

2001

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Recommended Citation

Janet L. Dolgin, *Ideologies of Discrimination: Personhood and the 'Genetic Group'*, 32 Stud. Hist. Phil. Biol. & Biomed. Sci., 705 (2001)
Available at: https://scholarlycommons.law.hofstra.edu/faculty_scholarship/218

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Ideologies of Discrimination: Personhood and the ‘Genetic Group’

*Janet L. Dolgin**

‘Ideologies of Discrimination’ considers the implications of the new genetics for understandings of personhood and for understandings of the relationship between people in groups. In particular, the essay delineates and examines the emerging notion of a ‘genetic group’ and considers the social implications of redefining families, racial groups and ethnic groups through express, and often exclusive, reference to a shared genome. One consequence of such redefinition has been the justification and elaboration of stigmatizing images of and discrimination against such groups—especially those, such as Jews and African-Americans, that have long been identified with specific somatic characteristics. A few worrisome trends begin to emerge in the response of the American legal system to the notion of genetic groups. Among these is a shift in the locus of privacy and identity from the autonomous individual to the genetic group. This shift challenges (and threatens) long-standing Western values (including equality and liberty) that depend upon the ideological centrality of autonomous individuality. © 2001 Elsevier Science Ltd. All rights reserved.

Keywords: Discrimination; Family; Genetic Group; Genome; Jews; Law; Privacy.

1. Introduction

For at least two centuries, the public order in the United States has been premised on the notion of the autonomous individual as the locus of value and the agent of social action. For most of that period, the private order—the domain of home and family—has been defined by a more complicated dynamic within which the notion of the autonomous individual has competed with, and provided a model against which to measure, an alternative vision of personhood and of relationships. For most of American history, that alternative vision was valued in domestic contexts, and the open incursion of the autonomous individual into the home was feared. In fact, however, personhood within the home—the person as exemplar of a status within a hierarchically structured whole—was long molded and defined in contrast with, and thus with express reference to, the autonomous individual that defined

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the domain of the marketplace. Until the last decades of the twentieth century, 'home' was expected to contrast broadly with 'work'. Then, beginning in the 1960s, American society began widely to reconstruct traditional understandings of family to accommodate autonomous individuality and choice.

More recently, another vision of personhood is being elaborated in the context of the new genetics and its institutional correlate, the Human Genome Project. More particularly, the notion of the 'human genome', the proliferation and communication of genetic information, and the increasing availability of tests indicating genetic alterations associated with illness encourage a novel vision of personhood and of relationships among people in groups.

In theory, this new vision and the postulates about personhood on which it rests, have assumed importance in only a few, clearly delimited contexts. In fact, however, these contexts begin inevitably to merge with others. As a result, postulates about personhood being constructed around the new genetics have far-reaching implications.

This essay concentrates on shifts in social understandings of groups emerging in contexts defined through reference to genetic information. First, the essay considers the development of both genetic discrimination and stigmatization in the U.S. and the law's fledgling responses. Then the essay describes the notion of a 'genetic' family, as it is being developed by judges, lawyers, geneticists and others concerned with the implications of genetic information. Next, the analogous notion of a 'genetic ethnic' or 'genetic racial' group¹ is described. The potential for genetic information to create or elaborate prejudicial images of people is considered concretely through the example of Ashkenazi Jews.² Jews, long identified in the West through reference to somatic characteristics, have submitted often and willingly to genetic screening and research programs in the last few decades. As a result, they are now associated with a disproportionate number of genetic alterations known to predispose people to serious illnesses. Finally, the essay considers various social implications of re-defining families as well as ethnicity and race through reference to mapped genomes, and suggests that long-standing Western values are directly challenged by a view that submerges the autonomous individual to the primacy of the genetic group.³ Those values, virtually all forged during the early years of the Enlightenment, molded by the Industrial Revolution, and reflected clearly in the

¹As used in this essay the terms 'ethnic' and 'race' or 'racial' refer to social, not biological, constructs. Within the American context, groups defined as 'ethnic' differ from those defined as 'racial' on the basis of the consistency and force with which those identified with the group are excluded from enjoying social and economic resources (Dolgin, 1977, p. 145). In the U.S., African-Americans have been treated in racial terms more often, and more harshly, than other groups. Unless otherwise indicated, this essay employs the term 'ethnic' to refer both to 'ethnic groups' and 'racial groups'.

²The term 'Ashkenazi' refers to Jews who settled in Europe and Russia. About 82% of the world's Jewish population is of Ashkenazi origin (Markel, 1997, p. 50). Unless otherwise indicated, this essay uses the term 'Jew' to refer to Jews of Ashkenazi origin.

