of genetic alterations associated with Ashkenazi Jews in terms that reflect historic images of the Jew as physically deformed and dangerous. Eeta Prince-Gibson explains:

²¹⁸ Levin, *supra* note 190, at 208.

²¹⁹ See *supra* note 212 (noting that only the homozygous condition results in the disease).

²²⁰ See Levin, *supra* note 190, at 208 (describing results of psychological studies of those identified as Tay-Sachs carriers).

²²¹ Prince-Gibson, *supra* note 202.

²²² *Id.*

Ashkenazi Jews are a relatively homogeneous group . . . who volunteer for testing and who tend to live in the large urban centers with medical research institutions . . . [and] are among the first groups in which ethnic-specific cancer-causing alterations have been found.

But these facts were not reflected in the newspaper headlines. *Newsday* ran a series on "Mutant-Gene Carriers." A midwest regional paper proclaimed: "Ashkenazi Jewish women stalked by second mutant breast-cancer gene." And a Jewish newspaper in the New York region published a series of articles on "tainted Jewish genes."²²³

Such responses recall images that punctuate Western history, portraits of Jews as marked in their bodies—as flawed, deformed, and diseased. "The marked body of the Jew," explains Laurie Zoloth-Dorfman, "has long been a source of reference against which to measure the normal human body, read generally as the body of the Christian male."²²⁴

In the thirteenth century, a version of the myth of the blood libel proclaimed that Jews needed Christian blood in order to disguise their demonic bodies.²²⁵ That myth was grounded in theological conjecture and devotional piety. By the eighteenth and nineteenth centuries, when science replaced religion as society's central ideological anchor, images of Jewish deformity were preserved in the language of science and objective truth.²²⁶ The ideology that defined the Jew as different shifted, but the Jew continued to represent spiritual and physical difference in the West. Sandor Gilman suggests a "generalized vocabulary of difference which seems to be part of Western (Christian or secularized) means of representing the Jew."²²⁷ Gilman continues:

This model of representing the Jew is present in the earliest Christian texts, including . . . the Gospels. The power of these images enables them to exist, with only shifts in their rhetorical form, through the ages. This sense of difference impacts on the Jew who is

²²³ *Id.*

²²⁴ Laurie Zoloth-Dorfman, *Mapping the Normal Human Self: The Jew and the Mark of Otherness*, in *GENETICS: ISSUES OF SOCIAL JUSTICE* 180, 181-82 (Ted Peters ed., 1998).

²²⁵ Levin, *supra* note 190, at 211.

²²⁶ Zoloth-Dorfman, *supra* note 224, at 180, 182.

²²⁷ SANDER GILMAN, *THE JEW'S BODY* 235 (1991). I am grateful to Laurie Zoloth-Dorfman's Article, *Mapping the Normal Human Self*, *supra* note 224, at 182, for the reference to Gilman's book.

caught in the web of power which controls and shapes his or her psyche and body.²²⁸

This view was reflected in the American eugenics movement, which flourished during the first several decades of the twentieth century²²⁹ and which dedicated itself to "upgrad[ing] the hereditary quality of the American people."²³⁰ Several leading eugenicists,²³¹ committed to the notion of Nordic superiority, justified dislike for non-Nordic people as a "matter of science, not of prejudice or ill-will,"²³² and thus attempted to legitimate hostility toward (among others) Jews, African-Americans, Hindus, Catholics, and Indians.²³³ An American eugenicist named Madison Grant described Jews as people of " 'dwarf stature, peculiar mentality, and ruthless concentration on self-interests' " who were " 'being engrafted upon the stock of the nation.' "²³⁴

Similarly, in nineteenth- and twentieth-century Germany, Jews were identified and documented (and thus distinguished from Germans) through the languages of science and medicine. Medieval religious images of the Jew as Other were recast by scientific discourse that depended upon measurement and observation.²³⁵ They remained, however, essentially unchanged. The tenacity of these images is evident from Gilman's study of the shifting image of the "Jewish foot."²³⁶ Gilman explores the treatment of the Jewish foot by nineteenth- and twentieth-century German doctors and scientists as an illustration of the broader social effort of contemporary German culture to prove that "some 'races' are inherently weaker, 'degenerate,' more at risk for certain types of disease than oth-

²²⁸ GILMAN, *supra* note 227, at 235.

²²⁹ LUDMERER, *supra* note 51, at 7.

²³⁰ *Id.*

²³¹ Among this group were Madison Grant, Lothrop Stoddard, Ellsworth Huntington, Harry H. Laughlin, Henry F. Osborn, Prescott Hall, and Robert deC. Ward. *Id.* at 25-26.

²³² *Id.* at 26.

²³³ *Id.* at 28.

²³⁴ LUDMERER, *supra* note 51, at 28 (quoting MADISON GRANT, *PASSING OF THE GREAT RACE* 218 (1933)).

²³⁵ See generally GILMAN, *supra* note 227 (describing "scientific" descriptions and analyses of the Jewish foot in nineteenth- and twentieth-century Germany).

²³⁶ GILMAN, *supra* note 227, at 38-59. Only one essay in Gilman's book is concerned with the Jewish foot. Others consider various anatomical, emotional, and behavioral dimensions that were taken to define the Jew as marginal.

ers.²³⁷ "In the world of nineteenth century medicine," Gilman notes, "this difference becomes labeled as the 'pathological' or 'pathogenic' qualities of the Jewish body."²³⁸

The particular claim Gilman considers was that the feet of the Jew²³⁹ were weak, as evidenced in the flatness of Jews' feet or in the Jews' peculiar gait.²⁴⁰ German scientists drew charts detailing the deviance of the Jewish foot. Jewish scientists accepted the evidence and agreed that the Jewish foot was abnormal. Jewish feet were observed, measured, and compared with Christian feet. A 1936 German textbook reported: "Flat feet are especially frequent among the Jews. Salaman reports during the World War that about a sixth of the 5,000 Jewish soldiers examined had flat feet while in a similar sample of other English soldiers it occurred in about a fortieth."²⁴¹ Almost always, reports Gilman, anatomical discussions of the abnormalities of the Jewish foot were related to the consequent inability of the Jew to serve adequately as a foot soldier.²⁴² Thus, the Jewish foot symbolized and explained the inability of the Jew to participate adequately in national life. Gilman connects the nineteenth-century German vision of the Jewish foot with earlier images of deformed Jewish feet as symbolic of Jewish spiritual deformity (an inevitable product of the Jew's standing outside Christendom):

The idea that the Jew's foot is unique has analogies with the hidden sign of difference attributed to the cloven-footed devil of the middle ages By the nineteenth century the relationship between the image of the Jew and that of the hidden devil is to be found not in a religious but in a secularized scientific context. It still revolves in part around the particular nature of the Jew's foot—no longer the foot of the devil but now the pathognomonic foot of the "bad" citizen of the new national state. The political significance of the Jew's foot within the world of nineteenth century medicine is thus closely related to the idea of the "foot"-soldier, of the popular militia, which

²³⁷ GILMAN, *supra* note 227, at 39.

²³⁸ GILMAN, *supra* note 227, at 39.

²³⁹ The "Jew" at issue in Gilman's analysis of nineteenth century studies of Jewish bodies was the male Jew ("the Jew with the circumcised penis"). GILMAN, *supra* note 227, at 5.

²⁴⁰ GILMAN, *supra* note 227, at 40.

²⁴¹ GILMAN, *supra* note 227, at 52 (quoting a "standard textbook of German racial eugenics," ENSCLICHE ERBLEHRE UND RASSENHYGIENE: 1 : MENSCHLICHE ERBLEHRE 396 (Erwin Baur et al. eds., 1936)).

