

2003

Human Rights and Genetic Discrimination: Protecting Genomics' Promise for Public Health

Anita Silvers

Michael Ashley Stein

Repository Citation

Silvers, Anita and Stein, Michael Ashley, "Human Rights and Genetic Discrimination: Protecting Genomics' Promise for Public Health" (2003). *Faculty Publications*. 712.
<https://scholarship.law.wm.edu/facpubs/712>

Human Rights and Genetic Discrimination: Protecting Genomics' Promise For Public Health

Anita Silvers and Michael Ashley Stein

The potential power of predictive genetic testing as a risk regulator is impressive. By identifying asymptomatic individuals who are at risk of becoming ill, predictive genetic testing may enable those individuals to take prophylactic measures. As new therapies become available, the usefulness of genetic testing undoubtedly will increase. Further, when a person's family medical history indicates a propensity towards a particular genetic disease, a negative test result may open up otherwise denied opportunities by showing that this person has not inherited suspect genes. In the latter type of case, a negative test result may reassure the individual that pursuing a particular course of action (such as planning a family or training for a job) is worthwhile, or may convince prospective employers that the individual will be a serviceable employee.

Concomitant with these benefits are prospective harms that can arise from the use of information derived from predictive genetic testing to discriminate against employees.¹ For example, to mitigate responsibility for an employee's injury or disease, an employer might argue that the individual was genetically disposed to such an outcome by, for instance, a gene for carpal tunnel syndrome, or the employer may fire an individual if testing reveals a genetic susceptibility to workplace toxins or to a genetic condition that results in disability.² In general, asymptomatic people who believe they will be denied opportunities, compensation, and benefits if classified as genetically flawed will adopt defensive strategies against being so categorized. The most obvious defense is not to be tested.³ Regrettably, in protecting themselves by evading testing, individuals relinquish the advantage of

prophylactic and therapeutic intervention. They also delay any gain of knowledge (for themselves or others) about their genotype by refusing to participate in research protocols. Thus, fear of discrimination (whether or not factually justified) has the potential to block benefits that otherwise might be gained from genomic knowledge. As a consequence, scientists like Dr. Francis Collins, head of the National Human Genome Institute, recommend strong legal protections against genetic discrimination.⁴

Nevertheless, effective federal regulation specifically protecting individuals from genetic discrimination is almost nonexistent. Advocates for protection have sought measures that either protect against certain violations of individuals' privacy or that prohibit specified discriminatory actions. As we show, however, each of these solutions contains a fatal flaw. Privacy-based protections seek to sequester genetic information, but they do not adequately address the practical realities of how genetic information is disseminated. Antidiscrimination mandates attempt to prohibit certain actions based on genetic information, but do not address the practical realities of how discriminatory action is precipitated. Ultimately, both approaches leave many people who are genetically disposed to disease and disability, or have family histories of such dispositions, vulnerable to social threats that may prevent the realization of the benefits genomics promises.⁵

We argue in this article for a much broader approach, an equality-based protection similar to the bans against race and sex discrimination. In doing so, we identify some problems that have made current prohibitions against disability discrimination less effective than was originally hoped, and we show that the prevailing approach to protection against genetic discrimination is subject to similar weaknesses. In particular, we show that neither existing federal law banning disability discrimination nor proposed

federal genetic discrimination law protects asymptomatic individuals with genetic anomalies who pursue prophylactic or mitigating measures. The diseases associated with these anomalies may never be expressed or, if expressed, may not manifest as unmitigatable functional impairments. Yet genetic anomalies may be used as proxies to disqualify their possessors from opportunity, as biological properties associated with race and female sex have been used in the past. We therefore advocate a novel civil rights paradigm that safeguards individuals from discrimination on the basis of genetic identity, as they now are protected from discrimination based on their identities with respect to race and sex.

CRITIQUES OF EXISTING APPROACHES TO PROTECTING AGAINST GENETIC DISCRIMINATION

In the main, two lines of thought about the grounds for protection against genetic discrimination have been pursued. Initially, the appeal was to citizens' rights to privacy. More recently, antidiscrimination safeguards have been invoked.

Privacy

The privacy model has been variously advocated and interpreted by many commentators. As demonstrated by Anita Allen and Mark Rothstein in discussions of genetic privacy, the desire for "privacy" can be inspired by and encompass divergent values and goals, including moral, proprietary, and decisional ones.⁶ Pauline Kim and George Annas, for example, ground their respective arguments for privacy protection in the value of protecting an individual's autonomy to control her own destiny.⁷ These commentators advocate privacy-based protection, seeking, as a general matter, to sequester access to individuals' genetic information.⁸

At least two areas of U.S. law speak to privacy rights. Constitutional law, in application of the Fourth, Fifth, and Fourteenth Amendments, emphasizes preserving individuals' control over intimate information affecting their personal identities, particularly as it relates to the development of the emotional, cognitive, and spiritual dimensions essential to autonomous beings.⁹ Tort law also offers individuals some privacy protection by penalizing encroachment upon or revelation (or misrepresentation) of personal facts. As June Madiski has noted, the common law has long recognized the right to be "let alone" from intrusion by others,¹⁰ especially in regard to those private affairs which comprise personal identity, where information is conceived to have been wrongly appropriated if disclosed for advantage without the person's consent. Statute and precedent present a complex picture of the ways that various kinds of personal facts may or may not be constitutive of one's personal identity, and, as well, of the conditions under which

consent to disclosure may be explicitly required or instead presumed. By awarding damages for past violation of individuals' privacy rights, tort law helps protect their monetary interests but may be inadequate to preserve other interests, especially those related to individuals' dignity and autonomy.¹¹

Privacy rights also are protected by evidentiary privileges, contract and property law, and federal and state statutes. Medical patients' privacy is covered by a patchwork of federal and state provisions, including the accreditation standards for hospitals.¹² The Privacy Act of 1974 limits federal agencies' use of information to those which are "relevant and necessary" for their authorized mandates, permits individuals to access their own records and to request emendations, and proscribes the disclosure of information to third parties.¹³ On the state level, the 1996 New Jersey Genetic Privacy Act makes genetic information the patient's private property (regardless of who has paid for the genetic tests) and requires informed consent to any disclosure of test results.¹⁴

