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Can You Keep a (Genetic) Secret? The Genetic Privacy Movement

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This paper reviews the literature on genetic privacy, especially since 1995 and the first proposal for national genetic privacy legislation. Since that time, a majority of states have passed some form of genetic privacy legislation, and efforts to pass federal legislation are ongoing. Such new laws, however, remain untested in the courts and their effects are unclear. If they fail to provide additional protections against discrimination for most people, their most significant impact may be in their ability to either diminish or enhance the power of genetic information and to influence the way individuals view themselves and others. How does "genetic exceptionalism"—the idea that genetic information is different from other types of medical information—relate to "genetic essentialism"—the idea that we are to a large extent shaped by our genes? Anthropological views on genetics and personhood bring a new perspective to this ongoing debate. Implications for counseling practices are also explored.

KEY WORDS: genetic privacy; genetic exceptionalism; legislation; discrimination.

[P]erhaps what is most worrisome is that our genetic risks are occult, hidden; attributes that others could know even as we remain ignorant about them. Here lurks an image of genetic information as a mysterious, powerful, and inexorable force that will dominate and control our futures.

—Thomas Murray, "Genetic Exceptionalism and 'Future Diaries,'" 1999

Somewhere in a medical laboratory, there may be a scientist who knows far more about you than you do yourself.

—Businessweek, 15 April 2002

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INTRODUCTION

In the early 1990s, "genetic privacy" was hardly a phrase on the lips of most Americans, much less a major policy concern. By 1995, however, proposals for genetic privacy legislation were gaining widespread attention, and state governments were beginning to pass the first comprehensive genetic privacy statutes. By 2003, at least 29 states had passed some form of genetic privacy legislation, and a proliferation of media stories about the potential for genetic discrimination attested to a growing public concern. What one might call a "genetic privacy movement" emerged, spurred by a proposal for national legislation by a group of prominent bioethicists. The movement is a response to the Human Genome Project and the growing anticipation of, and anxiety over, the importance of genetics for clinical medicine and biotech research. This review essay describes this movement, including the proposed Genetic Privacy Act. Legislators have enacted a wide range of laws, reflecting differing approaches to the protection of genetic information. These laws, and the context in which they were written, are the subject of an ongoing research project on genetic privacy legislation. This paper considers whether and how genetic "exceptionalism"—the idea that genetic information is different from other types of medical information—is related to genetic "essentialism"—the idea that we are to a large extent shaped by our genes. Anthropological views of genetic determinism provide a useful perspective to consider some of the possible unintended consequences of privacy legislation. Finally, issues for genetics counselors, especially given the uncertainties of current genetic privacy policies, will be considered.

CURRENT STATE AND FEDERAL LAW AND GENETIC PRIVACY

A thorough discussion of the legislation itself can be found elsewhere (see Everett, 2003; Gostin *et al.*, 2001; Mulholland and Jaeger, 1999; Rothstein, ed. 1999). To summarize here, currently 29 states have passed some form of genetic privacy law, most enacted since 1995. All but a few treat genetic information as having unique characteristics ("genetic exceptionalism," see below). Some states distinguish between "DNA samples" and "genetic information," but "genetic information" is usually defined narrowly as the presence or absence of a genetic characteristic through a laboratory test of DNA, RNA, or mitochondrial DNA. Typically, family history and the request for or receipt of genetic counseling or genetic services are not protected. Four states (Colorado, Florida, Georgia, Louisiana) define genetic information as the personal property of the individual. Oregon repealed its own property provision in 2001. Sixteen states require informed consent for a third party to perform a genetic test or obtain genetic

information. Twenty-three require informed consent for the disclosure of genetic information.[3]

The Health Insurance Portability and Accountability Act (HIPAA), which Congress passed in 1996 and began to take effect in 2001, is the first federal law protecting health information received or created by health plans or health-care providers. Under the new law, genetic information is treated the same as any other "Protected Health Information" (PHI), which includes information about past, present, or future health, the provision of health care, and payment for care. This definition clearly covers information on genetic tests, counseling, and family history. HIPAA provides more stringent rules for written and oral consent for procedures and the transfer of health information to third parties, and limits disclosures of health information by insurers and group health plans and employers. Under HIPAA, genetic information may not be treated as a preexisting condition in the absence of a diagnosis of current illness. The law also prohibits group health plans from using the health status of individuals, including genetic information, to deny coverage or charge higher rates.

Critics argue that HIPAA, though significant, leaves many areas unprotected. The law does not cover those outside of group plans, such as the self-insured (Hamrin, 1999). It is also unclear whether the law protects information, including genetic test results, gathered in a research context (Hustead and Goldman, 2002). Perhaps most importantly, HIPAA does not prevent insurers from requiring genetic tests or voluntary disclosures of genetic information. Also, the law regulates employer access to genetic information only indirectly, in that it limits the flow of health information between insurance providers and employers.