²⁴² GILMAN, *supra* note 227, at 52.

was the hallmark of all of the liberal movements of the mid-century. The Jew's foot marked him . . . as congenitally unable and, therefore, unworthy of being completely integrated into the social fabric of the modern state.²⁴³

The persistence throughout Western history of discrimination against Jews rooted in malevolent imagery should prompt suspicion about the emergence of such imagery in modern genetics.²⁴⁴ A mode of discourse constructed around the notion of DNA and fueled by genetic facts and metaphors can clearly be used for racist ends (vis-a-vis Jews and other groups identified with distinct genetic alterations). Whether that will occur depends in significant part on how society will envision the individual person, and on how it will understand the relation between individuals and larger groups. Ironically, the new genetics may itself facilitate and encourage shifts in social understandings of personhood that will undermine some of the social mechanisms that now limit and discourage genetic discrimination.²⁴⁵

IV. THE "GENETIC" INDIVIDUAL AND THE "GENETIC" GROUP: ELABORATING AN IDEOLOGY OF GENETIC INHERITANCE

The law has not yet considered many cases that involve discrimination against ethnic groups in genetic terms.²⁴⁶ However, a number of cases and commentaries about the use of genetic information in familial contexts are suggestive of how the law may respond to such discrimination because American culture has long understood familial and ethnic groups in analogous terms.

In 1969, the anthropologist David Schneider defined an ideological universe that encompassed relationships within diverse groups.²⁴⁷ Schneider did not directly address the case

²⁴³ GILMAN, *supra* note 227, at 39-40.

²⁴⁴ Prince-Gibson, *supra* note 202 (noting media descriptions of Jews as genetic mutants).

²⁴⁵ See *infra* notes 254-259 and accompanying text (describing shifting understanding of personhood facilitated by new genetics).

²⁴⁶ See *Norman-Bloodsaw v. Lawrence Berkeley Laboratory*, 135 F.3d 1260, 1264 (9th Cir. 1998) (allowing application of Title VII of Civil Rights Act of 1964 to employer's screening of African-American employees for sickle-cell trait).

²⁴⁷ David M. Schneider, *Kinship, Nationality, and Religion in American Culture: Toward a Definition of Kinship*, in *SYMBOLIC ANTHROPOLOGY: A READER IN THE*

of ethnic groups, but they could easily be considered within the broad analytic scheme that he presented. Schneider showed that, within American culture, relations among family members were structured in the same terms as relationships among members of religious and national groups.²⁴⁸ Within each of these apparently distinct domains, social relationships were predicated on an assumed "unity of substance" (e.g., blood, land), and on the assumption of a unifying sentiment (e.g., love, patriotism).²⁴⁹

An ideological frame within which contemporary genetics can be used to define apparently distinct social units (families, ethnic groups) in similar terms long predated the decoding of the human genome and, more specifically, predated practical concerns about discriminatory uses of genetic information. For at least two centuries, a far-reaching ideology of relationships within American culture has encouraged familial and ethnic loyalties and, at the same time, antipathy to those defined as Other.²⁵⁰

Schneider identified the ideological grounding of a long-standing tendency within the culture to perceive various sorts of identities and communal relationships through similar forms.²⁵¹ However, contemporary understandings of relationships within American culture differ in several significant regards from those described by Schneider in the 1960s. In particular, the balance between what Schneider referred to as relationships of "natural substance" ("blood") and what he referred to as relationships "as code for conduct,"²⁵² has shift-

STUDY OF SYMBOLS AND MEANINGS 63 (Janet L. Dolgin et al. eds., 1977).

²⁴⁸ See *id.* at 70.

²⁴⁹ More specifically, Schneider argued:

If we consider only the "pure" domain of kinship and treat this as a system of diffuse, enduring solidarity, it seems possible that what is called "nationality" and "religion" are defined and structured in identical terms, namely, in terms of the dual aspects of relationship as natural substance and relationship as code for conduct, and that most if not all of the major diacritical marks which are found in kinship are also found in nationality and religion.

Id. at 70-71.

²⁵⁰ See LOUIS DUMONT, *HOMO HIERARCHICUS: AN ESSAY ON THE CASTE SYSTEM* 239-58 (Mark Sainsbury trans., 1970) (analyzing ideology of racism in the United States).

²⁵¹ See Schneider, *supra* note 247, at 65.

²⁵² *Id.*

ed widely during the last several decades. Increased emphasis on the centrality of the autonomous individual, and on that individual's right of choice in communal (including familial) settings, has reduced the significance of relationships as "natural substance" in familial, national, and other communal settings.²⁵³ The availability of genetic testing and the proliferation of genetic information produce a strikingly contrary effect—one that minimizes the importance of relationships grounded in "code-for-conduct" and provides for a more exclusive stress on relationships grounded in "natural substance." Thus, American culture is undergoing a broad fragmentation of the ideology that has long defined relationships within groups defined by reference to natural substance. Increasingly, American society defines kinship differently *for different purposes*.

The anthropologist Kaja Finkler concludes her study of the conjunction of the new genetics and American kinship by commenting on a disassociation between genes, as the "natural substance" that delimits familial groups, and the actual experience of being related to others as kin:

With the ideology of genetic inheritance and the medicalization of kinship, interaction with family and kin may no longer be required in order for people to recognize relatedness and connection [I]n the past, the family was identified by honor, status, power, or even poverty, whereas in contemporary times family and kin tend to be stabilized and bounded by the sharing of DNA molecules, which lack the moral responsibilities associated with relatedness.

Phenomenologically there is a distinction between experiencing oneself as a member of a significant same group, which feels a sense of unity and relatedness associated with shared experiences from the beginning of life, and experiencing oneself as a member of a group that shares DNA molecules, which are not easily discernible. The notion of shared experiences suggests being in the world and interacting with others, whereas being part of the same DNA circle requires no social interaction.²⁵⁴

In a world defined through amoral DNA, differences and similarities between individuals and their genetic groups are defined only in biological terms. No rules about the character and scope of communal relationships balance the *fact* of shared

²⁵³ See, e.g., JANET L. DOLGIN, *DEFINING THE FAMILY: LAW, TECHNOLOGY, AND REPRODUCTION IN AN UNEASY AGE* 14-31 (1997) (summarizing transformation of American family during early decades of twentieth century).

²⁵⁴ FINKLER, *supra* note 48, at 206.

genes. The genetic family (or the genetic ethnic group) is defined exclusively with reference to a genome. In consequence, the locus of social value shifts from the individual to groups of apparently fungible individuals, and the autonomous individual, constructed through, and understood in terms of, Enlightenment values, ceases to be essential. Moreover, the view that genes are shared substance *and* information²⁵⁵ facilitates depersonalization. The genetic "substance" taken to define each person is also collapsed into a network of information that defines the group exactly as it defines the person and that defines every person exactly as it defines each other person. A universe predicated on the notion of a genetic group would view the preservation of autonomy, and the protection of the individual, with indifference. And in such a universe, social, and presumably legal, protections now afforded the individual person—protections, for instance, of privacy, equality, and choice—would also become matters of indifference.

The possibility that such a universe is evolving is evident in the discussion, to which we now turn, of institutional responses to some of the questions presented by the use, and potential abuse, especially within familial contexts, of genetic information. The discussion focuses first on the implications of genetic information in familial contexts, more than ethnic or racial contexts, because these contexts have been subjected to professional consideration and legal analysis.²⁵⁶ A number of litigated cases involving the obligations of physicians to protect or reveal genetic information about patients, several legal commentaries, and at least one professional society's statement on disclosure of genetic information²⁵⁷ suggest a remarkable

²⁵⁵ See MARILYN STRATHERN, THOUGHT EXPERIMENTS 19 (1998) (draft in possession of author) (noting that "in popular parlance [genes] are both substance (the 'blood' that is inherited) and information (codes for saying how cells will develop)").