Despite these foundations, privacy-based solutions to genetic discrimination that seek to sequester genetic information do not effectively address the practical realities of how genetic information may be misused. First, in many businesses, individuals who administer health-care benefits or manage health and safety programs also have responsibility for some aspects of managing personnel. In these circumstances, the expectation that employers can maintain a firewall so that information found in health-care records never influences personnel decisions may be unrealistic. Second, when a proprietor waives a privacy right for one purpose, the information may in practice be used for another purpose, especially if, in the future, a genetic anomaly currently correlated with one condition is found to correlate with another. For example, individuals who provide DNA to be tested for susceptibility to heart disease could, years later, find that they have been dismissed from their employment as airline pilots because of new data that the gene has some expression for an early onset of Alzheimer's disease. Third, where more than one person has a property right in certain information, it is not clear whose interests have priority in respect to maintaining control. For example, when test results for one family member yield information about another family member, it is unclear whether courts will defer to the individual who wishes to preserve privacy or to the one who will benefit from disclosure. Other considerations that may also warrant overriding individual privacy rights include threats to public safety and assertions of business necessity.¹⁵

It should also be noted that genetic information about an individual is discovered in several different ways. Although informed consent for medical testing is in principle necessary, patients often are asked to consent only to contributing a specimen or sample, or else to the use of their

body materials for certain panels of tests. Or they are informed of the tests to be run without specifying what is learned from the tests. The physician may order the panel for one reason, which she discusses with the patient, but the entire set of test results becomes part of the patient's employment record. In all these cases, patients' consent to be tested might be construed to imply workers' consent to treat all test results as ordinary medical records that are available, under the usual conditions, to employers.

Regulations proposed to control access to genetic information must specify what data will come under control. Yet there is no bright line dividing genetic from nongenetic information. A chance remark about family history, or a formal requirement to relate it, may reveal significant data. Information that ordinarily makes no reference to genetics may, in a particular context, be extrapolated to hypotheses regarding individuals' heightened susceptibility to genetic disease. Well-supported and ill-supported hypotheses may be equally provocative of adverse action, and therefore equally damaging to their subjects. It is impracticable to place an embargo on all information from which people's genetic conditions might be inferred.¹⁶

Antidiscrimination: disability discrimination

Where the privacy model extends protection by sequestering information, the antidiscrimination model assumes that such attempts may be unsuccessful, and consequently regulates the uses to which genetic information may be put. To date, the most pertinent theoretical discussion has centered on application of the "regarded as" prong of the Americans with Disabilities Act (ADA)¹⁷ to genetic discrimination. The premier proponent of this position has been Paul Miller, who, as a Commissioner of the Equal Employment Opportunity Commission (EEOC), has also directed its practical application.¹⁸

Federal courts require individuals who hope to be safeguarded by the ADA to prove that they have disabilities. Being disabled means having "(a) a physical or mental impairment that substantially limits one or more of the major life activities of such individual, (b) a record of such an impairment; or (c) being regarded as having such an impairment."¹⁹ To establish a claim for protection based on being regarded as disabled, the plaintiff must demonstrate that her employer mistakenly believed she had a physical or mental impairment which limited a major life activity, when she in fact had no such impairment.²⁰ As an example of such a mistake, consider an individual utilizing a lower leg prosthetic device to mitigate the impact of an amputation, but whose functional ability had not actually been impaired. Such an individual would be regarded as disabled under the ADA if her employer nevertheless believed her to be limited in a major life activity, for example, walking or standing.²¹

Although the ADA does not specifically address genetic conditions, there are reasons, according to Miller, for thinking that the "regarded as" prong is applicable to them. First, the congressional record offers some evidence of legislative intent. During hearings, congress members characterized genetic discrimination as exhibiting the myths, fear, and stereotypes that historically have excluded people perceived as biologically anomalous from fair equality of opportunity.²² Second, citing the congressional record, the EEOC has offered policy and enforcement guidance statements, as well as opinion letters, bringing actions arising from genetic information relating to genetic disease or disabling conditions under the regulation of the ADA's "regarded as" criteria.²³ In sum, the position adopted by the EEOC, as explained by Commissioner Miller, is that:

[a] person is "regarded as" disabled within the meaning of the ADA, if a covered entity mistakenly believes an individual has a substantially limiting impairment, when in fact, the impairment is not so limiting. Under such a theory, coverage for individuals with a genetic predisposition would generally rely on demonstrating a mistaken belief concerning the major life activity of working.²⁴

Application of the ADA's "regarded as" prong to instances of genetic discrimination is, however, fraught with difficulties. To begin with, the Supreme Court has interpreted the ADA so as to limit the number of people who fall under its protection.²⁵ Additionally, the Court has given clear warning that the deference traditionally granted to federal regulatory agencies will not always be extended to the EEOC's understanding of the ADA (which by inference includes its guidelines on genetic discrimination).

Moreover, several defenses which have been successfully asserted by employers under the ADA in regard to conventional types of disabilities can be raised in response to genetic discrimination allegations. Employers can assert that potentially disabling conditions preclude workers from fulfilling "essential" job functions, thus banning them from ADA protection.²⁶ Similarly, employers may aver that a requested accommodation would create an "undue hardship," and that as a result, the worker failed to satisfy the statutory prerequisite of being "qualified" for that particular employment.²⁷ Further, the employer may claim that when an adverse action is triggered by concern about an employee's future state (for example, about the costs incurred if the employee develops the genetic disease to which she is predisposed), the employee is not regarded as being currently disabled and therefore is not protected by the ADA.²⁸ The ADA also contains a semi-exemption for insurance coverage, as a result of which employers are not required to offer any particular coverage to disabled

individuals so long as the coverage offered is equivalent to that of nondisabled people.²⁹ Last, it bears noting that the ADA itself may not even be applied because employers may argue successfully (as they do in other antidiscrimination suits) that their employment decisions were based on factors other than those alleged.³⁰

A significant impediment to the pursuit of ADA claims on the ground of genetic discrimination is the defense that the plaintiff poses a direct threat to others, a defense which has recently been expanded to include workers who pose threats to themselves. Although the paradigm application of the direct threat defense involves the potential for "significant risk" to others — for example, the risk posed by food handlers with highly contagious conditions like typhoid that are transmitted in food³¹ — the potential for expansion into the realm of genetic potential for risk is enormous. Employers could argue that an individual who currently does not pose a direct threat to others is a potential future risk. Consider, for example, the situation of an airline pilot with a genetic predisposition to Alzheimer's. For example, an employer might defend the exclusion of such a genetically atypical airline pilot on the ground that he posed a hazard to passengers because of his greater than species-typical potential for developing degradations of coordination and judgment.³² Moreover, the Supreme Court's recent decision in *Chevron U.S.A. Inc. v. Echazabal* unanimously upheld an EEOC regulation expanding the "direct threat" defense to authorize exclusion of an employee whose work could "endanger his own health."³³ As a result, employers may deny employment opportunities on the ground that work site conditions or job responsibilities could make workers' own biological anomalies develop into pathologies or disabilities. The potential for success of the direct threat defense is great.

