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What Makes Genetic Discrimination Exceptional?

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Introduction

Recent advances in understanding the genetic basis of disease have inspired hope but also have led to fear. Scientists, physicians, and genetic counselors, along with their patients and potential patients, worry that those whose genetics place them at risk for a serious disease will face discrimination. Denial of health insurance is one concern, but people also fear discrimination in such other aspects of life as employment and child custody decisions. In response to these concerns, many state legislatures have passed laws forbidding genetic discrimination. Most legislation of this sort addresses discrimination in health insurance, but some legislation is directed to employment, or to life or disability insurance.

These laws have been met with both praise and criticism. Defenders of the laws see them as important and necessary—even if they do not go far enough. Critics view such legislation as unjustified and unwarranted. After addressing an important preliminary issue: the problem of defining “genetic discrimination” in a way that adequately differentiates it from health status discrimination more generally, I turn to the central question of genetic exceptionalism. That is, I ask: Is genetic discrimination different from discrimination on the basis of health such that it warrants special protective legislation? To do this, I exam-

ine—and reject—most familiar arguments in support of genetic exceptionalism. However, one of these arguments merits further consideration. If genetic discrimination discourages individual participation in research and treatment, then opportunities to gain further knowledge beneficial to the wider public would be lost. Legislative protection might be justifiable in order to remove barriers that genetic discrimination places on medical advances, which are essential in the promotion of the general welfare.

A second argument that warrants a closer look implicitly underlies many of the arguments in the literature. Genetic discrimination might be meaningfully different (and worse) than health status discrimination because of what it expresses. Many commentators refer to the history of eugenics in this country and elsewhere without clearly articulating why that history matters. I try to fill that gap by developing the argument that, because the social meaning of treating people differently on the basis of their genetic makeup is different from the social meaning of discrimination on the basis of health or illness, special legislation to prohibit genetic discrimination is warranted.

Defining "Genetic Discrimination"

Some who oppose prohibitions on genetic discrimination believe that it is theoretically or practically impossible to distinguish genetic discrimination from discrimination on the basis of health more generally. These critics argue that if genetic discrimination is legally defined as discrimination based on information derived from a test of a person's genetic material—an examination of DNA, for example—then laws will fail to capture many instances of discrimination on the basis of genetic predisposition to disease. For example, a family medical history—the common starting point of any medical record or doctor's visit—contains a wealth of information about a person's genetic makeup. Critics thus contend that state laws that define "genetic information" as information resulting from a test of DNA are overly narrow. In response, newer laws define genetic discrimination more broadly. However, these laws inadvertently seem to prohibit almost all forms of discrimination on the basis of health (except perhaps illness or disability caused by accident). As many diseases are at least partly influenced by our genes, common tests ordinarily not considered "genetic tests"—a blood pressure reading, for example—arguably could fall within the purview of these new laws.

Medical ethicist Henry Greely offers a helpful resolution to this definitional problem. In his measured support for limited federal legislation prohibiting genetic discrimination in health insurance and employment, Greely suggests that health insurers should be prohibited from denying coverage or charging higher premiums based on information about genotype (unexpressed genetic traits)—no matter the source of that information. As he explains, "[g]enetic information should thus be defined broadly to encompass any . . . information that provides probabilistic information about a person's genotype . . . from genetic tests, other medical tests, family history, diagnoses of traits or conditions, or the taking of (or even making inquires about) a genetic test." For Greely, once a genetic predisposition is manifest (phenotype)—as illness or at least as a medically relevant symptom—it becomes a matter of one's health status, and discrimination would not be prohibited.

This distinction between discrimination based on unexpressed genetic traits and discrimination based on manifested illness takes us to the point where we can evaluate arguments in support of genetic exceptionalism. That is, we must consider whether genetic discrimination is different from other forms of health status discrimination such that it warrants special legislative attention.

Genetic Exceptionalism: The Familiar Arguments

Most Americans with health insurance are covered through group rated plans—that is, no individual risk assessment is made at the time of their request for coverage. However, individual risk assessment is common for those who buy *individual* health insurance policies as well as in the life, disability, and long-term-care insurance markets. At present, a person who is sick may be charged higher insurance rates or denied coverage. Why then forbid similar treatment of someone with a genetic predisposition to the very same illness?