²⁵⁶ Even in the context of family settings, there are only a few cases that deal directly with the use of genetic information. See *infra* Part IV.A. Direct testing for genetic alterations is a recent phenomenon. Thus, concern with the use of such testing and with the information it reveals is likely to increase in familial and in other sorts of contexts. See, e.g., Holmes, *supra* note 89, at 506 (noting that consequences of new genetics for insurance consumers and insurance industry remain conjectural, and quoting Ohio Task Force on Genetic Testing, Final Report iii-iv (Dec. 31, 1995), concluding that "[i]nsurers will not use genetic tests, if ever, until such tests are in common use").

²⁵⁷ The American Society of Human Genetics Social Issues Subcommittee on Familial Disclosure, *ASHG Statement: Professional Disclosure of Familial Genetic*

shift in understandings of personhood and of relationships among people in settings defined through reference to genetic information.

More particularly, courts, legal commentators, and others, considering the implications of genetic information for individuals and for groups, have begun to assume, and to countenance, the "genetic family" as a social and legal construction. And by implication they have also begun to assume, and to countenance, genetic ethnic,²⁵⁸ racial, and national groups as constructs.²⁵⁹ These constructs depend on, and further encourage, the emergence of an ideology that deconstructs personhood, as understood in the West at least since the Enlightenment, and that (more importantly) could threaten the political and legal structures that seem best able to protect against the use of genetic information in the service of discriminatory ends.

A. Constructing a "Genetic Family"

Some of the ramifications of an ideology of genetic inheritance are suggested by the assumptions underlying two cases,²⁶⁰ both decided in the 1990s, the statement on "disclosure of familial genetic information" of the American Society of Human Genetics,²⁶¹ and a few published proposals for legal reform.

In the first of the two cases, *Pate v. Threlkel*,²⁶² the Florida Supreme Court was, in effect, asked by the plaintiff to rec-

Information, 62 AM. J. HUM. GENET. 474 (1998) [hereinafter *ASHG Statement*]. See *infra* notes 296-305 and accompanying text (describing and summarizing this statement).

²⁵⁸ See *infra* notes 328-329 and accompanying text (considering ethnic and racial groups).

²⁵⁹ Hróbjartur Jonatansson, *Iceland's Health Sector Database: A Significant Head Start in the Search for the Biological Grail or an Irreversible Error*, 26 AM. J.L. & MED. 31 (considering potential consequences of 1998 decision of Iceland's Parliament to permit the development of a Health Sector Database to collect genetic information about the national population).

²⁶⁰ *Safer v. Pack*, 677 A.2d 1188 (N.J. Super. Ct. App. Div. 1996); *Pate v. Threlkel*, 661 So. 2d 278 (Fla. 1995).

²⁶¹ The American Society of Human Genetics Social Issues Subcommittee on Familial Disclosure, *Professional Disclosure of Familial Genetic Information*, 62 AM. J. HUM. GENET. 474 (1998).

²⁶² 661 So. 2d 278.

ognize a genetic family as a legal unit, but it refrained from acceding completely to that request. In the second case, *Safer v. Pack*,²⁶³ a New Jersey appellate court recognized such a family. In doing so, the court delineated the ideological contours of a universe grounded on novel understandings of privacy, individuality, and of the ties that link people to one another.

*Pate v. Threlkel*²⁶⁴ was commenced in the early 1990s by Heidi Pate, who claimed that Dr. James Threlkel, the physician of Pate's mother, Marianne New, was obliged to warn New that she suffered from a hereditary disease (medullary thyroid carcinoma) that placed her children (including Pate) at risk for the same disorder.²⁶⁵ At the time of suit, Pate, who had indeed fallen ill with the cancer, claimed that had she been warned about the hereditary risk in 1987, when Dr. Threlkel first treated her mother for thyroid cancer, her own condition would have been discovered in a timely fashion and might well have been curable.²⁶⁶ The Florida Supreme Court decided that Dr. Threlkel had a duty to warn New about the hereditary implications of her disease, and that the duty extended to Heidi, as well as to her mother.²⁶⁷ Thus, the court recognized a duty owed by the doctor to his patient's child to provide information about the consequences for that child of the patient's genetic condition, even though the doctor had never treated that child.

Threlkel was not unprecedented,²⁶⁸ and the decision did not impose a duty on Dr. Threlkel to warn Heidi *directly*. A

²⁶³ 677 A.2d 1188.

²⁶⁴ 661 So. 2d 278.

²⁶⁵ *Id.* at 279.

²⁶⁶ *Id.*

²⁶⁷ *Id.* at 280-82.

²⁶⁸ *Threlkel* follows a line of cases, all decided outside Florida, that impose a duty on healthcare workers to warn third-parties. See, e.g., *Tarasoff v. Regents of the Univ. of Cal.*, 551 P.2d 334, 345-47 (Cal. 1976) (imposing duty on psychotherapist to warn intended victim of a patient's murder intentions); *Bradshaw v. Daniel*, 854 S.W.2d 865, 872 (Tenn. 1993) (imposing duty on physician to warn patient's wife that she was at risk of becoming ill with Rocky Mountain Spotted Fever, from which disease patient died; suit was commenced by patient's step-son after death of his mother from the illness); see also L.J. Deftos, *Genomic Torts: The Law of the Future—the Duty of Physicians to Disclose the Presence of a Genetic Disease to the Relatives of Their Patients with the Disease*, 32 U.S.F. L. REV. 105, 111-29 (1997) (reviewing cases imposing a "duty to warn").

warning to Heidi's mother would have sufficed. The court wrote:

To require the physician to seek out and warn various members of the patient's family would often be difficult or impractical and would place too heavy a burden upon the physician. Thus, we emphasize that in any circumstances in which the physician has a duty to warn of a genetically transferable disease, that duty will be satisfied by warning the patient.²⁶⁹

The New Jersey court that decided *Safer v. Pack*²⁷⁰ imposed just such a duty on the physician-defendant. The facts of *Safer* resemble those of *Threlkel*. In 1990, Donna Safer, then thirty-six years old, was diagnosed with a hereditary form of colon cancer from which her father, Robert Batkin, had died twenty-six years earlier.²⁷¹ In 1992, Donna commenced suit against Dr. George Pack, the physician who had treated her father during his last illness.²⁷² Dr. Pack never treated Donna or served as her physician in any way.²⁷³ Yet, Donna, in effect, asserted that Dr. Pack had provided her with negligent medical care.²⁷⁴ In particular, Donna argued that Dr. Pack was obliged "to warn those at risk" that his patient's condition was hereditary,²⁷⁵ "so that they might have the benefits of early examination, monitoring, detection and treatment, and thus, the opportunity to avoid the most baneful consequences of the condition."²⁷⁶

Ida Batkin, Donna Safer's mother and Robert Batkin's wife, testified at trial that Dr. Pack had informed her that his patient suffered from a "blockage" and an "infection."²⁷⁷ Ida asserted that when she asked Dr. Pack whether her husband's

²⁶⁹ *Threlkel*, 661 So. 2d at 292.

²⁷⁰ 677 A.2d 1188.

²⁷¹ *Id.* at 1190.

²⁷² *Id.*

²⁷³ *Id.*

²⁷⁴ *Id.*

²⁷⁵ Robert Batkin was diagnosed with adenocarcinoma. The pathology report issued at the time of Batkin's first operation for colon cancer in 1956 indicated the existence of diffuse intestinal polyposis. This condition is hereditary and leads to colon cancer. Plaintiffs Amended Complaint at 4, 7, *Safer v. Pack*, 677 A.2d 1188 (N.J. Sup. Ct. App. Div. 1996) (No. A2234-94T2). I am grateful to Gary Maher, attorney for Donna Safer, and Ms. Safer's husband, Robert Safer, for sending this complaint to the Hofstra Law Library.

²⁷⁶ *Safer*, 677 A.2d at 1190.