Last, although enacted as a civil rights statute, the ADA has sometimes been interpreted (wrongly, in our view), by both courts and commentators, as a specialized benefits statute for enhancing the welfare of the disabled. On this interpretation, its application to genetic discrimination is even more tenuous.³⁴ That is because, it will be argued, the class of individuals who have a greater than species-typical likelihood of developing some genetic disease is very large. It is implausible to construe this class as being especially needy and therefore deserving of benefits not offered to other people.³⁵

Not surprisingly, then, almost no cases clearly charging genetic discrimination have been filed by the EEOC. The most prominent (and only successful) one was a settlement in *E.E.O.C. v. Burlington Northern Santa Fe Railroad Co.* In this case, however, the wrongs the employer allegedly committed included failure to obtain patients' informed consent to being genetically tested.³⁶ (A related suit, *EEOC v. Woodbridge Corporation*, was dismissed by the court at the summary judgment stage on the ground that the employer did not regard the job

applicants as being disabled, despite their disposition to carpal tunnel injury, for they were still capable of performing other jobs at the same plant.³⁷)

Even more problematic, however, is that, under current interpretations, the ADA (even if successfully applied) bifurcates the population into protected and unprotected groups. The ADA applies only to those individuals who are seriously symptomatic, or to those who can show that they have been treated adversely because they are regarded as seriously symptomatic.³⁸ People with genetic anomalies which are not expressing, or may never express, are unlikely to qualify for ADA protection.

The case of Terri Sergeant

The circumstances surrounding Terri Sergeant and her potential genetic discrimination suit³⁹ illustrate our point that neither privacy-based protections sequestering genetic information nor antidiscrimination mandates prohibiting adverse actions based on genetic disabilities, effectively protects the large group of presymptomatic individuals.

Sergeant is an individual with a family history of Alpha-1-antitrypsin, an often fatal deterioration of the lungs. When asymptomatic, she tested positive for the genetic disposition for this disease, which had killed her brother at age thirty-seven. As a result of the test, her physician initiated preventative therapy that deters the development of the disease and protects against lung infection. This treatment costs more than \$45,000 annually but permits her to work and engage in all other life activities without limitations.

Sergeant worked for a firm that self-insured for employees' health insurance. During her employment, she had repeatedly received outstanding performance evaluations and merit salary increases. In November 1999, seven months after her preventative treatment began, she received another excellent review and increase. One month later, after her employer was apprised of her medical treatment and the likely reason for it, her employment was terminated, and she lost her health and disability insurance.

There is no certainty that Sergeant would have become symptomatic even without the preventative therapy. Nevertheless, preventative intervention reduces or eliminates her risk, and she remains able to perform activities like walking and breathing, major life activities that are severely compromised in symptomatic cases of Alpha-1-antitrypsin. There is no reason to believe her employers, who observed her daily, regarded her as currently unable to perform these activities.

The circular nature of her dilemma is clear. Positive genetic testing permits her to take preventative measures against the substantial limitations of major life activities that could result from Alpha-1-antitrypsin in the absence of medical prevention. The success of these measures, however, lessens her legal protection against losing her

job and her medical benefits. Their effectiveness prevents her being limited in major life activities and therefore reduces the likelihood that she will be, or will be regarded as, impaired. Ironically, people may have to forgo the medical benefits genetic information can bring if they are to be protected by the ADA from genetic discrimination. This catch-22 situation, which so adversely affects asymptomatic and presymptomatic individuals such as Ms. Sergeant, is not addressed by existing statutory provisions.

Antidiscrimination: genetic discrimination

Sergeant's story came to Congress's attention as the result of her testimony before the Senate Health, Education, Labor and Pension Committee. A bill intended to address genetic discrimination independently of the ADA, H.R. 602, is currently pending (in its fifth reincarnation) before Congress.⁴⁰ Even if passed, however, people like Terri Sergeant will remain vulnerable to genetic discrimination because, while the bill incorporates elements of both the privacy and antidiscrimination models, certain situations that arise in regard to asymptomatic individuals continue to be ignored.⁴¹ Specifically, the Genetic Nondiscrimination in Health Insurance and Employment Act would prohibit employment discrimination in hiring, terms of employment, and the provision of health insurance enrollment, on the basis of genetic information. The proposed legislation prohibits employers and certain other entities from taking adverse action against prospective and current employees based on information about genetic test results or the occurrences of genetic disease in family members.⁴² It does not cover other sources of information about an individual's health.⁴³

As drafted, the legislation's protection does not extend to important kinds of information. Once again, the case of Terri Sergeant illustrates the problem. Sergeant's employer could have gained knowledge about her genetic condition from several sources, not all of which qualify as protected under H.R. 602. Data pointing to Sergeant's condition included the history of her sibling's illness and death, medical appointments to treat chronic respiratory problems that Sergeant attributed to an allergy, positive genetic test results for Alpha-1-antitrypsin, and medical records and \$45,000 annual bills for preventative treatment. H.R. 602 would prohibit Sergeant's employer from basing an employment decision on the first and third items in this list, but not on the second and fourth. Indeed, all the information the employer needs to identify her genetic condition is manifested in the record of her prophylactic treatment. An Internet search can quickly identify the conditions for which the treatment is prescribed.

PROPOSED APPROACHES

Analysis of Terri Sergeant's case reveals a difficulty in the application of antidiscrimination law to genetic discrimination, whether provided by the ADA or by specialized legislation. This is the problem of determining who will be protected and who not, when no bright line separates vulnerable from impervious, and deserving from undeserving, populations. The ADA and the proposed specialized legislation each bifurcate the population into protected and unprotected groups. The ADA's umbrella covers people who are symptomatic or mistakenly regarded as symptomatic. Specialized genetic protection is aimed at asymptomatic genetically anomalous individuals who, in former times, could have escaped discrimination but who now can be identified through genetic testing.

Whether an individual who is genetically disposed to a disease is symptomatic often is not very clear. For example, a person who finds herself under stress and forgetting things might describe these circumstances to a physician. Forgetting things is no strict indicator of Alzheimer's disease, as witness young parents who lock up their cars on sweltering summer days, forgetting that their infants are still inside. In the case we are considering, the physician, knowing that this patient's family has a history of early onset Alzheimer's disease, orders genetic testing, which gives a positive result for a gene associated with Alzheimer's disease.