³See *infra*, notes 51–52 and accompanying text (noting Louis Dumont's description of a similar process in another context).

Bill of Rights and in later amendments to and interpretations of the U.S. Constitution, depend on the notion of the individual person as worthwhile and distinct.

2. Genetic Discrimination and Stigmatization

Lawrence Gostin defines 'genetic discrimination' as 'the denial of rights, privileges or opportunities on the basis of information obtained from genetically-based diagnostic and prognostic tests'.⁴ The term 'genetic stigmatization', as used in this essay, refers to the creation of prejudicial, generally dehumanizing images of, or speech about, an individual or a group through reference to genetic information. In practice, genetic discrimination and genetic stigmatization merge.

Genetic discrimination can affect individuals as such or individuals as members of groups. Employers have refused to hire, and insurers to cover, individuals who test positive for harmful genetic alterations as well as individuals identified, through familial or ethnic associations, with groups linked with particular genetic alterations. One study, carried out almost a decade ago, reported numerous instances of discrimination, especially in insurance and employment contexts, against individuals who tested positive for genetic alterations associated with illness. Some of those who suffered discrimination were carriers, at no risk of becoming ill with the condition in question.⁵ A more recent survey of people at risk of developing a genetic illness identified 200 cases of genetic discrimination among 917 respondents.⁶ A 1998 U.S. government report concluded that '[g]enetic predisposition or conditions can lead to workplace discrimination, even in cases where workers are healthy and unlikely to develop disease or where the genetic condition has no effect on the ability to perform work'.⁷ Other reports indicate genetic discrimination in an even wider variety of contexts. Genetic information can influence institutional and legal decisions about parental rights, criminal sentencing and parole status.⁸

Some cases of genetic discrimination have developed from screening or research projects that focused on members of particular ethnic groups. In the 1970s, over a decade before the initiation of the Human Genome Project, the U.S. Congress passed a law that financed and encouraged states to screen African-Americans for the sickle-cell trait.⁹ Although African-American groups had originally lobbied in favor of the legislation, they were dismayed by the consequences, which included about a dozen states, mostly in the south, making receipt of marriage licenses and

⁴Gostin (1991), p. 110.

⁵Billings *et al.* (1992), p. 478.

⁶National Human Genome Research Institute (1998).

⁷The report was produced jointly by the Department of Labor, Department of Health and Human Services, Equal Employment Opportunity Commission and the Department of Justice (National Human Genome Research Institute, 1998).

⁸Stolberg (1994), p. A1.

⁹National Sickle Cell Anemia Control Act, 42 U.S.C. Secs. 300(b)(1) *et seq.* The Act was passed in 1972, as an amendment to the Public Health Service Act (Public Law 92-294). It was amended in part and repealed in part in 1981, Omnibus Budget Reconciliation Act, 95 Stat. 827 (1981).

admission to primary school dependent on sickle-cell screening. Moreover, in the 1970s, the Air Force Academy barred African-Americans who tested positive for the sickle-cell trait from participating in pilot training programs because of a belief, ultimately proven erroneous, that they were likely to become ill at high altitudes.¹⁰

The case suggests the coalescence, in practice, of genetic discrimination and genetic stigmatization. The association between African-Americans and sickle-cell anemia was used to reinforce existing racism and to justify discriminatory policies. In the end, the African-American community felt betrayed by the management of state-sponsored screening projects for the sickle-cell trait and by unsupported suggestions by scientists that carriers were hyper-sensitive to a series of workplace toxins.¹¹ African-Americans have resisted participation in further genetic testing and screening programs. The case suggests that statistical associations between harmful genetic alterations and ethnic groups can lead to discrimination (sometimes simply in the form of mandatory testing). Such discrimination may be fueled by existing prejudices and may, in turn, rekindle old prejudices with new evidence of group marginality.

As genetic testing becomes more common and less expensive, genetic discrimination and stigmatization will likely occur more frequently. The specter of genetic discrimination suggests that participation in genetic screening and testing programs can be economically and socially hazardous.¹² Researchers and industry representatives are concerned that people will increasingly refuse to participate in genetic research and screening. Indeed, Francis Collins, Director of the Human Genome Research Institute, has encouraged legislators to assist genetic research by calming popular fears about potentially invasive and discriminatory uses of genetic information.¹³ U.S. lawmakers have begun to respond to concerns about the invasion of genetic privacy and about discriminatory uses of genetic information. The results are inconsistent and inadequate. There is only one federal statute that responds directly to concerns about the use of genetic information. That law, the Health Insurance Portability and Accountability Act of 1996¹⁴ prohibits insurance companies from relying on genetic information to establish eligibility for health insurance coverage. However, the statute does not define 'genetic information', and thus leaves open the possibility that insurers can refuse coverage on the basis of information obtained through medical histories. Moreover, the statute does not prohibit insurance companies from raising rates or excluding coverage completely for parti-

¹⁰Kaufman (1999), n. 72.