Some might say that drawing the distinction between sick and healthy individuals is "fair," while distinguishing between two healthy persons (only one of whom carries a genetic mutation that predisposes him to disease), is "unfair." The sick person is already sick, so the thinking goes, and surely will need to make an insurance claim (perhaps many claims); the healthy person with a genetic *predisposition* to an illness might never need to make a claim. This intuition is misguided however. The sick person will not *necessarily* need health care services—she might be hit by a bus and killed on the first day of the policy peri-

od. Moreover, some with a genetic predisposition to an illness *will* develop the predicted illness, so long as they do not die of something else first. Insurers make predictions about the likelihood that claims will be made; the difference between the person who is already sick and the person who *might* become sick is a difference in degree and not in kind.

Although these considerations focus on insurance, the question whether genetic discrimination is different, morally speaking, from discrimination on the basis of health or illness also can be raised in other contexts. Employment discrimination has attracted attention; some states have passed legislation forbidding genetic discrimination in employment. Here too, then, one must ask whether genetic discrimination in employment ought to be specifically forbidden.

Genetic discrimination is irrational. Some argue that legislative prohibitions on genetic discrimination are necessary because genetic discrimination is irrational. In the case of insurance, irrational discrimination would occur if the insurer charges higher rates to a group that is not in fact more likely than average to make a claim. Rational discrimination, by contrast, makes distinctions among groups in a way that reflects the *real risk* of loss posed by each group. More precisely, discrimination is irrational if the prices charged by the insurer do not reflect the actual risk of loss posed by each group *as well as the cost to the insurer of distinguishing between the groups*. Understood in this way, it is unclear what is morally important about the irrational character of discrimination. Irrational discrimination is simply synonymous with bad business.

Further, while it is true that many who carry a gene that predisposes them to a particular illness will not in fact become sick, it is also true that such persons are *more likely than average* to develop that illness. Thus, discrimination on this basis may well be rational. Moreover, the probabilistic nature of genetic information is no different from other information about a person's future health used by insurers to set rates. Not all smokers develop lung cancer, but because they are more likely than average to develop lung cancer, it is rational to charge smokers higher health insurance rates.

Some argue that genetic discrimination is more complex and less predictive of future health than smoking is of cancer. If insurers do not understand this complexity, they might discriminate in ways that are irrational. Perhaps. But if so, is this a problem that requires a legislative solution? Insurance statutes of all states already require that rates be grounded in actuarial data; state law generally requires that insurance

rates be rational. In employment law, by contrast, there exists no general requirement of rational behavior. If an employer wants to discriminate irrationally, hiring only brown-eyed applicants, for example, such irrational discrimination by itself is not prohibited. Irrational discrimination of a *special sort* is prohibited, but not *because* it is irrational. Race, sex, and disability discrimination, for example, are largely prohibited both when they are rational and when they are irrational.

At present, there is little evidence of genetic discrimination. However, were it to become a problem, three reasons would argue against prohibition. First, such a law would be overinclusive if its aim is to ban only irrational genetic discrimination, since some genetic discrimination is rational. Second, current law already bans irrational discrimination in insurance, though these laws are less potent than would be a law *specifically* banning genetic discrimination in insurance. Third and most importantly, it is not clear why being subject to irrational discrimination is a significant moral harm that requires remediation. Rational discrimination is simply the making of distinctions that are economically sensible, according to the insurer, employer, or other actor who draws such distinctions. A bad business judgment, without more, does not constitute a moral wrong to the person disadvantaged by that judgment.

Genes are beyond individual control. A common argument for singling out some attributes for protection from discrimination is that they are "immutable," or beyond individual control. The moral intuition underlying this argument is that a person ought to be granted or denied benefits on the basis of what she *does*, and not who she *is*.

Immutability fails as a reason to prohibit genetic discrimination for two reasons. First, most goods are distributed according to principles that often have little or nothing to do with what one does. The basketball player who earns millions of dollars for his performance earns that money only partly in recognition of his effort; his height, surely beyond his control, and his natural talent also play a role in making him a skilled player. Second, while the notion of personal responsibility has moral appeal, it is far more complex conceptually than is immediately apparent. We might say that a smoker ought to pay high insurance rates because, in choosing to smoke, she is partly responsible for her greater risk of illness. But even that example is problematic because of the additive quality of nicotine and the fact that individual differences in our bodies affect the degree to which smoking endangers health. Our bodies make demands on us unevenly.

A small number of people are especially burdened by genetic disease. A related argument is based on the recognition that genetic predisposition to disease is distributed quite unequally. While most of us may turn out to have roughly equivalent risk profiles—a higher than average risk of X, but a lower than average risk of Y—smaller groups of people are extremely lucky or extremely unlucky in their genetic make-up. Social policies that permit discrimination on the basis of genetics would seem to cruelly compound their misfortune. However, although this argument initially seems persuasive, it does not explain why those whose genetic makeup render them especially likely to *become* sick deserve special solicitation when those whose poor health is already manifest do not.