²⁷⁷ *Id.*

condition presented a danger to her two young children, Dr. Pack told her "not to worry."²⁷⁸ The trial court, considering a motion for summary judgment, assumed that Dr. Pack had told no one of the hereditary character of Robert's illness, but dismissed Donna's complaint because "there was no physician-patient relationship between Dr. Pack and his patient's daughter Donna."²⁷⁹

On appeal, the New Jersey Superior Court²⁸⁰ reversed the lower court's grant of summary judgment in favor of Dr. Pack.²⁸¹ The court rejected the limited duty to warn imposed by the Florida supreme court in *Threlkel*. That court required Dr. Threlkel to warn his *patient* (but not, directly, to warn members of that patient's family) of the hereditary character of the patient's medical condition.²⁸² Instead, the *Safer* court defined a broad duty to warn not only the patient, but also directly to warn those members of the patient's family at risk of falling ill with the hereditary illness at issue. Judge Kestin, writing for the court, explained:

Although an overly broad and general application of the physician's duty to warn might lead to confusion, conflict or unfairness in many types of circumstances, we are confident that the duty to warn of avertible risk from genetic causes, by definition a matter of familial concern, is sufficiently narrow to serve the interests of justice. Further, it is appropriate . . . that the duty be seen as owed not only to the patient himself but that it also "extends beyond the interests of a patient to members of the immediate family of the patient who may be adversely affected by a breach of that duty." We need not decide, in the present posture of this case, how, precisely, that duty is to be discharged, especially with respect to young children who may be at risk, except to require that reasonable steps be taken to assure that the information reaches those likely to be affected or is made available for their benefit.²⁸³

²⁷⁸ *Id.*

²⁷⁹ *Id.*

²⁸⁰ The appeal before the superior court involved a motion for summary judgment. Thus, the court accepted Donna Safer's claim that the prevailing standard of medical care at the time that Dr. Batkin cared for her father "required the physician to warn of the known genetic threat." *Id.* at 1191.

²⁸¹ Dr. Pack had died in 1969. The plaintiffs thus brought suit against Dr. Pack's estate. *Safer*, 677 A.2d at 1190.

²⁸² *Id.* at 1191.

²⁸³ *Id.* at 1192 (citing *Schroeder v. Perkel*, 432 A.2d 834, 839 (N.J. 1981)).

The court was explicit. In its view, the duty to warn in cases involving hereditary disorders should not always be limited to warning the patient, who, once informed, might—or might not—communicate that information to relevant family members. Judge Kestin explained:

We decline to hold as the Florida Supreme Court did in *Pate v. Threlkel* . . . that, in all circumstances, the duty to warn will be satisfied by informing the patient. It may be necessary, at some stage, to resolve a conflict between the physician's broader duty to warn and his fidelity to an expressed preference of the patient that nothing be said to family members about the details of the disease.²⁸⁴

Finally, the court suggested that even if Robert Batkin had asked his doctor to refrain from informing his family about the nature of his illness, the law might impose a duty to reveal on the doctor, "especially after the patient's death where a risk of harm survives the patient."²⁸⁵

Other courts (both in New Jersey and elsewhere—including the Florida court that decided *Threlkel*)—have found exceptions to the requirement that a suit against a healthcare provider for negligence depends on the plaintiff being in a relation of privity with the provider. Two decades before *Safer* was decided, courts in a number of jurisdictions began to recognize the right of third parties to be informed by health care workers about otherwise confidential matters concerning a patient. That right has generally been predicated on a foreseeable harm that might have been, but was not, avoided by revelation of confidential information concerning a patient.²⁸⁶ For instance, in *Tarasoff v. Regents of the University of California*, the California Supreme Court held a psychotherapist liable for failing to warn Tatiana Tarasoff or her parents that Prosenjit Poddar, one of the therapist's patients, intended to kill the girl.²⁸⁷ In fact, Poddar murdered the unsuspecting

²⁸⁴ *Id.* at 1192-93.

²⁸⁵ *Id.* at 1193.

²⁸⁶ See *supra* note 268. The cases in note 268 are considered in several law review articles and student notes. See, e.g., Alissa Brownrigg, Note, *Mother Still Knows Best: Cancer-Related Gene Mutations and a Physicians Duty to Warn*, 26 FORD. URB. L.J. 247 (1999); Jeffrey R. Burnett, Comment, *A Physician's Duty to Warn a Patient's Relatives of a Patient's Genetically Inheritable Disease*, 36 HOUS. L. REV. 559 (1999). See also generally Deftos, *supra* note 268.

²⁸⁷ 551 P.2d 334, 345-46 (Cal. 1976) (imposing duty on psychotherapist to warn

Tarasoff.²⁸⁸ The reasoning of *Tarasoff* has been applied in other contexts. A number of courts, both before and after *Tarasoff*, have imposed a similar duty on health care providers to warn those in contact with a patient suffering from a contagious disease.²⁸⁹ And in *Bradshaw v. Daniel*,²⁹⁰ the Tennessee Supreme Court held a physician liable for failing to warn a patient's wife that she might have been exposed to the same agent that caused the *non-contagious* disease (Rocky Mountain Spotted Fever) from which her husband suffered and died.²⁹¹

Finally, in a 1981 case that resembles *Safer*, the New Jersey Supreme Court held defendant-doctors legally at fault for failing to inform a pediatric patient's parents about the hereditary implications of the patient's condition (cystic fibrosis).²⁹² In *Schroeder v. Perkel*, a New Jersey court reasoned that the doctors' duty followed from the harm that might befall the patient's parents were they to conceive a second child, unaware that the second child might also suffer from cystic fibrosis.²⁹³ Despite the similarities between the facts of *Schroeder* and those of *Safer*, the implications of the two cases differ significantly. Both cases require a physician to reveal

third parties of foreseeable harm in cases in which there is special relationship between therapist and patient or therapist and victim).

²⁸⁸ *Id.* at 342-43. The duty to warn described in *Tarasoff* was codified in California statutory law. See CAL. CIV. CODE § 43.92 (West Supp. 1997) (imposing duty in cases in which "the patient has communicated to the psychotherapist a serious threat of physical violence against a reasonably identifiable victim or victims"). *Id.* § 43.92(a).

²⁸⁹ See, e.g., *Gammill v. United States*, 727 F.2d 950, 954 (10th Cir. 1984) (holding a doctor may be liable "for failing to warn a patient's family, treating attendants, or other persons likely to be exposed to the patient, of the nature of the disease and the danger of exposure"); *Wojcik v. Aluminum Co. of Am.*, 18 Misc.2d 740, 745, 183 N.Y.S.2d 351, 357 (Sup. Ct. Erie County 1959) (imposing duty to warn wife of patient with tuberculosis of contagious nature of patient's illness).

²⁹⁰ 854 S.W.2d 865 (Tenn. 1993).

²⁹¹ Rocky Mountain Spotted Fever is contracted from a tick bite. The patient and his wife had been on a camping trip together. The wife in fact became ill with the disease, from which she, like her husband, died. The case was commenced by the wife's son. *Id.* at 867.

²⁹² *Schroeder v. Perkel*, 432 A.2d 834 (N.J. 1981).

²⁹³ *Id.* at 839-40. In fact, the parents, Marion and John Schroeder, unaware of the hereditary implications of their daughter's illness, had a second child who, like his sister, suffered from cystic fibrosis. *Id.* at 836.