Some suggest that existing federal laws governing medical privacy may be sufficient protection. Currently, the best privacy protections for genetic information in federal law may come from the Americans with Disability Act. The act protects those whose mental or physical impairments substantially limit an individual in one or more major life activity, a person with a record of such impairment, and a person who is "regarded as" having such an impairment. While the ADA does not specifically mention genetic information, the EEOC issued an Interpretive Guidance in March of 1995 stating that discrimination based on genetic information should be considered unlawful under the ADA. President Clinton signed an executive order in 2000 prohibiting federal agencies from using genetic information in hiring and promotion decisions. Clinton intended to set a precedent with the ruling, encouraging private employers to refrain from using such information for employment purposes.

[3]Given the number of new laws and revisions in recent years, the best source for up-to-date information on state genetic privacy laws, and access to specific state laws, is the National Conference of State Legislatures, http://www.ncsl.org/programs/health/genetics/prt.htm.

In October 2003, the U.S. Senate unanimously passed the "Genetic Information Nondiscrimination Act of 2003" (S1053), which if passed by the House would be the first federal law to specifically address genetic privacy. Like many state laws, the senate bill treats genetic information as uniquely sensitive and as a potential source of employment and insurance discrimination. The law would also preempt many existing state statutes.

Unlike most state laws, S1053 defines genetic information more broadly, including family history, and also protects information about genetic services, including genetic counseling. Health insurers may not deny coverage or raise rates based on the genetic information of individuals or their family members, or based on information about a request for or receipt of genetic services, including counseling. Passage of the Genetic Information and Nondiscrimination Act in the Senate follows 6 years of gridlock and procedural delays. The insurance industry, through their lobbying groups, opposes the law. The Bush administration supports the law, but its future in the House of Representatives, where efforts to pass similar legislation have stalled, is uncertain.[4] Some criticize the law as being ineffective, lacking adequate safeguards against employment discrimination and adequate penalties for violations of the law (Groves, 2003). The law does not guarantee individuals the right to sue for economic or noneconomic damages and provides for relatively modest administrative penalties (fines).

Despite different strategies, some critics argue that none of the new state laws will have much affect for most Americans (Reilly, 1999). Current federal protections are often deemed inadequate and untested. The future of federal legislation, and its effects if passed, is uncertain. One might ask, then, what these laws are about—what new fears and anxieties do they reflect? If they fail to provide additional protections against discrimination for most, their most significant impact may be in their ability to either diminish or enhance the power of genetic information and to influence the way we think about ourselves and others.

WHAT IS GENETIC PRIVACY?

While there seems to be no agreement on how to define privacy as a concept, several descriptions have been offered. Margulis defines privacy as "control over transactions between person(s) and other(s), the ultimate aim of which is to enhance autonomy and/or to minimize vulnerability" (Margulis, 1977, p. 10, cited in Margulis, 2003, p. 245). Such transactions, according to Margulis, "usually entail limits on or regulation of access to self" (Margulis, 2003, p. 245). Margulis

[4] At this writing, the act awaits committee hearings in the house and no immediate action is anticipated. See Congressional Record, October 14, 2003 (S12494–S12500) for the senate debates. See http://thomas.loc.gov/ for the bill's status.

also contrasts this "limited-access approach" to privacy to "privacy as a constitutional/legal concept, especially the post-1965 constitutional right of privacy[, which] emphasizes decisional privacy, that is, the freedom to decide and to act in public or private as one deems appropriate, without government interference" (Margulis, 2003, p. 244). Westin, a noted expert on privacy, defines privacy as "the claim of an individual to determine what information about himself or herself should be known to others" (Westin, 2003, p. 431). Allen (1999) identifies four categories of privacy—informational, physical, decisional, and proprietary. Genetic privacy legislation often focuses on informational privacy, aimed at preventing insurance and employment discrimination. However, as Allen and others have argued, genetic privacy encompasses all four areas of privacy.

"Genetic privacy" alludes to fears of discrimination, social stigma, familial problems, loss of control over one's identity, as well as assertions of the rights to know and not know, and to freedom from government interference in private choices, including abortion. Other reasons for protecting genetic privacy are reviewed elsewhere (Everett, 2003), including issues of social stigma, self-identity, and psychological issues. These issues are well-known to genetic counselors and addressed extensively in the literature (for example, Andrews, 1999; Hood and Rowen, 1999; Johnson *et al.*, 1999). Genetic privacy advocates also raise the concern for "physical privacy" or "bodily integrity." Some may not want their tissue used in research, for example, even if individual confidentiality could be assured. Some may also resist the use of their tissue for research that may harm or stigmatize a kin, racial, or ethnic group to which they belong, even where risks to the individual were minimal (Clayton, 1999). Increasingly, privacy advocates have pushed for including such risks in consent forms.