Genetic traits overlap with racial or ethnic groups. One reason that the genetically unlucky may deserve special protection is because genetic predispositions affect identifiable racial or ethnic groups. For example, sickle-cell anemia generally affects Africans and African Americans; two mutations associated with breast cancer are more common among Ashkenazi Jews than others. Where the group affected is already stigmatized in our society, there is a risk of further entrenching negative attitudes and of overreacting to the significance of the association.

Although these associations are important, they do not justify a ban on genetic discrimination. Although the connection between some genetic diseases and stigmatized racial or ethnic groups such as African Americans or Jews seem significant today, this significance will probably wane. The nature of genetic research makes it easier to identify genetic mutations among relatively homogeneous and relatively small ethnic groups. But as scientists are able to identify the function of a greater number of genes, the relevance of small population studies will dissipate. Moreover, there are many disease-causing mutations that are not more prevalent among stigmatized populations—Huntington's disease and early onset Alzheimer's disease are two particularly devastating examples. To ban genetic discrimination because of the risk of the further stigmatization of racial and ethnic groups would be to enact a law that is quite dramatically both over- and underinclusive.

Stigma. Some argue that genetic predisposition to disease is *itself* stigmatizing. Similar to the concern that racial prejudice creates a color hierarchy in our society, some worry about a genetic hierarchy. For example, those with genetic predispositions to diseases may become less desirable as customers for insurance, as employees, or as marriage partners.

While superficially appealing, this argument is underdeveloped. First, one must claim not just that possession of a genetic predisposition to disease is stigmatizing, but that it is *more* stigmatizing than having an already manifest illness. More importantly, it is not clear what is meant by "stigma." Perhaps "stigma" refers to the *effect* on the persons with the genetic condition. If so, genetic discrimination is wrong because it causes harm. But questions remain: What harm in particular is at issue, and why does *this* harm render discrimination wrong? If someone is denied a job or insurance coverage because of genetic traits she carries, she *is* certainly harmed, but it is not a *stigmatic* harm. Perhaps stigmatic harm refers to the psychological effect on the person denied the good because of her genetic traits. This way of understanding stigma is familiar from arguments about what makes race discrimination wrong. But if harm to the person subject to discrimination were a necessary component of wrongful discrimination, then racial segregation of facilities for those in a permanent vegetative state would not be wrongful, because such persons are incapable of suffering psychological or emotional hurt. As this conclusion seems untenable, the claim that wrongful discrimination requires that those affected feel stigmatized fails.

Finally, "stigma" might refer to what the policy of genetic discrimination *expresses*. Perhaps genetic discrimination is wrong because of the meaning expressed in distinguishing people on this basis. (This expressivist argument is implicit in much of the critique of genetic discrimination. It has not, however, been carefully articulated and evaluated, a task I take up in the discussion, "Expressivism and Genetic Discrimination," below.)

The notion of stigma also carries with it the idea of a class or caste-like distinction between groups of people. Perhaps what is wrong with genetic discrimination—which distinguishes it from discrimination on the basis of health—is that it threatens to create a *genetic underclass*. This fear motivates an argument for legislation prohibiting genetic discrimination that has been most forcefully articulated by the philosopher Susan Wolf.

"Geneticism." Susan Wolf argues that the tendency to focus on genetics and to subordinate people on that basis is best termed "geneticism"—a term that she uses to call attention to a deeply ingrained mindset and set of structural practices. Her view is grounded in critiques of the antidiscrimination approach as applied to problems of racism and sexism. Similar to those cases, she believes that "clinging to 'genetic discrimination' . . . creat[es] a false genetic 'norm,' frustrating structural

reform, obscuring the deep psychological roots of genetic stereotyping and prejudice, and isolating genetic from other harms." Wolf's conception of the issue as something deep and entrenched leads her to argue that the eradication of geneticism requires a systemic approach.

Thus, while Wolf explicitly does not support laws prohibiting genetic discrimination, her approach does support the idea of genetic exceptionalism. But Wolf fails to address in what way the particular inequalities identified by *geneticism* are morally problematic. To complete her argument she must also claim that *this inequality* clashes with the commitment to treat each person with equal concern (or some similar formulation of a general principle of equality). As economist and philosopher Amartya Sen insightfully emphasizes, since equality among people across all dimensions of life is impossible, moral theories differentiate themselves by articulating what sort of equality is morally significant. To merely note a particular inequality—people with trait X have less of Y—is not enough. One must also explain *why* this sort of inequality is one that is morally problematic.