At the time, cystic fibrosis could not be detected in a fetus, but could be diagnosed in a baby through a method known as a "sweat test." *Id.*

confidential information to a patient's close family member, but the context of each case distinguishes it from the other. To order a pediatrician to tell a patient's parents about the implications of that patient's illness is far less surprising and less disruptive of basic cultural assumptions than to require a physician to reveal confidential information about a patient's illness to the patient's *children* (or siblings and other collateral relatives). In the range of disclosure mandated, the holding in *Safer*²⁹⁴ is unprecedented. Not surprisingly, it remains controversial.²⁹⁵

The essential message of the holding in *Safer* is reflected in a 1998 Statement of the American Society of Human Genetics ("ASHG").²⁹⁶ The ASHG proposed granting health care providers the "discretionary right"²⁹⁷ to contravene rules that normally protect patient confidentiality in certain cases involving patients with hereditary conditions.²⁹⁸ "[T]he principle of confidentiality is not absolute," the Society stated, "and, in

²⁹⁴ The case was remanded and tried to a jury in late 1999. The jury held for the defendant. No written decision was handed down by the court. Gary Maher, one of the plaintiff's attorneys, explained that, in his view, the decision was based on evidence presented at trial that Donna Safer did, in fact, know about the risk of falling ill with the illness from which her father died. See E-mail from Connie Lenz, Assistant Director, Maurice A. Deane Law Library, Hofstra University School of Law, to author (Oct. 6, 1999, 16:28 CST) (on file with author). In particular, evidence was presented showing that Donna Safer had probably been examined for evidence of colon cancer, even as a very young girl. The superior court, which held for Donna Safer, noted the possibility that Donna had, in effect, been warned as a child. *Safer v. Pack*, 677 A.2d 1188, 1193 (N.J. Sup. Ct. App. Div. 1996). The court noted the "possible existence of some offsetting evidence that Donna was rectally examined as a young child, suggesting that the risk to her had been disclosed." *Id.*

²⁹⁵ The more far-reaching implications of *Safer* were rejected by the New Jersey legislature in 1996. In that year, the state legislature passed a statute concerned with protecting genetic privacy. Under this law, health care workers are only allowed to warn relatives of those suffering from genetic disorders if the patient has consented to the disclosure or if the patient has died. Genetic Privacy Act, N.J. STAT. ANN. § 17B:30-12 (West 1998); see also Bob Groves, *New Jersey Has Yet to Implement Genetic Privacy Law: Health-Care Community Awaiting State Confidentiality Regulations*, THE RECORD (Bergen County, N.J.), May 29, 1998, at A5, available at LEXIS, News Library, NJrec File.

²⁹⁶ *ASHG Statement*, *supra* note 257, at 474.

²⁹⁷ *Id.* at 474.

²⁹⁸ The duty outlined in the Society's ASHG Statement, *supra* note 257, to provide a patient's family members with genetic information, is discretionary. In this regard the *ASHG Statement* differs from *Safer* which suggests a mandatory duty to disclose, at least in certain cases. See 677 A.2d 1188.

exceptional cases, ethical, legal, and statutory obligations may permit health-care professionals to disclose otherwise confidential information."²⁹⁹ Those cases are delimited by two sets of "exceptional circumstances."

[First, are cases] where attempts to encourage disclosure on the part of the patient have failed; where the harm is highly likely to occur and is serious and foreseeable; where the at-risk relative(s) is identifiable; and where either the disease is preventable/treatable or medically accepted standards indicate that early monitoring will reduce the genetic risk.³⁰⁰

Second, in cases in which disclosure is permitted, "[t]he harm that may result from failure to disclose should outweigh the harm that may result from disclosure."³⁰¹ The Society defined "at-risk relatives" to whom disclosure should be permitted in such cases to include a patient's children and siblings, as well as a patient's "identifiable parents, cousins, aunts and uncles, whom the health-care professional can reasonably contact."³⁰²

Safer,³⁰³ and the position espoused by the ASHG,³⁰⁴ suggest a far-reaching redefinition of family privacy.³⁰⁵ Both assume a *genetic family*, defined exclusively through reference to a shared genome, understood to reflect familial DNA. This redefinition presumes that each person replicates every other person and the larger whole. Thus, individuals and the larger whole are defined in terms of the genome that establishes their shared identity.

²⁹⁹ ASHG Statement, *supra* note 257, at 474.

³⁰⁰ *Id.*

³⁰¹ *Id.*

³⁰² *Id.* The Society further noted that the majority of foreign jurisdictions approve of "limited disclosure of genetic test results (without the consent of the patient) in cases where the harm to at-risk relatives is grave and imminent and where the disclosure of information could result in effect intervention." *Id.* at 475-76. Among the groups said to follow this position are the "World Health Organization, Council of Europe, Nuffield Council on Bioethics, Health Council of the Netherlands, and Privacy Commissioner of Australia." "Only a few," the Statement continues, "maintain that confidentiality is absolute and that the patient's wishes with regard to non-disclosure must be respected at all times." These groups and countries are said to include "Norway, Swiss Academy of Medical Sciences, and possibly France's National Ethics Committee. ASHG Statement, *supra* note 257, at 476.

³⁰³ 766 A.2d 1188.

³⁰⁴ See *supra* note 298.

³⁰⁵ See *supra* note 298 (noting difference between requirement of disclosure suggested in *Safer* and Statement's proposed "right" to disclose).

This construction of family and its consequences are implicit in *Safer* and at least arguably explicit in the statement of the ASHG. A note in that statement, clarifying the suggestion that genetic information may be viewed as a "family possession rather than simply a personal one,"³⁰⁶ explains, "[Wachbroit] suggests a family-health model that contemplates the physician's patient as the entire family; 'family' is understood to refer to a genetic network rather than a social institution. Therefore, the physician's duties pertain to the genetic family as a whole."³⁰⁷

³⁰⁶ ASHG Statement, *supra* note 257, at 476 (quoting DOROTHY WERTZ ET AL., GUIDELINES ON ETHICAL ISSUES IN MEDICAL-GENETICS AND THE PROVISION OF GENETIC SERVICES (1995)).

³⁰⁷ ASHG Statement, *supra* note 257, at 476 n.1 (citing Robert Wachbroit, *Biomedical Technology, Ethics, Public Policy, and the Law: Rethinking Medical Confidentiality: The Impact of Genetics*, 27 SUFFOLK U. L. REV. 1391 (1993) [hereinafter Wachbroit, *Biomedical Technology*] (Wachbroit's article is cited incorrectly in the Society's statement, ASHG Statement, *supra* note 257, at 476 n.1)); see also Robert Wachbroit, *Who is the Patient?: A Moral Problem*, 38 MD. MED. J. 557 (1989).

In a subsequent article, Wachbroit presents the following hypothetical case: A woman discovers that she is a carrier for the X-linked gene for Duchenne Muscular Dystrophy ("DMD"). Wachbroit, *Biomedical Technology, supra*, at 1395-96. She will not become ill with the disease, but if she has a son, he could become ill with the disease. Wachbroit, *Biomedical Technology, supra*, at 1396. Wachbroit further hypothesizes that the woman has a sister, who has a fifty percent chance of carrying the genetic alteration in question. He continues:

The [genetic] counselor wishes to inform the sister of her condition, since it might affect her reproductive plans, but the woman forbids it. The family has had a terrible falling-out, and the woman now sees withholding the information as a way of taking revenge on her sister. She therefore insists that her right to confidentiality be respected.

Wachbroit, *Biomedical Technology, supra*, at 1396. In thinking about this case, Wachbroit suggests relying on an "alternative framework" to one that focuses on the question of confidentiality, *per se*. This alternative framework involves redefining the "patient." He explains:

Allowing for the possibility that the patient may be more than just an individual does not amount to jettisoning the duty of medical confidentiality [T]he idea of privacy can be applied to more than just individuals. For example, a health professional's duty might be to respect the privacy of a family, rather than that of an individual. Indeed, by expanding the concept of "patient," it is possible to retain much of the structure of the standard approach to confidentiality

Wachbroit, *Biomedical Technology, supra*, at 1402.

This remarkable construction of family is further *assumed* by a recent law review comment³⁰⁸ that proposes, at least in certain contexts, that physicians be allowed, or even obliged, to inform a patient's family members that the patient suffers (or died) from a hereditary condition.³⁰⁹ The implicit assumptions that underlie the comment underscore the implications of *Safer*. The comment dismisses concerns about patient confidentiality by, in effect, *assuming* the preeminence of the genetic family, within which individual identity is subsumed by the identity of the whole:

[T]here is no need to consider confidentiality in the genetic context because, arguably, confidentiality is not sacrificed.