¹¹Rhodes (2000), p. 118; Pugh and Ridder (1998).

¹²In contrast, some social commentators suggest that genetic discrimination is 'rational' and will therefore not stimulate or exacerbate racial or ethnic discrimination. Andrew Sullivan, writing in a recent issue of the *New York Times Magazine*, explained that '[t]he point of laws against racial bias is to outlaw irrational discrimination based on irrelevant characteristics. The point of laws against genetic discrimination is to outlaw rational bias based on relevant information' (Sullivan, 2000, p. 16).

¹³Mansoura and Collins (1998) p. 344, citing Collins (1997).

¹⁴Health Insurance Portability and Accountability Act, Pub. L. No. 104-191, 110 Stat. 1936 (1995) (codified in scattered sections of 29 U.S.C., 42 U.S.C., 26 U.S.C. and 18 U.S.C.).

cular conditions. And the statute does not, and was not intended to, protect against genetic discrimination outside the context of health insurance.

The majority of states have laws aimed at prohibiting genetic discrimination or at safeguarding genetic privacy, but many of these statutes provide only limited protection and suffer from limited applicability. A few state statutes protect only against genetic discrimination involving specific illnesses.¹⁵ Others provide broader protection, but even the most comprehensive of the state laws¹⁶ are inapplicable to self-funded health plans.¹⁷

Virtually all the laws that have been promulgated to channel the uses of genetic information either protect genetic privacy or limit genetic discrimination, but do not expressly preclude the use of genetic information to develop stigmatizing images of groups. That task is generally beyond the scope of the American legal system. Indeed, American constitutional law, unlike that of many other nations, largely precludes laws prohibiting group libel on the ground that such laws would violate the right to free speech. Professor David Richards, in support of this rule, comments that '[p]rotecting the rights of the speakers and speech we hate affirms the deeper fraternal bonds of a political community based on universal human rights'.¹⁸ Ironically, however, those bonds and the rights on which they are presumably based could themselves be threatened by the ideological construction of genetic groups, especially if that construction undermines the notion of the autonomous individual as the locus of social value.

The notion of genetic groups—especially of the 'genetic family'—takes form in U.S. courts of law, asked to resolve disputes about genetic information, in the official statement of at least one American professional association concerned with the ethics of professionals' disclosing or refusing to disclose genetic information about clients, and, even more self-consciously, in the commentaries of legal theorists.

3. Genetic Families

The notion of a genetic family eclipses both the notion of the autonomous individual that anchors the construct of the modern family-by-choice and the notion of the hierarchically structured community that anchors the construct of the traditional family.

¹⁵See, for example, La. Rev. Stat. Ann. Sec. 22:652.1 (West 1995); Tenn. Code Ann. Sec. 56-7-207 (Supp. 1997).

¹⁶See, for example, New Jersey Genetic Privacy Act, N.J. Stat. Ann. 17B:30-12 (West 1996).

¹⁷Under the Employee Retirement Income Security Act of 1974 (ERISA), federal law preempts state law with regard to such plans. Pub. L. No. 93-406, 88 Stat. 829 (1974).

¹⁸Richards (1999), p. 821.

3.1. Constructing the Genetic Family

The parameters and ramifications of the 'genetic family' are suggested by two legal cases, both decided in the 1990s. In the first of these cases, *Pate v. Threlkel*,¹⁹ the Florida Supreme Court found an exception to the general rule that a professional can only be sued for malpractice by someone in a relation of legal privity with that professional. The court granted Heidi Pate standing to sue Dr. James Threlkel. Dr. Threlkel had treated Heidi Pate's mother, Marianne New, for medullary thyroid carcinoma. Pate argued, and the court agreed, that Threlkel was obligated to warn New of the implications for New's children of her hereditary condition. The court explained:

[W]hen the prevailing standard of care creates a duty that is obviously for the benefit of certain identified third parties and the physician knows of the existence of those third parties, then the physician's duty runs to those third parties. Therefore, . . . we hold that privity does not bar Heidi Pate's pursuit of a medical malpractice action . . . [U]nder the duty alleged in this case, a patient's children fall within the zone of foreseeable risk.²⁰