The case for treating DNA as unique and especially sensitive medical information is often called "genetic exceptionalism." Calls for special protections for genetic information are based on the assertion that such information is different from other types of medical information in a number of ways. George Annas, the leading proponent of genetic privacy protections, argues "Genetic information is both potentially embarrassing and uniquely personal" (Annas, 1993, p. 106). In another article, Annas portrays genetic information as "toxic," asking, "Would you really want to know how (or when) you are likely to die or to lose your mind? And even if you do, would you want your family, your business clients, your law partners, or your life or health insurance company to have this information?" (Annas, 1996, p. 19). Because molecular medicine offers primarily diagnostic and predictive information but few treatments or preventive measures, Annas and others therefore worry that such information will primarily be used to identify and stigmatize those who carry certain genes. Because of its predictive nature, Annas calls genetic information "a coded probabilistic future diary" (Annas, 1996, p. 20). DNA is also unique in that it may reveal information about a person's relatives, exposing them to possible discrimination, and affecting the way family members

relate to one another. For some, genetic information merits special protection because DNA samples can be stored indefinitely, and may be analyzed in the future for reasons we can't predict now (Troy, 1997). Finally, Annas and others worry about the psychological impact of genetic information, noting "the analysis of a person's DNA will have a significant impact on how individuals view themselves and are viewed by others" (Roche *et al.*, 1996, p. 2).

The distinction between genetic and nongenetic medical information is central to the legal changes arising from the genetic privacy movement. Cheye Calvo of the National Conference of State Legislatures told the House Subcommittee on Employer–Employee Relations, "The central policy issue is whether genetic information is special and requires higher legal protections or whether it is simply another form of health information and should be treated the same. The answer to this question largely influences the policy approach" (Calvo, 2001, p. 1). Calvo reported in 2001 that of 28 states with laws regarding the use of genetic information, 26 have followed the "exceptional approach."

EMPLOYMENT AND INSURANCE DISCRIMINATION

Efforts to pass genetic privacy legislation often focus on the threat of employment and insurance discrimination. Employers' use of medical screening dates back at least to the early twentieth century, and use of "predictive" testing, to indicate the risk of future illness or assess susceptibility to workplace hazards, became more common after World War II (Rothstein, 1999a). By the 1980s, preemployment screenings were commonplace, with 90% of companies with over 500 employees performing them (Rothstein, 1999).

Despite employer access to a wide range of medical information, evidence of actual discrimination based on genetic information has been largely anecdotal. Testifying before the House Subcommittee on Employer–Employee Relations, Eric Greenberg of the American Management Association told lawmakers that "genetic testing [in the workplace] is rare; where done it is performed with the health and safety of workers foremost in mind" (Greenberg, 2001, p. 2). The management association surveys between 1999 and 2001 reveal only a handful of over 1000 companies reporting DNA testing of employees (Greenberg, 2001, p. 2). Those companies conducting such tests claimed they related solely to worker health and safety concerns.

The discovery of genetic testing of employees by Burlington Northern Santa Fe Railway drew attention from the media and legal scholars (Hustead and Goldman, 2002; Roche, 2002; Rothstein, 1999a). Though the railroad's testing for a gene supposedly linked to Carpel Tunnel Syndrome drew criticism as "junk science," it seemed to confirm for some the arrival of a new era of genetic discrimination. As one columnist warned, "In shades of an Orwellian novel, groups of potential workers with particular genetic profiles could be excluded from entire

areas of employment and selected for others" (Kahn, 2001, p. 2). Employee reactions, such as those of Gary Avary testifying before a House subcommittee, indicate a sense of personal violation and fear of being penalized for something they cannot control—their DNA: "[Genetic testing by employers] is a direct infringement on our fundamental right to be who we are. No one can help how they are put together, only God knows that, and your employer, insurance companies or anyone else has no business of that knowledge" (Avary, 2001). Following the intervention of the EEOC, Burlington Northern stopped its testing program.

The media have also reported on a handful of possible cases of genetic discrimination in life and health insurance. While representatives of the insurance industry have denied the use of genetic testing for insurance writing to date (Trautwein, 2001), they are concerned about adverse selection, when individuals buy insurance based on information about their health not shared with insurance providers (see Kass, 1999). Some worry that unregulated use of genetic information by insurers could lead to "good gene" discounts and the exclusion of many from affordable coverage (Longman and Brownlee, 2000; Rothstein, 1999b). Still, if insurers are prevented from using genetic information in underwriting, a number of observers predict that a private, risk-based insurance system will become increasingly untenable (Hamrin, 1999; Powers, 1999). Universal health coverage in Canada and Europe makes genetic privacy legislation there less compelling generally and privacy debates tend to focus on life insurance.