Confidentiality is not in danger because, even assuming that policies in favor of confidentiality outweigh a duty to warn, a duty of confidentiality is not violated in the situation involving the warning of genetic diseases. The *Safer* court mentioned that by their very nature, genetic diseases are a familial concern.³¹⁰

"Now," the comment continues, "with the introduction of genetic mapping . . . the patient/physician relationship has been reconfigured to reflect the individual's ties to his or her ancestors and descendants."³¹¹ And so, the comment concludes:

[I]t would seem that if a doctor warns a patient's at-risk relatives (which is really the "multitude" of family) of a patient's genetic disorder, the patient's interest in keeping the information confidential is not sacrificed. This new analysis of the duty of confidentiality demonstrates that, arguably, such a duty does not pose a barrier to the duty to warn of genetic defects.³¹²

Rules of confidentiality are moot when individuals are indistinguishable from one another. In effect, in the implicit view of the comment, the right to privacy is simply inapplicable to a genetic family. To claim otherwise, this comment suggests, would be to presume erroneously that the autonomous individual, to whom rules of medical confidentiality apply, has survived the redefinition of personhood that attends the successes of the new genetics, including the mapping of a "human genome."³¹³ The ease with which the comment dismisses con-

³⁰⁸ Burnett, *supra* note 286.

³⁰⁹ Burnett, *supra* note 286, at 563.

³¹⁰ Burnett, *supra* note 286, at 577-78.

³¹¹ Burnett, *supra* note 286, at 578.

³¹² Burnett, *supra* note 286, at 578 (emphasis added).

³¹³ In fact, the comment, published in 1999, precedes by one year the an-

cern about patient confidentiality³¹⁴ (and thus privacy) suggests a society prepared to embrace the redefinition of family that undergirds *Safer*.

The notion of patient-as-family (regardless of the wishes and needs of individuals) implies that the family understood as a "genetic network" can be distinguished from the family understood as a "social institution." As a theoretical matter, such a distinction may be drawn, but as a practical matter it is illusory. Requiring or encouraging health care workers to tell family members about one another's medical diagnoses and about their implications will inevitably alter relations among those involved. As Kaja Finkler shows in detail in her anthropological study of people's responses to information about the hereditary conditions of family members, genetic information almost invariably "influences day-to-day experience" for families.³¹⁵ Moreover, defining families through genetic information displaces a moral frame with the amorality of DNA.³¹⁶ As the British anthropologist Marilyn Strathern explains, "Genetic information which appears to extract relatedness from relationships simultaneously encourages people to seek out far flung connections—which may or may not be turned back into active relationships. *The point is that they do not have to be.*"³¹⁷

B. *The Implications of the "Genetic Family" and the "Genetic Ethnic Group"*

For members of a genetic family or a genetic ethnic group, the implications of defining people and groups of people

nouncement that a preliminary draft of the human genome had been completed. In 1999, however, it was clear that the announcement was soon to be forthcoming. See, e.g., Justin Gillis, *Gene Map is on Fast Track; Millions in Grants Speed Up Project*, WASH. POST, Mar. 16, 1999, at A19, available at 1999 WL 2205533 (predicting completion of Human Genome Project earlier than 2003, "the previously announced deadline").

³¹⁴ See Burnett, *supra* note 286, at 578 (concluding that the holding in *Safer* does not endanger confidentiality because the doctor/patient relationship has "been reconfigured to reflect the individual's ties to his or her ancestors and descendants").

³¹⁵ FINKLER, *supra* note 48, at 175.

³¹⁶ FINKLER, *supra* note 48, at 206.

³¹⁷ MARILYN STRATHERN, EMERGENT PROPERTIES: NEW TECHNOLOGIES, NEW PERSONS, NEW CLAIMS 23 (draft in possession of author) (emphasis added).

through reference to a genome are startling. Individuality, with all that it implies, is replaced by a notion of persons as indistinguishable from one another, and from the group they compose.

1. The Genetic Family

The family defined through DNA is an amoral unit that contrasts dramatically with both the traditional family of the nineteenth- and early twentieth-centuries³¹⁸ and with the more modern "family-by-choice"³¹⁹ that developed in the second half of the twentieth century.³²⁰ Within the traditional family, the locus of value (and thus of privacy) is a hierarchical, holistic unit, represented by the *pater familias*. Within the more modern "family-by-choice," the locus of value is the individual, who relates to others "as family" because he or she *chooses* to do so (and not because biology and custom define "family").

Within the traditional family, relations of status (delimited largely through differences in gender and age) distinguish individual family members from one another and define their relationships, as well as the manner in which outsiders are expected to interact with family members.³²¹ Within the mod-

³¹⁸ The so-called "traditional" family was constructed in the nineteenth century, largely as a product of industrial capitalism. See JOHN DEMOS, *PAST PRESENT AND PERSONAL: THE FAMILY AND THE LIFE COURSE IN AMERICAN HISTORY* 30-31 (1986).

³¹⁹ See WESTON, *supra* note 9, at 213. Weston concludes that families-by-choice should not be imagined in complete opposition to traditional families. Rather, she explains, families-by-choice "undercut procreation's status as a master term imagined to provide the template for all possible kinship relations." See WESTON, *supra* note 9, at 213.

³²⁰ A fuller consideration of these contrasts is found in Janet L. Dolgin, *Choice, Tradition, and the New Genetics: The Fragmentation of the Ideology of Family*, 32 CONN L. REV. 523 (2000).

³²¹ Throughout the nineteenth- and much of the twentieth-century, family law in the United States reflected this view of family. The law's commitment to safeguarding "family privacy" (generally actualized as the privacy of the family's *pater familias*) represented that position. See, e.g., *McGuire v. McGuire*, 59 N.W.2d 336, 342 (Neb. 1963) (refusing to intervene in dispute between spouses in which wife alleged husband did not adequately provide for her). The law reflected this view as well in medical contexts. Husbands, for instance, were privy to knowledge about their wives. See, e.g., *Tooley v. Provident Life & Accident Ins. Co.*, 154 So.2d 617, 618 (La. Ct. App. 1963) (finding physician and insurance companies not obligated to protect a woman's medical privacy from her husband's purview). The husband, explained the *Tooley* court, is "head and master of the community," and thus, his

ern family, the locus of value is the autonomous individual, whose continued inclusion within the family is viewed largely, though not exclusively, as a matter of choice. Both varieties of family³²² imply a moral frame that establishes rules for governing relationships between family members, and between family members and others. By contrast, the unit of value within the genetic family can variously be identified as individual family members—indistinguishable from one another—or the larger genetic whole, itself defined as indistinguishable from the individuals who compose it. The genetic family, thus described, is an emerging ideological construct.

And at the heart of the construct is the obliteration of privacy. Regardless of how genetic families are delimited and of how relationships within them are actualized, those identified within a genetic family have no clear right to privacy vis-a-vis one another because, from the perspective of the genetic family, they are indistinguishable. For members of a genetic family, privacy is not protected either by the *pater familias*, who safeguarded the communal whole that was the traditional family, or by the *right* of individual family members to *choose* to remain private that pertains within the modern family-by-choice.

Within the genetic family, each unit (each individual) is privileged to learn the others' secrets because each is, in effect, identical to—literally consubstantial with—each other. So, for instance, for Dr. Pack to tell Donna Safer about her father's illness is, in effect, only to tell her about herself. Within the relevant "genetic" frame, nothing distinguishes the daughter from her father. The amorality of the genetic family is implied by a single decisive *fact*: A shared genome. For those identified

wife's medical secrets cannot be private from him. *Id.* Ironically, the court's ruling in *Tooley* helped the husband divorce his wife. See Deftos, *supra* note 268, at 113 (discussing *Tooley*); see also *Curry v. Corn*, 277 N.Y.S.2d 470, 471 (N.Y. Sup. Ct. 1966) (recognizing physician's right to reveal medical information to patient's husband). *Curry* is considered in Deftos, *supra* note 268, at 113.