However, an examination of the patient's cognitive functioning, with attention to the cognitive deficits diagnostic of Alzheimer's, is inconclusive. Although no diagnosis of Alzheimer's can be made on the existing evidence, the physician starts the patient on donepezil hydrochloride as a prophylactic to delay cognitive impairment, just in case the patient's memory problems signal the onset of Alzheimer's.⁴⁴ In this case, an employer who regards the employee as likely to develop Alzheimer's could claim to have based personnel decisions on inferences made from the unprotected parts of the medical record (the patient's report of memory problems and the prescription for Donepezil hydrochloride) but not from the protected parts (the genetic testing and family history). As the Sergeant case and this case both show, prescribing medication to ward off onset of disease symptoms in individuals whom genetic tests show to be at risk may be as revealing as the test results themselves.

Individuals claiming harm specifically from genetic discrimination must establish that the adverse action occurred prior to their being symptomatic and indeed, prior to the employer's imagining there is such a sign. Questions about whether an employer's decision was influenced by unprotected parts of the medical record, rather than by the results of genetic tests or by family history, may preempt bringing cases to trial. Because prophylaxis is not a

medical strategy specific to genetic disease, and prophylactic prescriptions are separate from the protected record, individuals who use genetic information to pursue preventative measures to benefit their health may, in doing so, lose their legal recourse against genetic discrimination. Thus, the goal of genetic antidiscrimination law — namely, to free currently healthy citizens with anomalous genetic identities to improve their health through applications of genomic knowledge — may not be realized.

In general, plaintiffs will find it difficult to demonstrate that genetic information, rather than some other kind of information, triggered the employer's adverse action. In this regard, legislation that counts action based on genetic information as discriminatory faces the same difficulty as legislation that attempts to block access to that information. There is no bright line between genetic and nongenetic information, especially in cases of multifactorial disease. Consequently, protective approaches that focus on reducing the possibility that people will be targeted because a genetic identification of them is made can never be more than half-measures, as it is impracticable to specify all of the routes to such identification in legislation.

The ADA has been read as extending civil rights protection to individuals whose physical or mental impairments substantially limit their participation in major life activities, or who are so regarded, but as giving no protection to individuals who can adapt to or mitigate their impairments sufficiently to engage substantially in such activities.⁴⁵ On the other hand, specialized legislation that targets genetic discrimination will protect individuals until they evidence limitation of major life activities, or some other observable sign of their propensity to or manifestation of genetic disease.⁴⁶ Here, the protected population is almost a mirror (reverse) image of the population protected by the ADA, but once again individuals who take mitigating measures are unprotected.

Regrettably neither the prevailing interpretation of protection against disability discrimination, nor the most prominent current attempt to formulate a separate approach for protection against genetic discrimination, shields people who take mitigating measures to escape dysfunction. Further, the lines drawn between protected and unprotected groups do not reflect the difference between people who can and people who cannot function successfully. Existing approaches to both disability discrimination and genetic discrimination thus fail in large part to reduce the costs of excluding otherwise productive citizens from equal opportunity if these citizens act to mitigate the effects of the biological anomalies on the basis of which they suffer discrimination. Consequently, we propose a broader approach that in principle protects everyone equally, rather than limiting eligibility for protection to individuals who have been identified as substantially limited in capability, or who have been identified as being at higher than species-typical risk of such limitation on the basis of genetic information alone.

Protecting individuals “on the basis of genetic identity”

No matter what their race and sex, all citizens may, in principle, seek recourse through the law if they are harmed by race or sex discrimination. What would be required to take a similar approach and to extend genetic discrimination protection to the general population?

The Civil Rights Act of 1964 (Title VII), the key federal protection against bias because of biological atypicality, prohibits discrimination “on the basis of” sex and race.⁴⁷ We recommend borrowing from Title VII jurisprudence by enacting an antidiscrimination mandate which prohibits discrimination towards individuals on the basis of their genetic identity. Alternatively, Title VII could be amended to add this stipulation. This paradigm would permit plaintiffs to proceed regardless of the sources from which defendants' beliefs about their genetic identity derive — for example, regardless of whether genetic or nongenetic information, confirmed or speculative claims about genetic determinism, evidence of prophylactic measures or of symptomatic limitations prompted the action of which the plaintiff complains.⁴⁸

In support of our approach, we argue that equality entails a methodological prohibition against the general characterization of members of some classifications, but not of others, in terms of the limitations of a subgroup of the classification. In doing so, we borrow from contemporary constructions of the classification of sex and race. Thus, for instance, we note that equal protection requires that women in general not be classified as unable to defend themselves because a subclass cannot do so unless men in general also are so classified in recognition of the subclass of men who cannot do so.⁴⁹ Nor does equal protection permit the social opportunities of people of a particular geographically-identified heritage, such as African-Americans, to be limited because a subclass may not be positioned to realize them.

Half a century ago, equal protection did not reach to women because, as a class, they were characterized as unable to defend themselves and others against rowdy or violent males, even though only a subclass of women was too weak to do so.⁵⁰ Today, the class of women generally is thought competent in this regard,⁵¹ although presumably the existence of a subclass too weak to do so remains the same.⁵² Similarly, following the U.S. Civil War, African Americans “had to contend with claims, issued with scientific certainty, that, however acculturated they were, their color was a visible marker for an inherent savagery. Journalists chided them for feeling superior to their scantily clad, undulating cousins dancing to ‘tom-toms.’”⁵³ Today, the class of people who trace their ancestry to Africa generally is thought capable of behavior as civilized as that of people of every other heritage, nor is any variation of

dermal pigmentation imagined to dispose to, or protect against, an individual's acting savagely.

Just as, in principle, everybody can be identified in terms of race and sex, everybody also has a genetic identity. We take a person's genetic identity to be constructed in terms of inheritable species-typical biological characteristics, and inheritable anomalous biological characteristics. We speak of "inheritable" rather than "inherited" characteristics advisedly in order to include the first generation of a mutation that might be inherited by future offspring. There are three reasons why "genetic identity" should be understood somewhat broadly here. First, in the future, biologists may discover additional mechanisms of biological inheritance that are not properly "genetic" but affect the inheritable constituents of people's identity. Second, multifactorial diseases for which there is a genetic disposition should be considered to affect an individual's genetic profile, even though nongenetic factors also come into play. Third, discrimination protection should be available in cases of adverse actions prompted by mistaken beliefs that a characteristic is genetically based, not just in cases occasioned by accurate understanding of the mechanisms of biological inheritance.