While insurers may not yet require genetic testing of applicants, there is some evidence that insurance concerns may dissuade individuals from pursuing genetic testing. Media reports profile individuals who are afraid to be tested for mutations linked to Huntington's disease or breast cancer for fear of losing jobs and/or insurance (see, for example, Otchet, 2001). In a survey by the Council of State Governments, 18% of respondents answered "yes" to the question "Have you ever been asked to release genetic information while trying to obtain insurance or employment?" and 2% believed they had been denied insurance or employment based on the results of a genetic test (see Hamrin, 1999). One problem with such surveys is that "genetic information" is difficult to define and may not be well understood by the public. A survey of genetic counselors in several states did indicate that fear of genetic discrimination factored significantly in decisions to undergo testing (Hall and Rich, 2000). However, the same survey also found that other concerns, especially about the psychological impact of testing, were more significant to testing decisions. Discrimination fears were also most likely to influence decision-making when the need for information was low, such as when tests results were unlikely to lead to viable treatment options or other interventions.

While some proponents of genetic privacy argue that special legal protections are necessary to reassure those considering undergoing genetic testing for clinical or research purposes, Hall and Rich note that whether or not a state had passed such legislation had little impact on testing decisions. Rothstein argues that proposing privacy laws as a way to remove presumed obstacles to widespread

genetic testing is flawed: "[T]he purpose of laws related to genetics, including anti-discrimination laws, is not to make the world safe for the unfettered pursuit of genomic research or mass genetic screening programs of unproven need or efficacy" (Rothstein, 1999b, p. 453). According to Rothstein, before considering the social and legal consequences of testing, the validity and utility of a specific test, and the cost-effectiveness of medical intervention, should be established.

GENETIC EXCEPTIONALISM AND THE GENETIC PRIVACY ACT

Genetic exceptionalism finds clear expression in the *Genetic Privacy Act: A Proposal for National Legislation* (GPA). This model legislation, drafted by Annas and colleagues at Boston University with funding from the National Institute of Health, seeks to protect genetic privacy by regulating the collection, retention, and disclosure of genetic information. The act focuses on procedural guidelines rather than specifying how genetic information may or may not be used. Rather than specifically prohibiting discrimination, the GPA provides specific and detailed requirements for the consent process, including verbal and written disclosures of potential risks, the purpose of testing, and assurances of confidentiality. The authors explain their reasoning for this approach:

> [T]o effectively protect genetic privacy unauthorized collection and analysis of individually identifiable DNA must be prohibited. As a result, the overarching premise of the Act is that no stranger should have or control identifiable DNA samples or genetic information about an individual unless that individual specifically authorizes the collection of DNA samples for the purpose of genetic analysis, authorizes the creation of that private information, and has access to and control over the dissemination of that information. (Annas *et al.*, 1995, p. vi)

The Act narrowly defines "private genetic information" as information derived from the analysis of an individual's DNA or of a relatives DNA. Family history, then, is not covered by the act.

Perhaps the act's most controversial provision is the statement that "An individually identifiable DNA sample is the property of the sample source" (Annas *et al.*, 1995, p. 12). In their discussion, the authors make clear that the property provision was designed not only to preserve privacy, but individual autonomy as well, a value that figures prominently in Western bioethics. The act requires that DNA samples be destroyed on completion of either clinical or research testing, and allows individuals to revoke disclosure authorization at any time. The authors do not discuss gene patenting, and it is not directly addressed in the GPA, but property debates clearly influence their approach.

The GPA treats genetic information as unique and separable from other medical information. They describe genetic information as "powerful and personal" and "uniquely sensitive" (Annas *et al.*, 1995, pp. i–ii). Continuing the "future diary" analogy created by Annas, they explain:

> A diary is perhaps the most personal and private document a person can create. It contains a person's innermost thoughts and perceptions, and is usually hidden and locked to assure its secrecy. Diaries describe the past. The information in one's genetic code can be thought of as a coded probabilistic future diary because it describes an important part of a unique and personal future. (Annas *et al.*, 1995, p. ii)

Given its important status, the authors insist that when genetic information enters a person's medical records, it should be kept separate and should not be disclosed to third parties (such as insurers or employers) without specific authorization. This provision has been widely criticized as impractical, given the increasingly commonplace use of genetic tests and its relationships to clinical findings and treatment considerations.