Thus, the court allowed Pate to proceed with her case. But it refused to impose a duty on the doctor to provide genetic information about his patient directly to the patient's child or to other similarly situated third parties. The doctor's duty to warn about the hereditary implications of New's condition extended only to New, herself. 'To require the physician', explained the court, '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'.²¹

Yet, in 1996, a New Jersey appellate court concluded that a physician might be required to do just that. The facts that occasioned *Safer v. Pack* resemble the facts of *Pate*.²² In 1990, Donna Safer, then thirty-six years old, was diagnosed with a hereditary form of colon cancer.²³ Twenty-six years earlier, when Donna was ten, her father, Robert Batkin, died of the same condition. In 1992 Donna commenced suit against Dr. George Pack,²⁴ who had treated Donna's father from the time that Batkin was diagnosed with colon cancer in 1956 until his death in early 1964. Donna argued, first, that she had standing to sue Pack, despite never having been his patient, and, second, that Dr. Pack's duty to warn extended beyond Pack's

¹⁹661 So.2d 278 (Fla. 1995).

²⁰661 So.2d at 282.

²¹661 So.2d at 282.

²²*Safer v. Pack*, 677 A.2d 1188 (N.J. Super. 1996). The trial court had dismissed plaintiffs' complaint. The appellate court reversed the order dismissing the complaint, and thus sent the case back for a trial on the merits.

²³The pathology report, done after Robert Batkin's first operation for colon cancer in 1956, concluded that he had adenocarcinoma 'with diffuse intestinal polyposis'. Dr. Pack noted this finding in his discharge summary. Polyposis is a hereditary condition which leads to colon cancer (Amended Complaint, *Safer v. Pack*, 667 A.2d 1188, at 4, 7; filed Dec. 10, 1992). I am grateful to Gary Maher, attorney for plaintiffs Donna and Robert Safer for sending this complaint to the Hofstra Law Library.

²⁴Actually, Donna sued George Pack's estate, since Pack had died in 1969 (677 A.2d at 1190). Donna's husband, Robert Safer, joined Donna in initiating the suit.

patient, Robert Batkin, to Batkin's daughter, Donna Safer, at least through Ida Batkin, Safer's mother and Robert Batkin's wife. Ida Batkin testified that neither her husband nor Dr. Pack had ever informed her about the hereditary implications of her husband's illness. Rather, she testified that Dr. Pack variously informed her that her husband suffered from a 'blockage' or an 'infection'. Ida Batkin further testified that when she inquired as to whether the illness could affect her children, she was told 'not to worry'.²⁵

The New Jersey appellate court accepted both of Donna's arguments. By 1996, a number of courts in New Jersey and elsewhere had concluded that the right to sue in duty-to-warn cases was not premised on the plaintiff's having been in a relation of privity with the defendant. Not only had the Florida Supreme Court decided *Pate v. Threlkel* a year earlier, but in the previous two decades a growing number of state courts had found exceptions to the traditional rule that limited plaintiffs in medical malpractice cases to people who had themselves been patients of the defendant.²⁶

Donna's second argument—that Dr. Pack was obliged to warn not only his patient but his patient's child (presumably by informing that child's mother, perhaps after Robert Batkin's death) about the hereditary implications of Batkin's illness—was more controversial. A 1981 New Jersey malpractice case that involved a hereditary disorder provided some support. In *Schroeder v. Perkel*,²⁷ the New Jersey Supreme Court imposed a duty to warn that resembled the duty that Donna Safer asked the state appellate court to impose. *Schroeder* was initiated by Marion and John Schroeder, who argued successfully that the pediatricians of their young daughter, Ann, were negligent in failing to warn them that Ann suffered from a hereditary condition (cystic fibrosis) that could affect a subsequent child. The Schoeders, unaware of the nature of Ann's illness, had had a second child who, like his older sister, suffered from cystic fibrosis. The pediatricians who had treated Ann Schroeder argued that they owed no duty to their patient's parents that extended beyond their duty to the patient herself. The court disagreed:

A physician's duty thus may extend 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. Here, the physicians had not only a duty to Ann, but an independent duty to Mr. and Mrs. Schroeder to disclose to them that Ann suffered from cystic fibrosis . . . The defendants should have foreseen that parents of childbearing years, such as Mr. and Mrs. Schroeder, would, in the absence of knowledge that Ann suffered from cystic fibrosis, conceive another child.²⁸

²⁵677 A.2d at 1190.