In current practice, individuals whose inheritable characteristics dispose them toward a species-typical biological life course usually are thought of as having a normal genetic identity, whereas individuals whose inheritable characteristics dispose toward an anomalous biological life course are likely to be assigned "non-normal" genetic identities. Individuals who have a genetic disposition toward disease, but whose biological life courses do not diverge markedly from species-typicality, nevertheless are likely to be labeled as "non-normal." Further, individuals whose biological life courses do diverge from species-typicality as a result of infection or accident, rather than inheritance, sometimes have been labeled with a genetic identity as a proxy for characteristics that are not, in fact, inheritable. Thus, for instance, offspring of families in which successive generations engage in disapproved behavior, such as having children out of wedlock, sometimes have been labeled as "feeble-minded" and have been sterilized to interrupt the transmission of the "disease."⁵⁴

For purposes of the law, we argue, the population of the legal classification of genetically anomalous people should be characterized not in terms of stereotypes but, instead, through empirical study of the relevant biological groups. This is the standard articulated in *UAW v. Johnson Controls, Inc.*⁵⁵ where the Supreme Court held that to justify the exclusion of women of child-bearing age from jobs involving lead exposure, the employer was required to show that the workers' "sex or pregnancy actually interfere[d]" with their ability to perform their jobs,⁵⁶ in order to establish that belonging to the class of women of child-bearing age was a bona fide occupational disqualification. Because Johnson Controls had not established this connection empirically, the Court reasoned that the

exclusionary fetal protection policy was driven by indefensible self-serving motivations (for example, seeking to avoid tort liability).⁵⁷ To prevent genetic anomalies from being used as proxies to disqualify their possessors from opportunity, employers would equally be required to prove that having a certain genetic identity constitutes a bone fide job disqualification by showing, empirically, that it manifests without exception as an unmitigatable dysfunction that actually prevents performing the job.

As a practical matter, due to the Supreme Court's decision in *McDonnell Douglas Corp. v. Green*,⁵⁸ Title VII claimants must plead a prima facie case of discrimination to avoid dismissal at the summary judgment stage of proceedings. According to *McDonnell Douglas* (and its progeny), the level of proof required for a Title VII plaintiff, whether a woman or a person of color, to meet the burden of production is "minimal."⁵⁹ Moreover, case law applying proscriptions against discrimination on the basis of race and sex now proceeds from the initial presumption that the prevalent characteristic of all protected individuals is their competence to perform, with a subcategory of individuals within the classification who will be unable to so function.⁶⁰ This initial presumption will either be borne out or disproved by empirical evidence when particular actions are challenged.

In line with our current treatment of women and racial minorities, the burden of proof in genetic discrimination cases should shift from requiring individuals who are anomalous to demonstrate that they can be competent and productive despite being anomalous to requiring whoever would exclude them from productive opportunity based on their anomalies to prove that they cannot.⁶¹ Such a proscription would tailor genetic antidiscrimination protection to those instances when individuals have had their opportunities inequitably reduced because of stereotypic beliefs about the significance of their genetic identity. The presumption would be that members of the class of genetically anomalous people will remain competent and productive, although a subclass will not do so, rather than that class membership means future deficiency even though a (possibly very large) subclass may escape this fate.⁶² People with higher than typical risk of genetic disease as a class would be presumed to remain viable employees, although some will not do so. We thereby would cease to use genetic anomalies as proxies for performance limitations.

Some might argue that being assigned a genetic identity is only peripherally like being identified in terms of race and sex.⁶³ Genetic risk might be thought to be more specifiable than risks associated with race and sex. In response, we point out that the attribution of risk associated with biological inheritance is no more specifiable in principle than that associated with race or sex. The challenge in all three domains is to guard against unconfirmed or poorly understood associations and to act only on

empirically well-verified, finely detailed ones.

Like some assignments of identity in terms of race and sex, some genetic identities have been made especially vulnerable to adverse action based on pretexts and stereotypes. Historically, impairments have served as proxies for genetic identities. For example, in the name of relieving future generations of so-called burdensome populations, California sterilized individuals with blindness or epilepsy during the 1930s. Only in a comparatively small number of instances are these conditions inherited, but courts permitted California to ignore this distinction.⁶⁴

Attention to the social history of classifying people in terms of biological inheritance is important here. Historically, certain genetic identities have been characterized as burdensome to individuals and to society as a whole. Such attributions very often emerge from admixtures of little fact and much fiction. Thus, courts should carefully scrutinize genetic categorization to protect groups that historically have been constructed as minorities subject to unequal treatment and denied opportunity on the basis of stereotypical assumptions about inheritable defects. To do so, jurists will need to have the benefit of extensive research from social and medical history, rather than be influenced by unsubstantiated proxies reflecting social convention. The task requires careful empirical study of the capabilities and limitations of people with genetic anomalies, and an understanding that the accuracy with which a genetic test can predict either the onset or effect of disease depends on many factors. These include variances in gene expression, a test's technical precision, the stability of linkage between genetic markers and suspect genes, the frequency of false positives and false negatives, and interference from genetic recombination. With few exceptions, extrapolating from the presence of given genetic anomalies to a prediction that the individual will develop the associated disabilities is statistically uncertain. For example, perhaps 50 to 60 percent of women who inherit the "defective" mutations of the BRCA1 or BRCA2 gene associated with cancer will develop breast or ovarian cancer during their lifetimes. Moreover, in circumstances involving these, penetrance estimates for breast cancer range from 36 to 85 percent, and for ovarian cancer from 10 to 44 percent. Thus, although the presence of particular genes may identify individuals as belonging to an increased risk group (an extremely useful category from a public health perspective), the likelihood of those genes expressing themselves, if at all, is unclear.⁶⁵ Legal theory would benefit from the development of better models for sorting, weighing, and applying, and for preventing the misapplication of, genetic information. How, then, can legal classifications do justice to the nature of genetic identity?

We propose that classification of genetic identities be constructed to acknowledge that genetic science supports judgments that are probable at best. This approach recog-

nizes that in most cases genes associated with genetic diseases have less than 100 percent penetrance and also that many genetic diseases are multivariant, meaning that several factors must combine to induce the onset of symptoms. Individuals who are at higher than species-typical risk for onset are nevertheless very often unlikely to become symptomatic. Further, even individuals who are symptomatic may maintain their competence and productivity, especially if mitigating measures for their disease can be found.⁶⁶

It follows that there is at least one other feature our model requires. The standard of proof for excluding individuals on the basis of their genetic identities must present a reasonably high bar. Defending the exclusion of individuals on the basis of their genetic identities must require far more than a mere showing that their propensity to a genetic disease is more than species-typical. We propose a high standard of protection to align the law with current scientific realities regarding genetic knowledge. With few exceptions, employers (and society at large) cannot predict accurately the effect DNA anomalies have on particular individuals. Thus, in the absence of those rare instances of 100 percent penetrance where it can also be demonstrated that the individual can no longer perform her job functions, the presumption must remain that members of the class of genetically anomalous people will remain competent and productive.⁶⁷ Placing the hurdle so high for legitimating exclusion from employment gives courts a clear standard that they can enforce when faced with the difficult issues raised by genetic discrimination. For any level of penetrance below 100 percent, employers will be unable, given current scientific knowledge, to prove an unexceptionable connection between an individual's genetic identity and her inability to perform the social function of work.