While the GPA drew support from some legal scholars (Lin, 1996; Markett, 1996) and inspired a flurry of proposals for state and federal laws, it also received widespread criticism from law, medicine, and bioethics. Much of the outcry related to the practical implications of such legislation for medicine and biomedical research. Some say, for example, that as genetic testing becomes more common the formal consent process mandated by the GPA will quickly become too costly and impractical, especially given the shortage of genetics counselors (Reilly, 1995; Troy, 1997). Mandatory written consent for all testing could jeopardize newborn screening programs in place in many states. Critics also charge that the procedural guidelines are confusing and overly complex, and might be easily circumvented by hospitals with broadly worded consent forms. While the GPA focuses on preventing unlawful or inadvertent disclosures, it does nothing to regulate authorized disclosures. The act does not address insurance questions directly, and does not prevent insurers or employers from seeking genetic information through voluntary consent (Parmet, 2001). In other words, informed consent does not guarantee that information won't be used against individuals (Rothstein, 1999b), or that individuals will have enough information to weigh the risks and benefits of voluntary disclosures. Many critics charge that regulating genetic disclosures will do little to prevent discrimination without sweeping reforms of health-care financing in the United States (Rothstein, 1999b).

The GPA provisions that allow individuals to revoke consent and request the destruction of their samples at any time have also drawn sharp debate. Allowing patients to prevent the potential future use of their samples for research is "socially harmful," according to Reilly, and could threaten important epidemiological studies that rely on large numbers of samples (Reilly, 1995, p. 381). Others suggest that such provisions are harmful to patient care as well, by allowing patients to conceal medical information from their own doctors (Troy, 1997, p. 266). But others argue that GPA protections are inadequate, failing to ensure control over the use of anonymous samples. Clayton argues that by focusing exclusively on the risks to individuals, the act fails to address potential harms to groups, even where individual confidentiality is assured. For example, "Native Americans may be quite concerned about efforts to find an 'alcoholism' gene common to their population" (Clayton, 1995, p. 376).

THE CRITIQUE OF GENETIC EXCEPTIONALISM

The GPA presupposes genetic exceptionalism, and its authors use the analogy of the "genetic future diary" to illustrate the unique status of genetic information, but is DNA really a "diary" of future health? Rothstein argues that the reasons for treating genetic information as different from other medical information are "overwhelmingly social rather than scientific phenomena. Genetic information is unique because it is regarded as unique" (Rothstein, 1999b, p. 459). The "future diary" analogy does seem to capture the social power of genetic information in society. But many commentators find the analogy misleading: "It implies that the contents of that future diary reflect what is most intimate, central, and important about us—that it reveals, in some fundamental way, our social and personal identity, our loves and interests, and our actions. In fact, our genomes have little or nothing to say about any of these crucial matters" (Murray, 1999, p. 67). Troy prefers "genetic blueprint" to "genetic diary," explaining "our genetic diary is not being written as time passes" but rather our DNA is "more akin to a biochemical plant, whose construction and future operations are defined by the blueprint" (Troy, 1997, pp. 257–258). Does it matter whether we consider our DNA a "blueprint" or a "diary"? Troy suggests that a diary is secret and personal, highlighting the individual and confidential nature of DNA, whereas blueprints fit better with the idea that most of our genetic makeup is shared and does not require maximum protection. Anderson's study of media discourses on genetics found common metaphors such as code, computer program, and book of life were used to convey complex ideas. According to Anderson, "These metaphors lend support to the idea that the scientific enterprise will reveal objective 'truths' about the secrets of life" (Anderson, 2002, p. 330). Anderson's review also notes a tendency of the media to ignore nongenetic disease factors. One important point is that such metaphors are socially constructed, revealing cultural predispositions to view DNA a certain way more than "natural" facts about genetics.

Critics also question the degree to which genetic information poses unique concerns about confidentiality and discrimination. Other nongenetic information can be predictive of future health and can be hidden and unknown, even to the individual. These include cholesterol levels, early HIV infection, early tuberculosis infection, and blood pressure (Green and Botkin, 2003; Murray, 1999). Genetic privacy advocates emphasize the looming threat of discrimination, but institutions discriminate based on nongenetic information routinely, such as in health and life insurance underwriting. Perhaps it is the immutable nature of DNA that leads some to worry that, without special protections, people will be blamed for that which they can't control. But is that unique to genetic conditions? And would it be more tolerable to discriminate based on conditions that can be influenced by lifestyle and environment? As Murray notes, most connections between genes and disease won't be a straightforward causal connection, as with Huntington's disease, for

example, but rather a complex result of genes, environment, and behavior. "If we are less inclined to worry about discrimination on the basis of health risk factors that are open to modification and individual choice, then let us recognize *that* as the relevant difference, and not confuse it with the distinction between genetic and nongenetic factors" (Murray, 1999, p. 66, emphasis his).