Promoting Health

The scientific advances in understanding the genetic basis for disease have enormous potential to improve health. Understanding individual predispositions to disease might allow medical advice to be individually tailored, both for prevention and for treatment. Most exciting of all, a greater understanding of genetics could allow doctors to treat people with strong predispositions to serious illness prophylactically so that the illness itself never develops. Genetic discrimination is a problem, then, because it may get in the way of each of these beneficial developments. If people fear genetic discrimination, they may be reluctant to be tested for genetic conditions. If so, achievement of the health benefits described above may be thwarted in two ways. First, if people avoid testing, they may fail to partake in the therapeutic benefits that are currently available. Second, and perhaps more importantly, people who fear discrimination may decline to participate in research involving testing—research that could lead to discoveries that ultimately make presymptomatic treatment of genetic conditions possible. This argument is important but rests on several empirical assumptions that require further consideration.

In order for legislation forbidding genetic discrimination to be successful in removing this barrier to testing, the legislation must forbid

the sorts of genetic discrimination that people actually fear. If people also fear discrimination in life, disability and long-term-care insurance, for example, legislation that is limited to the health care and employment contexts is unlikely to promote health. Consider the case of someone contemplating enrollment in a research study dealing with the genetic predisposition to early onset Alzheimer's disease. For this person, the availability of long-term-care and disability insurance are critical issues. People's fears of genetic discrimination might extend further still. Perhaps their central worry is that they will be unable to adopt children, or that in a custody battle they will be denied custody of the children because of their genetic condition, or that mates or family members will abandon them. Research to date suggests that people's fears are not assuaged by protective legislation, but more research is needed to fully understand whether legislation can affect decisions about whether to undergo genetic testing.

Expressivism and Genetic Discrimination

Much of the commentary about genetic discrimination refers to the history of eugenics both in this country and in Europe. It seems obvious that this history is relevant to the question of whether genetic discrimination is wrong as well as to whether genetic discrimination is different from discrimination on the basis of health such that it warrants special legislation. Exactly why this history matters, however, is not clear from the arguments currently found in the literature. The expressivist argument fills that gap; the history of eugenics is relevant because it changes the social meaning of current practices. Genetic discrimination expresses something different because of our experience with illegitimate uses of genetics.

The expressivist account is an especially close cousin of the argument that genetic discrimination is wrong because it is stigmatizing. Although "stigma" is an elusive term, it is fair to say that it generally calls attention to the *effect* of a law or policy. An expressivist approach, in contrast, focuses on what is *expressed* by a law or policy—regardless whether this expression actually harms an identifiable group in a particular way.

Expressivism contends that what an action expresses—its meaning—is relevant in determining its moral permissibility. In contrast, moral permissibility typically depends on the *intent* of the actor, the *effect* of the action, or both. For example, in criminal law both intent and

effect are relevant in judging the moral acceptability of an action. The person who kills another by accident will not likely be guilty of murder, which requires that the actor have a particular intent. In addition, if someone intends to kill another but fails, she may be guilty only of attempted murder and thereby be punished more lightly because her action resulted in no significant harm. To claim that the expressive character of an action is relevant is to call attention to a third dimension of action: my spitting on a homeless person, for instance, is wrong because it *expresses* disrespect. In this example, the *effect* of the action (and the experience of being spit on is certainly unpleasant) clearly is far less important than what it *expresses*. Further, if I intend disrespect by spitting, an account of intent alone cannot explain why—or the depth to which—spitting is disrespectful. And even if I do not intend disrespect by spitting, I cannot spit blamelessly: the *meaning* of spitting on someone in our culture is as an act of disrespect. The expressive dimension of action allows for assessment of moral permissibility that is not reducible simply to consideration of intentions or consequences.

The history of eugenics chronicles the misuse of genetic information, and colors the way that we—our society and people—understand the practice of genetic discrimination. Although the beginning of the systematic, scientific understanding of genetics and its effect on health stretches back about 150 years, it was not until the twentieth century that these scientific developments began to have significant social consequences. Some scientists and social reformers viewed the promise of genetics as the power to affect reproductive choices—eugenics. Eugenicists wanted to encourage those perceived as having “better” genetic endowments to reproduce more, and toward that end, for example, in the 1920s state fairs around the country sponsored “Fitter Families” contests, with prizes for “Grade A individuals” in the “human stock” category. This interest in encouraging the “better” to reproduce was coupled with a fear that the “defective” were over-producing. In the US, the eugenics movement had racial overtones as well, with “white Protestants of Northern European Stock” superior to “blacks and Jewish and Catholic immigrants.” It was not until the Second World War, with revelations of Nazi atrocities, that the use of genetic science for eugenic purposes was discredited.