Parenthetically, our proposal does not take the thesis of genetic exceptionalism as a premise. In most versions, genetic exceptionalism involves a claim about how genetic information is different from other information. Commentators such as Lainie Friedman Ross,⁶⁸ Sonia Suter,⁶⁹ and others⁷⁰ who either support or reject the doctrine of genetic exceptionalism argue either that protection against genetic discrimination requires specially targeted legislation because of the special characteristics of genetic information, or else that familiar broad approaches to protection will suffice because genetic information introduces no new problems. We agree with genetic exceptionalists as to the especially problematic character of genetic information, but we argue that no advantage is gained by characterizing it as unique.

The issue of personal and social cost

We also do not argue for the abolition of any use of genetically informed medical information in employment

decisions. In the future, more and more medical information will have a genetic component. Instead, we take issue with distorting such information into proxies, based upon empirically unfounded stereotypes that motivate the general exclusion of people with genetic differences regardless of competence or qualification.

Denying individuals work on the basis of their genetic identities may seem, from an individual employer's personal point of view, to be statistically rational because it reduces the chance of hiring and training people who subsequently manifest dysfunctions and either require a disability-related accommodation or increase insurance costs.⁷¹ Similar arguments about their burdensomeness used to be rolled out to defend excluding women from desirable workplaces. Nevertheless, it is neither statistically justifiable nor in the interests of the collective social good to keep productive individuals out of the economy and thereby to require that public resources be devoted to supporting them while they themselves are prevented from being productive.

The view that few people warrant being protected and that discrimination protection should therefore be narrowly targeted, appears to emerge from concern about the costs of covering a broad range of individuals. For example, Colin Diver and Jane Cohen maintain that banning genetic discrimination within the employment markets would "cause significant welfare losses due to the distortion of allocative efficiency."⁷² They adopt a neoclassical model of the labor market, one which presumes that voluntary exchanges between willing and informed individuals are "the paradigm of efficiency-enhancing transaction."⁷³ Consequently, prohibiting employers from obtaining and acting on information about their employees' genetic identities is thought to cause unjustified "significant efficiency losses" by preventing them from properly assessing (and avoiding) the supposed higher costs of those conditions.⁷⁴

Diver and Cohen's assessment fails for several reasons. Primarily, they make presumptive errors regarding the accuracy (and thus rationality) of predictive testing. Their argument stands up only if genetic screening can accurately predict whether an anomalous gene will express a debilitating condition *and also* correctly assess whether and to what extent each individual with the gene will be functionally impaired. Available scientific evidence about current and potential accuracy of genetic testing indicates that this is rarely the case.⁷⁵

Of course, courts have authorized employers to exclude employees on the ground that their past actions (for example, working under the influence of alcohol) may be used as a proxy for future behavior, but this line of argument cannot convincingly be extended to authorize the use of proxies for future performance in circumstances involving genetic discrimination. The analogy fails because, by its very nature, genetic discrimination is not prompted

by an employee's past record of impaired performance and therefore cannot be defended on the basis of expectations that the future will resemble the past. Unlike the formerly inebriated employee, the genetically atypical but asymptomatic worker has no history of genetically related impaired performance to give her employer a basis for expecting inadequate execution of the job.

Diver and Cohen propose that "armed with genetic test results and corresponding epidemiological data on the correlation between genotype and phenotype, employers may be able to improve the quality of the predictions they can make about the two determinants of job performance: intensity and quality of effort."⁷⁶ They also suppose that "genetic information may someday provide a more reliable basis for measuring deficits in job-relevant skills that can be corrected by the design of training programs."⁷⁷ In other words, by administering medical tests, employers could determine whether medicating, re-educating, or firing a worker who cannot execute job tasks is the optimally effective approach. As is characteristic of such discussions about permitting or prohibiting medical information to influence employment decisions, these authors deny that they are embracing genetic determinism. Equally characteristically, they fail to provide an alternative model which would support claims to predict the intensity and quality of individuals' job performance on the basis of inherited characteristics of their phenotypes.

Yet, even if predictive genetic testing could make these prognostications, Diver and Cohen also err in their assertion that economic efficiency mandates the allowance of genetic discrimination within the labor market. Strong policy reasons, in fact, militate against such a conclusion. Everyone is potentially vulnerable to genetic discrimination because we each have some atypical or anomalous genes that may, in future, become suspect as new scientific knowledge increases the pool of individuals believed to be at heightened risk of one or another genetic dysfunction. Consequently, society's interests in bringing about the most productive overall arrangement of its citizens override individual employers' interests in reducing the risk that their particular cohorts of workers will be less net-productive. It also bears repeating that the considerable public investment in genomic research is aimed at securing a public benefit by improving the long-term health and consequently the productivity of the population. Individual employers who create an environment in which employees fear genetic testing risk are sacrificing this investment's return.

Acknowledging genetic difference

Many commentators who consider the implications of genetic difference label genetic differences as diseases rather than regarding these differences as variations which sometimes indicate when certain individuals may be at greater

risk of disease.⁷⁸ In so doing, they import a criterion of genetic normality which, in a thoughtful article published in 1995, Susan Wolf termed "Geneticism."⁷⁹ Wolf cautioned that approaches to genetic discrimination may mistakenly focus on individual acts of discrimination rather than on the practice that promotes discrimination, namely, "creating genetic categories, actively looking for any kind of information about people in order to sort them into those categories, and harboring attitudes and prejudices that motivate such behavior."⁸⁰ She believed that formal equality theory wrongly requires groups manifesting differences to be treated as if they had none of these differences. Thus, she argued, when applied to genetics, antidiscrimination policy cannot help but presume that "there is such a thing as a 'normal' genotype, and that the goal is to change the treatment of people who deviate."⁸¹ In reality, however, there is no biological underclass. "There is nothing neutral or scientifically 'real' about identifying a genetic norm ... if no one actually possesses this fictive 'normal' genotype, it is completely unclear what it means to treat someone as if they did have it."⁸²

Wolf argued that as a society we must not be misled into thinking that a strategy which failed in regard to sex discrimination — namely, attempting to assimilate members of a subordinated group to the dominant group — will work for genetic discrimination.⁸³ By reifying the properties of the dominant group into "a norm that does not exist," assimilation serves to "merely entrench genetic bias."⁸⁴ Rather, we must abandon the stereotype that individuals with genetic variations are deviant, abnormal, or defective, rather than simply variant.