Genetic privacy advocates defend genetic exceptionalism based on the fact that genetic information has implications for family members, but is this unique to genetics? A positive TB test would certainly have implications for members of a household, even in the absence of symptoms. A positive gonorrhea test would certainly affect relations between partners and raise difficult disclosure issues (Green and Botkin, 2003). Anthropologists have demonstrated that a variety of diseases, such as leprosy, carry heavy social stigma and discrimination in many cultural settings, with often significant affects for family members and even broader social groups. Much attention has been given to the psychological and ethical risks of predictive genetic testing, but again the issues relate more to predictive tests, especially in the absence of effective interventions, rather than to the genetic nature of the tests. Supporting this, a recent study of attitudes toward familial disclosure issues and confidentiality found little difference in views between participants affected by genetic versus nongenetic conditions (Plantinga *et al.*, 2003).

EXCEPTIONALISM AND GENETIC DETERMINISM

While the majority of articles on genetic privacy accept genetic exceptionalism, a growing number have challenged this premise (Sankar, 2003). One of the most common themes in the criticism of genetic exceptionalism is that such an approach promotes genetic determinism. Rather than diminishing the power of genetics, critics argue, the exceptionalist argument enhances "the DNA mystique" and the reduction of our identities and life chances to our genes. The irony is obvious, since the genetic privacy movement itself is a response to fears of genetic determinism, or "loss of autonomy." Media reports further this "crystal ball" or "future diary" view of genes when they focus on rare diseases, such as Huntington's, an inherited and fatal disease, rather than the more complex interaction between genetics and environment (Juengst, 1995). Murray calls genetic exceptionalism "an overly dramatic view of the significance of genetic information in our lives" and warns that "The more genetic information is treated as special, the more special treatment will be necessary" (Murray, 1999, p. 71). Privacy advocates do acknowledge that the uniqueness of genetic information has as much to do with social perception as it does science. For Annas, this itself makes privacy protections necessary: "To the extent that we accord special status to our genes and what they reveal, genetic information is uniquely powerful and uniquely personal, and thus merits unique privacy protections" (Annas, 1996, p. 25). But others say

special legislation will not protect us from such perceptions, but rather "reinforce the stigma of genetic conditions, creating a self-fulfilling prophecy" (Rothstein, 1999b, p. 459).

Those who favor treating DNA the same as any other medical information charge that special protections reinforce genetic determinism. The notion that DNA is the "'sacred vessel' of an individual's inviolate personality" (Miller, 1998, p. 200) can be seen not only in the popular media, but in the commentary of scientists and scholars. Francis Crick, codiscoverer of the structure of DNA, once made the "astonishing hypothesis" that "'You,' your joys and sorrows, your memories and your ambitions, your sense of personal identity and free will, are in fact no more than the [genetically determined] behavior of a vast assembly of nerve cells and their associated molecules" (cited in Miller, 1998, p. 179). Nelkin and Lindee, in their influential book *The DNA Mystique*, argue that DNA has taken on such a central place in our identity that it has acquired a cultural meaning akin to the Biblical soul: "Just as the Christian soul has provided an archetypal concept through which to understand the person and continuity of self, so DNA appears in popular culture as a soul-like entity, a holy and immortal relic, a forbidden territory" (Nelkin and Lindee, 1995, p. 41). Other religious images can be found in discussions of the human genome. Wolpe, in his critique of genetic essentialism, calls the genome "the modern prophet" and the effort to decipher it a "holy mission." Wolpe writes,

> Molecular geneticists have spoken of the Human Genome as the "Human Bible," the "Holy Grail," the "Code of Codes," and the "Book of Life." The genome has become our modern oracle . . . We gaze into our petri dishes, our modern crystal balls, to see our future health, our children's personalities, and our possibilities for happiness. (Wolpe, 1997, p. 216)

The religious and cultural symbolism surrounding the human genome reflects the emergence of the "genetic self," but Wolpe isn't blaming the scientists entirely: "Science could not foist such a profound reinterpretation of the self onto a society without a cultural predisposition to accept it" (Wolpe, 1997, p. 219).

Miller warns that by treating DNA with such reverence, and by advancing special legal protections for genetic information, we threaten to undermine the very foundation of Western law and morality: free will. Miller (1998) opposes genetic exceptionalism, arguing that it weakens our belief that individuals choose to act as they do. Our existing legal and moral practices, he says, would not make sense or be justifiable unless we assume that such free will is possible.

ANTHROPOLOGICAL VIEWS ON GENETIC IDENTITIES

Genetic essentialism present different dilemmas for anthropologists. As Brodwin explains, anthropologists offer the perspective that "individuals craft their identities through social performances" and that "identity is not a fixed essence"

(Brodwin, 2002, p. 323). As genetic science moves out of the laboratory, what should we make of genetically based identity claims, where individuals might use genetic information to claim inclusion in racial, ethnic, or national groups? Are such claims more or less authentic than other claims? Brodwin considers the implications particularly for African Americans, but notes more broadly, "Current debates over genetically based identity claims . . . challenge the reflexive anti-essentialism of contemporary anthropology" (Brodwin, 2002, p. 329).