³²² To some extent, the differentiation suggested here, between traditional and modern families, misleadingly reifies the central dynamic that has defined the family in the West for more than two centuries. Families, in fact, are understood—and openly debated—in light of what society takes to be "traditional" and "modern" options. That notwithstanding, families are defined here as "traditional" and "modern" to more clearly demonstrate the conceptual difference between the genetic family and virtually all other understandings of family.

as belonging to a genetic family, no particular (familial) response is required. Various responses may develop, but the fact of the genetic relationship necessitates none of them. Members of a genetic family may, for instance, love one another and act like social kin, but nothing in the meaning or construction of the genetic family requires that they do so.³²³

As Marilyn Strathern explains, to constitute a genetic family, "nothing else need be known about the relationship between parent and child than the fact that the body of one held or holds information which could be useful to the other."³²⁴ The relational consequences of such information for those labeled as "family" are unspecified, and thus may vary widely.³²⁵ The *fact* of the genetic connection suggests no moral frame within which genetic family members interact. Genetic connections imply nothing about the dimensions of actual relationships among those defined as genetic kin. Kaja Finkler remarks in the conclusion to her study of the medicalization (or, more specifically, the geneticization) of kinship: "To sense that one forms part of a family chiefly because one shares the same genes, requiring no social participation nor sense of responsibility to those who are related except to provide blood samples for testing purposes, removes the moral context of family relationships."³²⁶

Other consequences of defining families through genetic kinship are similarly staggering. For example, the rights and responsibilities that attend the notion of the autonomous individual may be destroyed. More particularly, the individual whose interests are protected in the Bill of Rights may be among the central victims of the construction of a genetic family. As rules of confidentiality can be deemed moot in the context of a genetic family, so rules that protect privacy, equality, and liberty may be rendered irrelevant. Moreover, one does not choose whether or not to affiliate with a genetic family. Thus, the genetic family may eviscerate choice, a central element in the modern family.³²⁷ No one can *choose* to avoid the fact or

³²³ See FINKLER, *supra* note 48, at 57-172 (describing social experiences of members of genetic families).

³²⁴ STRATHERN, *supra* note 317, at 21.

³²⁵ See FINKLER, *supra* note 48, at 57-172 (providing ethnographic description of individual's experience of the "ideology of genetic inheritance").

³²⁶ FINKLER, *supra* note 48, at 206-07.

³²⁷ One may choose to relate to members of one's genetic family in various

consequences of belonging to a genetic family. These implications of the genetic family suggest that the development of an ideology of genetic inheritance may signal a fundamentally new social order within which personhood, as understood within American culture for two centuries, could be utterly transformed.

2. The Genetic Ethnic Group

Ethnic and racial groups may also be profoundly affected by the notion of a genetic family. Throughout American history, these groups, understood as socially constructed, have, like families, been described through metaphors of natural substances such as blood.³²⁸ In a universe that delimits people through genes, the ideology of the genetic family is mirrored in the ideology of other groups, delimited through reference to natural substance. In all these cases, many of the social implications of geneticization stem from a focus on natural substance (DNA) to the exclusion of social and behavioral correlates that might channel the implications of relationship-through-DNA.

In addition, the notion of genes, not only as substance—"stuff" that gets "passed down" from ancestors to descendants or that is "shared" among them—but as information,³²⁹ encourages depersonalization. Thus, as a practical matter, members of genetic families and genetic ethnic groups are liable to be viewed, especially by those outside the group, less as individuals and more as reflections of a larger genetic group.

The risks of geneticization, for both families and ethnic groups, follow directly from the same ideological shift. That shift encourages the view that people, individually and in groups, can be defined by a natural substance that provides decisive genetic information (i.e., DNA). However, the specific

ways, or not to relate to them at all. However, one cannot choose to disassociate oneself from identification with the unit; one cannot reject inclusion within a genetic family.

³²⁸ See *supra* notes 247-253 and accompanying text (noting Schneider's description of American ideology that encompasses various types of communal relationships).

³²⁹ See STRATHERN, *supra* note 317, at 19.

risks posed by the geneticization of family identity differ from risks posed by the geneticization of ethnic identity. For instance, genetic families face the collapse of a system of social presumptions and legal rules that have protected privacy in general, and confidentiality in medical settings, more particularly. In contrast, members of genetic ethnic groups are especially vulnerable to the abuse of genetic data to justify old and new prejudices about them.³³⁰

Despite these differences, the risk to each sort of group follows from the definition of group members as effectively indistinguishable from one another, and from the larger whole.³³¹ The *Safer* court premised Donna Safer's right to learn about her father's medical condition on the consubstantiality of father and daughter. The same premise is likely to harm ethnic or racial groups, defined through genetic information.

The proliferation of data suggesting the comparative genetic homogeneity of particular American ethnic groups encourages members of such groups to view themselves, and encourages outsiders to view them, as reflections of one another and of the larger whole.³³² Such a view can justify, and thus strengthen, historic prejudices. The process actually predates the decoding of the human genome and the identification of specific genetic alterations associated with disease, because it has been possible for several decades to detect carriers of a number of genetic disorders. But the likely proliferation and increased reliance on genetic testing in the next decade intensifies concern.

³³⁰ Moreover, as a statistical matter, the potential medical advantages said to justify the revelation of genetic information within family contexts are less certain to pertain within ethnic contexts. See, e.g., Brownrigg, *supra* note 286, at 248 (noting potential medical benefit to children from information about a parent's hereditary condition); Burnett, *supra* note 286, at 560 (noting possible therapeutic advantages of genetic information).

³³¹ See *supra* notes 260-285 and accompanying text (delineating implicit assumptions about genetic families in *Safer v. Pack*, 677 A.2d 1188, and in other texts).

³³² This vision may not be erased by other evidence, likely to be presented, that members of human groups, defined in ethnic and racial terms, are quite similar from a genetic perspective. See, e.g., Erhart, *supra* note 187. Mark Erhart is identified as a professor of molecular biology at Chicago State University.

An early example of genetic discrimination is revealing. In the 1970s, African-Americans were screened by the government and private industry for the sickle-cell trait.³³³ As a consequence, the United States Air Force Academy excluded African-Americans who tested positive for the sickle-cell trait from programs that trained pilots. The Academy feared, as it turned out erroneously, that such people were likely to become ill at high altitudes.³³⁴

At present, most genetic data presumed to describe ethnic groups concerns genetic alterations that predispose people to illness.³³⁵ As a result, those identified with such groups risk being portrayed as physically marginal and potentially deformed. The example of the African-American cadets is revealing because it indicates that even well-intentioned policies based on the correlation of genetic information and race (e.g., to protect *the pilots themselves* as well as those who could suffer harm by a pilot's becoming ill during flight)³³⁶ can reflect institutional racism and engender new forms of discrimination.³³⁷ Moreover, geneticists promise soon to identify genetic alterations associated with mood, intelligence, mental illness, creativity, addiction, and character.³³⁸ Should that happen,³³⁹ the potential abuse of genetic information will expand exponentially.

³³³ See *supra* notes 186-190 and accompanying text.

³³⁴ See Melinda B. Kaufman, *Genetic Discrimination in the Workplace: An Overview of Existing Protections*, 30 LOY. U. CHI. L.J. 393, 403 n.71 (citing Patricia A. King, *The Past as Prologue: Race, Class, and Gene Discrimination*, in GENE MAPPING 94, 98 (George J. Annas & Sherman Elias eds., 1992)); see also Pugh, *supra* note 187.