²⁶The first such case, decided in California in 1976, imposed a duty on a psychotherapist to warn a patient's intended murder victim of the risk. (*Tarasoff v. Regents of the University of California*, 551 P.2d 334 (Cal. 1976). In 1993, the highest court in Tennessee required a doctor to warn a patient's wife that she was at risk for becoming ill with rocky mountain spotted fever from which her husband was suffering. The 'duty to warn' cases are reviewed in Defetos (1999), pp. 111–29.

²⁷433 A.2d 834 (N.J. 1981).

²⁸432 A.2d 834, 839–40.

Although the decision imposed a duty on physicians to warn family members of the hereditary character of a patient's illness, the court's holding reflects common-sensical understandings of a pediatric practice which routinely involves physicians' discussing a patient's health with parents of the patient. Certainly, *Schroeder* raised no issues about Ann Schroeder's right to medical confidentiality. In contrast, Donna Safer asked that a physician be legally obligated to disclose information about his patient's condition with that patient's *child*.

The *Safer* court cited *Schroeder* approvingly, but did not discuss the broad differences between the two cases. The court simply noted:

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.²⁹

Judge Kestin, who wrote the opinion for the court, delimited a number of issues that would presumably have to be resolved at trial.³⁰ Among them was the effect of a directive (if such existed) from Robert Batkin that Dr. Pate not discuss the hereditary implications of his condition with family members. In general, the court did not foreclose the possible imposition of a duty on a physician to warn family members about the genetic implications of a patient's illness, even in contravention of the patient's preference. The court suggested that the law might impose a duty to reveal in such circumstances 'after the patient's death where a risk of harm survives the patient'.³¹

Safer suggests a far-reaching reconstruction of the locus of family privacy. A similar position has been suggested by the American Society of Human Genetics (ASHG), which proposed granting health care workers the 'discretionary right' to contravene rules that normally protect patient confidentiality in a set of cases involving 'familial' conditions.³² The ASHG *Statement* asserts that 'genetic information is both individual and familial'. Thus, 'depending on the circumstances', the *Statement* concludes, 'the health-care professional may have a privilege to warn at-risk relatives'.³³

²⁹677 A.2d at 1192.

³⁰The case was tried before a jury in late 1999. At trial, Donna Safer lost. No written decision was handed down by the trial court, but Gary Maher, one of the plaintiffs' attorneys explained that the decision apparently rested in large measure on the conclusion that Donna Safer or her mother, did, in fact, know about the hereditary implications of Robert Batkin's illness (information from Gary Maher to Connie Lenz, Assistant Director, Maurice A. Deane Law Library, Hofstra University School of Law, described in e-mail, dated 10/6/99, in file of author). The appellate court decision had noted this possibility. 'We note', the court wrote, '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'. 677 A.2d at 1193.

³¹677 A.2d at 1193.

³²American Society of Human Genetics Social Issues Subcommittee on Familial Disclosure (1998).

³³ASHG Statement, at p. 482. More fully, the *Statement's* conclusion reads:

At the very least, it is clear that a health-care professional has a positive duty to inform a patient about potential genetic risks to the patient's relatives. Then, depending on the circumstances, the health-care professional may have a privilege to warn at-risk relatives if the harm is serious, imminent, and likely; if prevention or treatment is available; and if the health-care professional, if she or he were in similar circumstances, would disclose.

More strongly still, a number of recent commentaries in law reviews have concluded that, in cases involving genetic illnesses, 'the patient' includes not only the ill individual but others in the patient's family who could be at risk of developing the same condition. So, for instance, Robert Wachbroit expressly redefines 'patient' in such circumstances:

Allowing for the possibility that the patient may be more than just an individual does not amount to jettisoning the duty of medical confidentiality . . . The 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.³⁴

Similarly, a 1999 law review *Comment* defines the genetic family to subsume the identity of individual family members and therein dismisses concern that a health worker's disclosing genetic information to a patient's family members would inappropriately interfere with the patient's right to privacy.

Confidentiality [in genetic contexts] 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 . . . [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.³⁵

Thus, the *Comment* suggests that established rules of confidentiality, and presumably rules that protect privacy more generally, are inapplicable to a universe in which the autonomous individual is effectively replaced by the larger, unstructured genetic group. That position reflects the assumptions that informed the *Safer* court when it delineated a duty to disclose genetic information to a patient's genetic family. In the implicit view of the *Safer* court, to require Dr. Pack to tell Donna Safer about her father's illness was, in effect, only to require Dr. Pack to tell Donna Safer about herself. That view of familial identity does not harmonize with understandings of personhood and of relationships within either traditional families or modern families.

3.2. 'Traditional' Families, 'Modern' Families and the Genetic Family

The implications of the genetic family become clear in express comparison to both 'traditional' and 'modern' understandings of family. Despite marked differences between notions of traditional families and modern families, both notions depend on a set of essential assumptions about the centrality of the autonomous

³⁴Wachbroit (1999), pp. 1395–6.