We agree with many of Wolf's assertions and take notice of her concerns. We nevertheless are more cautious than she about the usefulness of jettisoning equality as a value. We do not believe that equality-based paradigms necessarily impose the characteristics of the dominant or most populous group on other groups as norms or standards. Indeed, as we have argued, equality invites a methodology that acknowledges the differences between groups but eschews unfounded inferences based on these differences.

In sum, we do not object as strongly as Wolf to "seeing people as their genes"⁸⁵ because we think it possible for justice to acknowledge differences in genetic identity without using "genetic notions to privilege some individuals and subordinate others."⁸⁶ Broadly, constructing classifications on an equality basis means that no one may be treated with less favorable presumptions, or be forced to bear a heavier burden of proof, by virtue of being assigned to a group that is thought to be biologically atypical. Such an equality-based approach to classification addresses the concern that characteristics associated with one genetic class become a standard for members of other classes. On this approach to equality, characteristics of the

members of one genetic classification may not be made into a standard or norm for other classes. Consequently, on this approach no particular genetic identity is privileged.

CONCLUSION

We have argued for creating protection against discrimination "on the basis of genetic identity" for everyone, rather than only for "qualified individuals" who are symptomatic to the point of being disabled, or who have positive results of predictive genetic testing but are not symptomatic. Everyone has a racial and a sexual identity, and a genetic identity as well. Further, everyone is genetically anomalous in some way. Everyone exhibits some differences from genetic species-typicality because species-typicality is as much an idealized construction as the idea of the "average person." Given these considerations, equality-based protection against genetic discrimination, with a scope similar to that for race and sex discrimination, is needed by everyone alike.

What medicine will discover about the problems attendant on each individual's genetic configuration, and which genetic configurations any employer may read as being proxies for unsuitability, is, at present, a lottery. Yet medical research reveals more and more every day about using genetic information beneficially to prevent or delay the onset of genetic conditions that may be disadvantageous. The population of the group that can take such mitigating measures is growing fast and growing large. Excluding this group from social opportunities cannot help but be enormously costly to the group's members, to society, and, as well, to our faith that science can improve our lives. To save genomics, the major scientific achievement of our era, from occasioning such lamentable outcomes, we have proposed an approach to protect the people who have the most both to lose and to gain from genomics by protecting everyone alike.

REFERENCES

1. Although we focus on employment-related aspects of these potential harms throughout this article, potential harm also exists in other areas such as immigration, workmen's compensation, and especially the provision of health insurance.
2. We refer below to two employment discrimination suits in which workers alleged that their employers excluded them from workplace opportunity based on their disposition to carpal tunnel injury. See *E.E.O.C. v. Woodbridge Corporation*, 263 F.3d 812 (8th Cir. 2001); *E.E.O.C. v. Burlington Northern Santa Fe Railroad Co.*, No. C01-4013 (N.D. Iowa filed February 9, 2001) (settlement described at <<http://www.eeoc.gov/press/4-18-01.html>>).

3. A defense that, according to one health-care advocate, is becoming more frequent. See *Assessing HIPAA: How Federal Medical Record Privacy Regulations Can Be Improved: Hearing Before the Subcommittee on Health, House Committee on Energy and Commerce*, 107th Cong. (2001) (testimony of Janlori Goldman).

4. See G. Kolata, "Using Gene Tests to Customize Medical Treatment," *New York Times*, December 20, 1999, at A1.

5. The general inadequacy of federal protection was noted recently by J.L. Hustead and J. Goldman, "Genetics and Privacy," *American Journal of Law & Medicine*, 28 (2002): 285-307, but these commentators do not offer guidance on how to address this shortcoming.

6. See A.L. Allen, "Genetic Privacy: Emerging Concepts and Values" and M.A. Rothstein, "Genetic Secrets: A Policy Framework," in M.A. Rothstein, ed., *Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era* (New Haven, CT: Yale University Press, 1998): 31-59 and 451-496.

7. See P.T. Kim, "Genetic Discrimination, Genetic Privacy: Rethinking Employee Protections for a Brave New Workplace," *Northwestern University Law Review* (forthcoming).

8. *Id.*; see also G.J. Annas, "Privacy Rules for DNA Databanks: Protecting Coded Future Diaries," *JAMA*, 270 (1993): 2346-50.

9. See L.B. Andrews, "A Conceptual Framework for Genetic Policy: Comparing the Medical, Public Health, and Fundamental Rights Models," *Washington University Law Quarterly*, 79 (2001): 221-85, at 277-84 (arguing that protecting genetic privacy is a "fundamental rights issue" that "has implications for one's freedom of association, a constitutionally protected right").

10. M.Z. Madiski, "Genetic Privacy: New Intrusion on New Tort?," *Creighton Law Review*, 34 (2001): 965-1026.

11. We are grateful to an anonymous referee for bringing this point to our attention.

12. See B.R. Furrow et. al., *The Law of Health Care Organization and Finance* (4th ed.) (St. Paul, MN: West Group, 2001).

13. 5 U.S.C. § 552(a) (1999). Another example is the Standards for Privacy of Individually Identifiable Health Information, 65 Fed. Reg. 82, 462, 82,471 (December 28, 2000), which prohibit nonauthorized use of genetic material for research, but do not avoid the problems we set forth below. For a discussion of the regulation's implications for scientific research, see J. Kulynych and D. Korn, "Use and Disclosure of Health Information in Genetic Research: Weighing the Impact of the New Federal Medical Privacy Rule," *American Journal of Law & Medicine*, 28 (2002): 309-24.

14. 17B B.J. REV. STAT. 30-12 (1996). A catalog of state provisions is set out in the National Conference of

State Legislators website, *available at* <<http://www.ncsl.org/programs/health/genetics/prt.htm>>. Employment discrimination is not specifically proscribed in these statutes, but is incorporated through a privacy approach. Specifically, employers cannot refuse to hire individuals based on their refusal to submit to genetic tests. In other words, individuals who insist on the privacy of their genetic information cannot be penalized.

15. See A. Silvers, "Primary Care Physicians and the Duty to Inform about Genetic Discrimination," *American Journal of Bioethics*, 1, no. 3 (2001): 1a.