Anthropologists and other social scientists have become particularly interested in the role of biomedicine in constructions of personhood and identity. Through emerging and established biotechnologies, "bodies are made" and selves are fashioned (Downey and Dumit, 1997; Haraway, 1993; Nettleton and Watson, 1998). Rapp's (1997) observations of fetal sonography, for example, demonstrates the role doctor's play in granting personhood to the fetus. Rabinow, in his widely read essay on "biosociality," predicts that genetics will increasingly lead to the creation of identities around specific disease genes. Indeed, this is already the case with a number of prominent disease-specific organizations and support groups. Rabinow asserts that, "Such groups will have medical specialists, laboratories, narratives, traditions, and a heavy panoply of pastoral keepers to help them experience, share, intervene, and 'understand' their fate" (Rabinow, 1996, p. 102).

Anthropologists have identified disease groups not only as recipients of genetic services, but as cocreators of genetic knowledge. In their collaborations with researchers, such groups provide legitimacy to research projects and access to samples and research subjects. As Taussig *et al.* (2003) show convincingly in their study of the Little People of America, such collaborations can be fraught with tension when the new knowledge, such as the mapping of disease genes, leads to new eugenic possibilities. Such groups understand these discoveries with a mix of hope for new treatments and fear of new genetic exclusions and intolerance for those born with genetic faults. Tensions also arise when the commercial uses of research contradict the expectations of participants, as in the well-known controversy over Miami Children's Hospital's handling of their patent of the Canavan's gene (Merz, 2002). This example highlights the fact that the anxieties and expectations of those likely to access genetic services are more complex than the need for confidentiality.

Rapp's work on amniocentesis is probably the most complete ethnographic record available on the promise and peril of genetic knowledge from the perspective of patients. Rapp finds genetic essentialism, or "geneticization," and genetic discrimination closely linked: "Geneticization is an historically consonant ideology linking individual attributes and social problems as if they could be effectively reshaped or eliminated only in the realm of biomedicine now reduced to genetic diagnosis" (Rapp, 2000, p. 215; see also Lippman, 1993). For Rapp, genetic discrimination follows such a worldview, in which human problems are attributed to genetic differentiation. She is quick to point out that genetics professionals,

including counselors, do not usually embrace such reductionism and are often dismayed by the misleading simplifications of popular genetic discourses.

Rapp's interviews with clients and providers of amniocentesis speak eloquently to the promise and peril of emerging genetic knowledge. As genetic counselors work to help patients navigate these benefits and burdens, they may be increasingly called on to interpret, weigh, and protect genetic privacy. What is the cost of privacy? What is the cost of disclosure? Without downplaying the risk of insurance discrimination, anthropologists like Rapp make us aware that access to genetic services is a function of much more than insurance, including factors like race, cultural background, education, and class. Public health funding, funding for genetics clinics, and the commercialization of services and labs also come into play.

Intriguingly, Pálsson and Harðardóttir's study of the Icelandic database project suggests that genetic essentialism does not always lead to widespread fears of discrimination. While the database project, led by deCode Genetics, was criticized internationally for commercializing the Icelandic genome and failing to obtain informed consent from subjects, the Icelandic public largely embraced the effort. Rather than fearing the release of information about "faulty genes," "Icelanders seem proud of their 'Nordic' roots and their genetic makeup . . . and they are eager to offer their 'unique' blood samples and medical records, as the rhetoric goes, to science and the advancement of human well-being" (Pálsson and Harðardóttir, 2002, p. 283). While some of this enthusiasm must be attributed to the strength of the Icelandic welfare state and socialized medicine, the example also demonstrates the importance of cultural particularities and what Pálsson and Harðardóttir call "the phenomenology of genetic citizenship" for understanding the extent and character of genetic privacy anxieties.

Biological anthropologists have worked to debunk aspects of genetic determinism from another perspective. Marks (2002, 2003) shows that "molecular anthropology" can problematize our most relied on and supposedly reliable genetic facts. He demonstrates, for example, the way human's well-known genetic similarity to apes is culturally construed. Many suppose that this genetic similarity reveals deep truths about human nature, but Marks shows how it fails to say much that was not already known by other means. He is also critical of many of the discoveries of behavioral genetics and genetic definitions of race, again underscoring the cultural basis of supposedly neutral scientific facts.