³⁵Burnett (1999), pp. 577–8 (emphasis added).

individual in contemporary life. For traditionalists, the family is, and should be, defined in *express* contrast to the autonomous individual, who populates the marketplace. For those favoring 'modern' families, the person-at-home resembles the person-at-work in being the arbiter and agent of social action. Indeed, for almost two centuries—and more self-consciously and volubly within the last half century—a public debate about family within the U.S. has questioned the rigidity of tradition in the name of choice, and the flexibility of choice in the name of tradition. The debate, as Professor Marilyn Strathern insightfully suggests, has resulted in an apparent paradox. Society is characterised by 'both *more* tradition and *more* modernity at the same time'.³⁶

From the early years of the American Republic until the second half of the twentieth century, definitions of personhood and of relationships within families were forged in clear, almost self-conscious contrast with the world of the marketplace, created by the Industrial Revolution. Within family contexts, American society valued the status-oriented, hierarchically organized familial whole rather than the autonomous individual, *per se*. In consequence, relationships within families, unlike relationships within most social and economic domains, were not expected to be egalitarian. Largely determined by age and gender, family roles were defined in terms of status, and familial relationships were understood ideally as sentimental and enduring.³⁷

This so-called 'traditional' family, though distinct from the world of the marketplace in most regards, was a product, and thus an ideological correlate, of that world. The differences between 'home' and 'work' served among other things to justify the division of labor and differences in opportunity that kept women at home, caring for hearth and kin, while their children, beginning in the early decades of the nineteenth century, attended school and their husbands left home each day to labor in the market.

The 'family-by-choice'³⁸ that emerged clearly in the last decades of the twentieth century—and that was developing less publicly for over a century and a half—contrasted sharply with the traditional family in that it posited *choice*, rather than inexorable biological truth, to be the central determinant of domestic relationships. Despite that difference and others, the 'family-by-choice' and the traditional family represent aspects of one ideological frame that has defined and delimited the scope and parameters of family life for most of American history.

The emergence of the construct of the genetic family challenges the presumptions undergirding tradition and modernity alike. The unit of social value assumed by the *Safer* court was neither the traditional, holistic family nor the autonomous

³⁶Strathern (1996), p. 45.

³⁷David M. Schneider described the forms that defined the American family in the middle decades of the twentieth century, just before the 'traditional' family was challenged by alternative understandings of family (Schneider, 1968).

³⁸Kath Weston relies on the notion of choice to describe a variant of 'modern' families (Weston, 1991).

individual whose familial identity is understood as essentially a matter a choice. Rather, the court understood the unit of social value, defined through reference to mapped DNA, as the undifferentiated genetic family that included father and daughter, alike. That unit is indifferent to notions of hierarchy, holism and loyalty that define relationships within traditional families and to notions of personal privacy, equality and choice that define relationships within the modern family-by-choice.

4. Genetic Ethnic Groups

Throughout American history, ethnic groups, like families, have been described through metaphors of natural substance. Yet, as the geneticization of families transforms the scope of relationships and identity within domestic settings, the geneticization of ethnic groups—especially through the association of such groups with harmful genetic alterations—transforms the parameters of ethnic identity. Moreover, the geneticization of ethnic identity produces new data that can be used to justify the social marginalization of ethnic groups defined through reference to genetic information.

The proliferation of genetic information and the association of harmful genetic alterations with groups traditionally defined through reference to somatic traits pose a series of interconnected concerns that overlap with, while differing from, concerns about the implications of genetic families. First, the process of geneticization can justify discrimination, thereby limiting access to various social and economic resources for those identified with genetic ethnic groups. Second, geneticization can encourage the elaboration of stigmatizing group images. Third, and more broadly, the generalization of an ideology that assesses people through reference to a 'human genome' can undermine established social mechanisms most suited to limit genetic discrimination.