Read with this history as a backdrop, the meaning of genetic discrimination may be that those with genetic flaws (or more flaws than average) are less worthy or less important—even if those genetic aspects never see expression—that is, genetic discrimination is directed at geno-

type (not phenotype). If this understanding of the meaning of genetic discrimination as acceptance of moral inferiority is correct, then genetic discrimination is different from discrimination on the basis of health and, furthermore, genetic discrimination is morally impermissible. This argument’s strength depends on the claim that genetic discrimination does express a meaning that denigrates the equal moral worth of those with genetic predisposition to disease. Interpreting the social meaning of a policy or practice is a difficult interpretive task about which reasonable people will often differ. Expressivism’s contribution is the suggestion that we ought to turn our attention to this issue.

Conclusion

Recall that, to distinguish genetic discrimination from discrimination on the basis of health, I adopted Henry Greely’s proposed solution, which suggests that genetic discrimination should be defined as discrimination on the basis of information about genotype regardless the source of that information. However, once a person manifests illness (regardless whether it is of genetic, nongenetic, or mixed origin), then discrimination on this basis would not be considered *genetic discrimination*. I suggest that genetic discrimination, so defined, might be considered meaningfully different from health status discrimination if it *expresses* denigration of people with genetic disease. When discrimination is based on asymptomatic genetic predispositions or conditions, it is likely that such discrimination will be seen as *genetic*, thereby calling up the history of eugenics. In addition, genetic discrimination might warrant special legislation in order to fulfill the promises of genetic science.

Many questions remain, however. First, we must reach a better understanding of how legislation affects testing decisions. Second, we must continue the discussion, in public and private, about what, if anything, genetic discrimination expresses and in particular whether it denigrates the equal worth of people with genetic disease.

A fuller articulation of this view can be found in “What Makes Genetic Discrimination Exceptional? *American Journal of Law & Medicine*, vol. 29, no. 1 (Spring 2003), pp. 77-116; this article appears with the permission of the American Society of Law, Medicine & Ethics and Boston University. All rights reserved.

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Sources

For the state legislatures that have passed laws forbidding genetic discrimination in such areas as health insurance, employment, or life or disability insurance, see: National Conference of State Legislatures (NCSL), *State Genetic Discrimination in Health Insurance Laws*, (June 2001), available at <http://www.ncsl.org/programs/health/genetics/ndishlth.htm> (last modified April 3, 2002) and also NCSL, *State Genetics Employment Laws*, available at <http://www.ncsl.org/programs/health/genetics/ndiscrim.htm> (last modified April 29, 2002); for an example of a defender of laws against discrimination, but who also does not believe those laws go far enough, see Trudo Lemmens, "Selective Justice, Genetic Discrimination, and Insurance: Should We Single Out Genes In Our Laws?" *McGill Law Journal*, vol. 45 (2000); critics of legislative prohibitions against genetic discrimination include Colin S. Diver and Jane Maslow Cohen, "Genophobia: What Is Wrong with Genetic Discrimination?" *University of Pennsylvania Law Review*, vol. 149 (2001); for an example of a critic of prohibitions on genetic discrimination, because it is theoretically or practically impossible to distinguish genetic discrimination from discrimination on the basis of health more generally, see Thomas Murray, "Genetic Exceptionalism and Future Diaries: Is Genetic Information Different from other Medical Information?" in *Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era* (Yale University Press, 1997); Henry T. Greely has argued that state laws defining "genetic information" as information resulting from a test of DNA have applied an overly narrow definition, see: "Genotype Discrimination: The Complex Case For Some Legislative Protection," *University of Pennsylvania Law Review*, vol. 149 (2001). One instance of an overly broad application of "genetic information" is the Maryland statute, which provides: "[a]n insurer, nonprofit health service plan, or health maintenance organization may not: use a genetic test, or the results of a genetic test, genetic information, or a request for genetic services to reject, deny, limit, cancel, affect a health insurance policy or contract." Md. Ins. Code Ann. § 27-909(c)(1)(2002). The phrase "genetic exceptionalism" was first coined by Thomas Murray; for an example of arguments that legislative prohibitions of genetic discrimination are necessary because genetic discrimination is irrational, see: Larry Gostin, "Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers," *American Journal of Law & Medicine*, vol. 17 (1991); the discussion of rational discrimination as reflecting real risk of loss posed by an insured group occurs in Kenneth S. Abraham, *Distributing Risk:*

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