Finkler (2000) describes the growing importance of genetics for definitions of family and kinship as the "hegemony of the gene." Interviewing breast cancer patients, she found the ideology of genetic inheritance provided women with a causal explanation and helped them assign meaning to their experiences. But she also found that such an ideology may turn healthy individuals into "perpetual patients" (noting that through genetics, everyone is potentially unhealthy) and contributes to the "medicalization of kinship." Genetic inheritance has become the primary mode by which Americans determine their family and kin, or "significant

same." By itself, this fact is neither good nor bad, but Finkler argues, "With the medicalization of kinship, a connection is established irrespective of love or choice" (Finkler, 2000, p. 182). This can cause confusion and social complications for some. For example, the "hegemony of the gene" presents special problems for adoptees, who often feel compelled to search for blood relatives to access medical information. Consider another example from Alice Wexler, who has written about her family history of Huntington's disease. Of learning about her mother's diagnosis, she writes, "I did not want to be drawn back into the family dramas I had been struggling to escape. This is what Huntington's meant to me: a biological metaphor for the identification with my mother that I had fought all my life" (Wexler, 2000, p. 194). Finkler concludes, "Notwithstanding the elegance of genetic explanations, DNA molecules cannot stand in for human existence. They may symbolize it and contribute to it, but humans cannot be reduced to DNA molecules—or can they?" (Finkler, 2000, p. 211).

CONCLUSIONS

Treating genetic information as special or "exceptional" may well lead to the trap of having to provide greater restrictions on its use and dissemination. The dilemma is that the perception that DNA is exceptionally powerful information increases the risks of discrimination and stigma, "But, on the other hand, providing special legislation or regulation may just feed the cultural belief that genetics truly is special. If that is the case, one might win a small tactical victory against the misuse of genetics in ways that harm people while reinforcing dangerous misperceptions of the power of genetics" (Greely, 1998, p. 498). While slower to contribute to discussions of the ethical, legal and social issues of the new genetics than bioethicists from philosophy and law, anthropologists nonetheless demonstrate that the power of genetics as the basis for discrimination is overwhelmingly social. Blueprint, diary, bible, or code—these are all social constructs. How we describe and perceive DNA is important and has a real impact on individuals and families. If anthropologists have shown that genetic knowledge is not as stable as some might assume, this does nothing to diminish either its cultural importance or its potential for discrimination.

So far, despite legislation in 29 states, genetics laws are untested, but some say their impact is likely to be small. Reilly claims that state genetic laws passed as of 1999 were virtually irrelevant to most Americans, including the 60% of Americans insured through employer-based group plans, which do not rate the health status of individual members, as well as those covered by Medicare and Medicaid. In fact, he estimates that the laws might directly benefit only 3–4% of Americans (Reilly, 1999). Similarly, Rothstein argues, "most of the legislative enactments and proposals to date have been ineffective or ill-advised" (Rothstein, 1999b, p. 455). There is often a difficulty in identifying the purpose of genetic privacy laws—to promote widespread screening? Preempt discrimination? Facilitate research

participation? Without clear goals, legislative efforts seem to reflect anxiety around new technology rather than meaningful policy interventions.

Counselors may be called on not only to interpret these new laws, but to respond to concerns generated by the media about "genetic privacy." Privacy and autonomy are highly valued in our society, and are likely to be more important to some than to others. Privacy, then, is another "risk" that counselors will have to help their clients assess as they consider testing. This is likely to be particularly difficult since current laws are untested, federal law is still pending, and how state and federal laws will intersect is as yet unknown. One of the challenges currently is that most state laws do not protect information about requests for or receipt of genetic counseling, and such information could theoretically be the basis for discrimination with or without genetic test results. But counselors may provide a more realistic assessment than is sometimes found in the media. Genetic information, like all medical information, is now protected more carefully than ever through HIPAA guidelines and the ADA, even if medical privacy still falls short of the expectations of some. Furthermore, reports of employment discrimination to date have been largely anecdotal, and the few high-profile cases that have been reported have resolved in favor of the employees involved. Counselors are in the best position to provide this context and to help patients weigh the possible risks of testing.

Counselors, with their first-hand knowledge of patient concerns and the way privacy anxieties might interfere with testing decisions, are also in the best position to inform policymakers. However, counselors have been largely absent from the many ethics boards that often shape genetics laws and policies (Rapp, 2000).[5] Better inclusion of counselors on such boards would likely go a long way toward more effective policymaking. The relevant question to ask of recent and pending genetic privacy laws is whether they allay fears of genetic discrimination or simply encourage people to more jealously guard their genetic secrets, and to regard these as their true essence. Here, the role of counselors in informing policy is invaluable.

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[5]To give a few anecdotal examples, the author served on a committee that wrote Oregon's 2001 genetic privacy law, the Genetic Research Advisory Committee. No genetics counselor served on the committee, which was dominated by physicians, lawyers, and health-care and pharmaceutical lobbyists. Another state commission, the Michigan Commission on Genetic Privacy and Progress, also did not have a genetics counselor among its members.

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