The case of Ashkenazi Jews is illuminating. This group—understood variously as a religion, a race, a nation, an ethnic group—has experienced widespread discrimination and stigmatization throughout Western history. In recent years, Jews have been recruited for, and have willingly participated in, genetic screening and research programs. In consequence, a disproportionate number of harmful genetic alterations are now associated with Ashkenazi Jews. Among these are alterations that predispose people to Tay-Sachs disease, breast cancer, ovarian cancer, Bloom Syndrome and colon cancer.³⁹ Publicity surrounding these findings has resulted in a widespread, though mistaken, belief that Jews are more prone to genetic disorders than others. Even doctors and scientists echo the belief. At least one sperm bank in Boston has cautioned potential donees to avoid 'Jewish sperm', claiming that

³⁹Levin (1999), p. 208 (noting predisposition to Tay-Sachs); Rothenberg (1997), p. 98 (noting predisposition to breast cancer and ovarian cancer); Roa *et al.* (1999), p. 219 (noting predisposition to Bloom Syndrome); Nelson (1998), p. 884 (noting predisposition to colon cancer).

they are more likely than the sperm of other men to transmit genetic diseases to offspring.⁴⁰

Jews first volunteered to participate in mass genetic screening programs in the 1970s as part of an effort to identify carriers for Tay-Sachs, a neurological disorder inherited recessively that affects children in the first year of life.⁴¹ At least one journalist has asserted that blood samples taken from people who participated in the early Tay-Sachs screening programs have remained on file at medical facilities and have been used for research to which the subjects never consented.⁴² Further, this research is reported to have led to some of the early findings linking Jews with harmful genetic alterations.

Such data is open to a wide variety of social interpretations some of which suggest disconcerting historic parallels. Eeta Prince-Gibson refers to a number of journalistic responses:

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 factors 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'.⁴³

Such responses recall a long history in the West in which images of the Jew, developed by non-Jews, and sometimes internalized by Jews, defined the Jew as physically marginal and flawed. '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.'⁴⁴ Such images punctuate Western history. In feudal times, they were presented in the language of theological piety. Later, in nineteenth- and twentieth-century Germany, Jewish marginality was signaled in the language of science and medicine. Sander Gilman describes one example concerned with the presumed deformity of Jewish feet.⁴⁵ The weakness of the Jewish foot, associated with flatness or with the Jew's peculiar gait, was understood to disqualify the Jew from serving as a *foot* soldier, and thus from participating fully in national life. In a chapter entitled, 'The Jewish foot', Gilman writes:

⁴⁰This information was provided by a potential client of the sperm bank in question (Interview with Anonymous, May 2000, in files of author).

⁴¹An assay for the Tay-Sachs enzyme (Hexosaminidase A) was developed in 1971 (Edelson, 1997, p. 127).

⁴²Prince-Gibson (1998).

⁴³Prince-Gibson (1998).

⁴⁴Zoloth-Dorfman (1998), pp. 181–2.

⁴⁵Gilman (1991) pp. 38–59.

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 . . . [T]he association between the sign of the devil and the sign of disease was well established in the early modern era . . . 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 European medicine is thus closely related to the idea of the 'foot'-soldier, of the popular militia, which was the hallmark of all of the liberal movements of the mid-century.⁴⁶

Contemporary assertions that Jews are genetically distinct, or more provocatively that they carry 'mutant' genes, are reminiscent of Gilman's portrait of nineteenth- and twentieth-century claims about the abnormality of the Jewish foot. A mode of discourse grounded in the notion of mapped genomes could easily be appropriated to serve racist ends.

Neither Western history generally nor American history, more specifically, clearly discount the possibility that a mapped 'human genome' could become the map of the 'normal', against which groups presumed marginal will routinely be measured and defined. In the U.S., as elsewhere, law and political sentiment struggle—though not without opposition—to preclude or limit that construction.

Ironically, however, the political mechanisms and social assumptions on which efforts to protect against genetic discrimination are grounded are themselves challenged by the emerging ideology of genetic inheritance.⁴⁷ That ideology trivializes theories of personal and social responsibility, facilitates depersonalization through the association of genetic groups with mapped genomes, and, in the extreme, threatens to eviscerate the notion of the autonomous individual to which contemporary constitutional rights are anchored.

5. Social Implications of the Genetic Group

The effort to contain genetic discrimination in the U.S. depends on a set of social beliefs and legal rules that have supported virtually all American efforts to contain or preclude discrimination on the basis of race, gender, religion and national origin. At base, U.S. law and policy have long been committed, in theory if not always in practice, to safeguarding the social and political rights of the autonomous individual. Similarly, efforts to protect genetic privacy (or the privacy of medical records more generally) are anchored to the notion of the autonomous individual as the subject of the 'right to privacy'.

The rights to equality, liberty, free speech, privacy and choice are all premised

⁴⁶Gilman (1991), pp. 39–40.