³³⁵ See *supra* notes 38-47 and accompanying text.

³³⁶ Although the policy may have been well-intended when instituted, it was maintained until 1981, even though by 1974 adequate evidence had accumulated to disprove the presumed correlation between the sickle-cell trait and risk of becoming ill at high altitudes. See Kaufman, *supra* note 334, at 403 n.71.

³³⁷ Hannah Bradby, *Genetics and Racism*, in THE TROUBLED HELIX: SOCIAL AND PSYCHOLOGICAL IMPLICATIONS OF THE NEW HUMAN GENETICS 295, 296 (Theresa Marteau & Martin Richards eds., 1996) (noting the difficulty of identifying racism in cases in which "the expressed intention of the policy is not racist but the effect is to disadvantage one or more racialized groups").

³³⁸ NELKIN & LINDEE, *supra* note 49, at 9 (claiming many scientists believe genetic alterations will be found for "complex, socially important human traits").

³³⁹ Erica Goode, *Most Ills Are a Matter of More Than One Gene*, N.Y. TIMES, June 27, 2000, at F1 (describing difficulty of identifying genetic alterations associated with mental illnesses).

The hazards of society's increasing reliance on genetic information are clear, especially for groups that have historically been subjected to social marginality and discrimination. Genetic information, associated with groups (e.g., African-Americans and Jews) already defined prejudicially through reference to somatic traits, can be used to reinforce negative images of such groups, and to construct new ones, and thus to justify discrimination against those identified with them. Genetic information, as data, is likely to be many times more powerful as a social tool than the sort of data that was relied upon by nineteenth- and early twentieth-century German scientists and physicians to justify disparaging Jews—reports, for instance, of the flat Jewish foot.³⁴⁰

The stigmatizing use of genetic information to create or reinforce dehumanizing images of ethnic groups may be harder to protect against than the more concrete (and more frequently noted and discussed) dangers of discrimination, especially in institutional contexts. American law has widely prohibited government and various private groups, such as employers, from discriminating against people defined through reference to somatic traits. But the legal system is far less effective at combating stigmatization—the elaboration and communication of prejudicial images of, or speech about, groups defined as different from, and less adequate than, mainstream social groups.³⁴¹

A second, even greater danger may attend the construction of ethnic groups defined through genetic information. This danger could threaten even the social and legal mechanisms that now limit social discrimination. Shifts in the understanding of personhood that attend the construction of genetic families or genetic ethnic groups could, especially if widely institutionalized, portend even greater shifts in understandings of people, and of relationships among people.

The notion of a genetic group, composed of a potentially unlimited number of units, each defined through DNA, threatens ultimately to subordinate the interests of the individual to those of the whole. The French Indologist Louis Dumont described that possibility to “result[] from the attempt, in a soci-

³⁴⁰ See *supra* notes 236-243 and accompanying text.

³⁴¹ See *supra* notes 92-96 and accompanying text.

ety where individualism is deeply rooted and predominant, to subordinate it to the primacy of the society as a whole."³⁴² That construction of personhood and of the relation between people within the larger whole has been prized by theorists of social fascism.³⁴³ In fascist theory, the individual is valuable only as a reflection of the greater, national whole.³⁴⁴

The development in America of such a view of the individual—in effect, the submersion of individual identity as the autonomous individual is defined as isomorphic with, and is thus displaced by, larger groups defined through reference to genetic information—would threaten, at their core, the democratic values that now undergird virtually all efforts to protect against discrimination based on race or ethnicity. And it could happen, if Americans generally resolve to define ethnic groups in genetic terms. An unmarked gene would be defined as "normal," and those who failed, in various specific ways, to conform to the genetic map of the "normal," would be marginalized.

Neither equality nor liberty would long survive such a reconceptualization of the social order, for it would displace concern for the person with concern for an undifferentiated, unmarked social whole that would, by its very terms, exclude all those defined as genetically "Other."

CONCLUSION

The genetic family, suggested by *Safer*, and the genetic ethnic group, both defined only through reference to indifferent DNA, are constructs that exist outside of time and history. Within both, relationships are expected to resemble the genes

³⁴² DUMONT, *supra* note 250, at 12 (emphasis omitted).

³⁴³ These theorists include Hitler and Mussolini and their "philosophical progenitors" Rousseau, Fichte, and Nietzsche. See BERTRAND RUSSELL, HISTORY OF WESTERN PHILOSOPHY 755 (1961); see also EBERHARD JACKEL, HITLER'S WORLD VIEW: A BLUEPRINT FOR POWER 87 (Herbert Arnold trans., 1972) (noting that notions of "folk" and race were central to Hitler's ideology); MARTIN GILBERT, THE EUROPEAN POWERS 1900-1945 146 (1965) (characterizing Mussolini's fascism to have "elevated the state to the level of a deity").

³⁴⁴ See JACKEL, *supra* note 343, at 88 (explaining that "for Hitler, the bearers and the elements of history are people and races, not—as in other views of history—individuals, classes, cultures, or anything else" and further that for Hitler, history was understood as "the unfolding of the struggle for life or death of peoples and races, i.e., of ethnic background, not of social-economic groups").

that define their parameters, and therefore to be essentially amoral.

However, in contexts defined through genetic information, as in other contexts, people continue to experience themselves and their relationships *in time and in history*, and they continue, more or less intensely, to endow those relationships with meaning and with moral value. The actual experiences of people defined as part of groups delimited through reference to DNA result from a vast array of cultural presumptions that shape—and are shaped by—the construct of the genome that defines them.³⁴⁵

Thus, in theory, the proliferation of genetic information and the geneticization of identity do not inevitably portend essential and deeply discomfoting shifts in the meaning of personhood and the scope of relationships within larger, genetic groups. And in practice, many of the existing and proposed statutes aimed at avoiding or limiting the negative consequences of the new genetics simply presume a democratic system within which the autonomous individual remains the agent of social action and within which the rights of that individual must be protected.

Thus, developments in genetic information do not necessarily augur the decline of democracy in American society. They should, however, prompt due vigilance for several reasons. First, as a practical matter, it may be harder to preclude genetic discrimination and to protect genetic privacy than the statutory structures already erected by many states, and being proposed in the federal and state legislatures and in scores of law review articles, might suggest. The facility with which society can now collect and disseminate information of all sorts broadly challenges modern notions of individual privacy. Moreover, the legislative effort to protect privacy and preclude discrimination is hedged by a sense that the use of genetic information by employers, insurers, or others may often be rational, and thus equitable.³⁴⁶ Even more, American law is unlikely,

³⁴⁵ Kaja Finkler's *EXPERIENCING THE NEW GENETICS* provides a pioneering account of "the complexities [of each person's] construal of lived realities" within the context of genetic families. FINKLER, *supra* note 48, at 16.

³⁴⁶ See *supra* note 58 and accompanying text; see also Mary Terrell White, *Underlying Ambiguities in Genetic Privacy Legislation*, 3 *GENET. TEST.* 341, 344 (1999).

and as presently constituted largely unable, to dispel stigmatizing, dehumanizing images of groups defined through a mapped genome.

These practical concerns intensify when the genetic group is considered as an aspect of the ideology of genetic inheritance. The depersonalization implied by the notion of a genetic group abets the development of stigmatizing images, even when malicious intention is absent. Similarly, and even more important, the genetic group, as social construct, expressly displaces the individual as the agent of social action and as the unit of social value with the larger, unstructured, essentially amoral whole. That construct, widely validated, would undermine the very idea of privacy or equality as valuable, and could thus disrupt or completely halt efforts to protect privacy and to preclude or limit genetic discrimination.

In short, the decoding of the human genome and the proliferation of genetic information constitute a serious challenge to existing understandings of personhood and of the scope of relationships among people within groups defined through DNA. How society responds to that challenge will significantly affect the social order within which the consequences of the "new genetics" will unfold.