⁴⁷Professor Kaja Finkler has insightfully considered and analyzed the development of the ideology of genetic inheritance in contexts of genetic diseases and of adoption (Finkler, 2000).

on the notion of the autonomous individual as the uniquely valuable locus of social action. That notion of personhood was largely presumed in 1791 when the Constitution was amended through addition of the Bill of Rights;⁴⁸ in 1865 when the Constitution was amended to prohibit slavery,⁴⁹ and in 1868 when it was amended to protect the 'person' from state intrusions on 'life, liberty, or property, without due process of law' and to safeguard for all persons 'equal protection of the laws'.⁵⁰

The notion of a genetic group that undergirds *Safer*, and that is suggested, analogously, by the identification of ethnic groups with mapped genomes that differ from the 'normal genome', displaces the autonomous individual with an unspecified (and often unspecifiable) number of people—fungible, each with the others *and* with the larger genetic group that they compose. In short, within genetic families and genetic ethnic groups, the unit of ultimate importance is variously the genetic whole or any of its presumptively identical parts. The French Indologist Louis Dumont, writing about a different context, defined the social, political factors that facilitate the evisceration of autonomous individuality in a universe *that presumes to prize individuality*. Dumont suggested that 'totalitarianism results from the attempt, in a society where individualism is deeply rooted and predominant, to subordinate it to the primacy of the society as a whole'.⁵¹ Fascism understands the whole (the nation) through the metaphor of the individual. The totalitarian phenomenon, Dumont explained, 'is internal to the modern world'.⁵²

Genetic families and genetic ethnic groups are defined exclusively with reference to mapped DNA. Within such groups, the autonomous individual, understood with reference to Enlightenment values, vanishes and is replaced by the genetic group and its undifferentiated units. Social and personal responsibility are displaced. Choice—as well as the illusion of choice—is eviscerated. The essential a-morality of a universe defined through reference to mapped genomes augurs poorly for the preservation of a set of rights and safeguards that developed within an ideological frame constructed around the autonomous individual as the essential unit of social action and value. Thus, efforts to preclude or limit genetic discrimination are hampered doubly by the development of an ideology of genetic inheritance—by the essential a-morality of a universe that understands people through reference to DNA *and* by the construction of genetic groups that presume the 'subordination' of the individual to the primacy of the group.

A social universe defined through reference to genetic information is indifferent to the scope and form—indeed, even to the *fact*—of social relationships among its members. In practice, therefore, social relationships are likely to be variable and unstable. Relationships will vary insofar as those identified with genetic groups

⁴⁸U.S. Constitution, Amendments I–X.

⁴⁹U.S. Constitution, Amendment XIII.

⁵⁰U.S. Constitution, Amendment XIV.

⁵¹Dumont (1977), p. 12 (emphasis in original).

⁵²*Ibid.*

continue to invoke alternative understandings of families (or ethnic groups) as social institutions. Kaja Finkler shows insightfully how this occurs in her study of family members' responses to genetic information. Such relationships will be unstable insofar as the a-morality of the genetic group attenuates the apparent value of alternative understandings of social relationships. The central focus on 'nature' (presumed by the ideology of genetic inheritance) blurs the traditional significance of culture's *interacting with nature*, in delimiting personhood and in channeling behavior.

The practical consequences of an ideology of genetic inheritance for 'genetic families' will likely differ from the practical consequences for 'genetic ethnic groups'. The geneticization of family dislocates understandings of familial responsibility and, at the same time, precludes escaping from the familial group. Responsibility and choice are equally victims of the geneticization of family relationships. In addition, the process of geneticization threatens a system of social presumptions and legal rules that have protected family privacy and the privacy of the individual within familial settings. The geneticization of ethnicity presents different risks. Ethnic groups have been especially vulnerable to social stigmatization and discrimination. Thus members of genetic ethnic groups—those defined through ethnicity *and* through reference to specific genetic alterations—are susceptible to the abuse of genetic data to reinforce historical prejudices and to justify new ones. The risk is especially serious for members of groups that have been defined prejudicially through reference to somatic traits. Genetic information is far more powerful as a tool for creating and justifying prejudice than presumed correlations between physiognomic traits and other characteristics.

6. Conclusion

The proliferation of genetic information challenges existing conceptions of personhood, and thus of relationships. American law-makers, especially legislators, have begun to erect a body of rules aimed at protecting genetic privacy and safeguarding against genetic discrimination. Those rules presume a democratic system within which the autonomous individual is the agent of action and the locus of social value. Yet, the construction of genetic groups challenges that presumption, as does the generalization of an ideology of genetic inheritance beyond medical contexts—into the workplace, schools, prisons and families. Should the ideology of genetic inheritance become the central frame within which people view themselves and other people, individuality will be displaced by and submerged within the (genetic) whole. That shift will directly challenge social presumptions that facilitate legal and political efforts to counteract the worst abuses of the 'genome'.

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