16. We thank an anonymous reviewer for suggesting that we include this observation.

17. 42 U.S.C. § 12,001 (1994).

18. See P.S. Miller, "Is There a Pink Slip in my Genes? Genetic Discrimination in the Workplace," *Journal of Health Care Law & Policy*, 3 (2000): 225-65.

19. 42 U.S.C. § 12,102 (2)(A)-(C) (2002).

20. A thorough discussion of the "regarded as" prong can be found in M.B. Travis, "Leveling the Playing Field or Stacking the Deck? The 'Unfair Advantage' Critique of Perceived Disability Claims," *North Carolina Law Review*, 78 (2000): 901-1011.

21. 29 C.F.R. § 1630.2(1). The reasons an employer might so err are addressed in M.B. Travis, "A Disability or not a Disability? A Causal Attribution Analysis of Perceived Disability Claims," *Vanderbilt Law Review*, 55 (2002): 481-571.

22. See 136 CONG. REC. H4623 (daily ed. July 12, 1990).

23. See 2 U.S. EEOC Compliance Manual, Order 915.002, at 902-45 (1995); EEOC Policy Guidance on Executive Order 13145: To Prohibit Discrimination in Federal Employment Based on Genetic Information (July 26, 2000), *available at* <<http://www.eeoc.gov/docs/guidance-genetic.html>>; EEOC Enforcement Guidance: Disability-Related Inquiries and Medical Examinations of Employees Under the Americans with Disabilities Act (ADA) (July 27, 2000), *available at* <<http://www.eeoc.gov/docs/guidance-inquiries.html>>; "EEOC Letter re: Genetic Discrimination," *National Disability Law Reporter*, 7 (1995), 362.

24. See Miller, *supra* note 18, at 246.

25. A good example being *Sutton v. United Airlines, Inc.*, 527 U.S. 471 (1999), where the Court refused protection to plaintiffs rejected from employment on the basis of their myopia on the ground that the number of disabled people in the country would far exceed Congress's projections if myopics were included.

26. 42 U.S.C. § 12111(8).

27. *Id.*

28. We thank an anonymous referee for bringing this point to our attention.

29. 42 U.S.C.A. § 12201(c); 29 C.F.R. § 1630.16(f) and Appendix to Part 1630, at § 1630.16(f); *Doe v. Mutual of Omaha Ins. Co.*, 179 F.3d 557 (7th Cir. 1999); *Ford v. Schering-Plough Corp.*, 145 F.3d 601 (3rd Cir. 1998).

30. This is a difficult task in any context. See generally S. Sturm, "Second Generation Employment Discrimination: A Structural Approach," *Columbia Law Review*, 101 (2001): 458-568.

31. 42 U.S.C. § 12113(b). The standard is the same as that of "significant risk" under the Rehabilitation Act. See *School Board of Nassau County v. Arline*, 480 U.S. 273 (1987).

32. We thank an anonymous referee for alerting us to this point.

33. *Chevron U.S.A., Inc. v. Echazabal*, 122 S.Ct. 2045, 2047 (2002) (interpreting 29 C.F.R. § 1630.15(b)(2)).

34. A discussion of the way in which the ADA has been subject to constricted interpretation, especially as it relates to temporary or potential disabilities, is set forth in R.L. Burgdorf, Jr., "Substantially Limited" Protection From Disability Discrimination: The Special Treatment Model and Misconstructions of the Definition of Disability," *Villanova Law Review*, 42 (1997): 409-584.

35. As more of the genetic mechanisms that influence the development of disease are discovered, we are likely to find that almost everyone has a higher than species-typical probability of developing one or another disease. This is not to say, of course, that all, or even most, of those with such genetic dispositions actually will develop disease.

36. See *EEOC v. Burlington Northern Santa Fe Railroad Co.*, No. C01-4013 (N.D. Iowa filed Feb. 9, 2001), available at <<http://www.eeoc.gov/press/4-18-01.html>>.

37. *EEOC v. Woodbridge Corporation*, 124 F. Supp. 1132 (W.D. Mo. 2000). The ruling was affirmed by the Eighth Circuit Court of Appeals, which reasoned that since the applicants were not limited in a wide range of jobs, the employer could not have perceived them as being disabled. 263 F.3d 812 (8th Cir. 2001).

38. By which we reference, respectively, individuals whose symptoms include substantial limitations of major life activities; individuals who have no symptoms; and people to whom the causative agent of a disease is attributed, but who have not shown symptoms of that condition.

39. See G. Johnson, "Update on Terri Sergeant's Genetic Discrimination Case," available at <<http://www.alpha1.org/newsmakers/index.htm>>. Sergeant received an EEOC Letter dated November 21, 2001 (Charge No. 14AA00039), permitting her to file a complaint. We thank Ms. Sergeant's attorneys for providing us with this and other information, including a copy of the EEOC letter. What follows is drawn both from the website source and personal conversations.

40. H.R. 602, 107th Congress (2001). Most recently, the Subcommittee on Commerce, Trade, and Consumer Protection held a brief hearing on July 11, 2001, at which the measure's co-sponsors and five other supporters, including Dr. Craig Venter of Celera Genomics, advocated its passage. Written and audio transcripts are available at <<http://energycommerce.house.gov/107/hearings/>

07112001Hearing322/hearing.htm>.

41. Many state laws addressing genetic discrimination are similar in this respect. A chart of genetic information and health insurance enacted legislation is available at <http://www.nhgri.nih.gov/Policy_and_public_affairs/Legislation/insure.htm>.

42. See H.R. 602, 107th Cong. (2001).

43. See *id.* Many state laws addressing genetic discrimination are similar to H.R. 602 in scope.

44. Donepezil hydrochloride (brand name: Aricept), the number one prescribed Alzheimer's medication, is a clinically proven, well-tolerated, once-daily treatment for mild to moderate Alzheimer's disease. An analysis of 671 patients, presented at the 14th annual meeting of the American Association of Geriatric Psychiatry in 2001, indicated that persistent treatment with this drug may enable individuals to function at home for approximately 2 years longer than untreated patients. To obtain the best results, early intervention is indicated. In April of 2001, more than 1.4 million patients in the U.S. were being treated with this drug. See *AAGP: Alzheimer's Drug Aricept (Donepezil) May Delay Need For Nursing Home Placements*, available from the Doctor's Guide website at <<http://www.pslgroup.com/dg/1f7166.htm>>.

45. See *Sutton v. United Airlines*, 527 U.S. 471 (1999) (finding that plaintiffs with severe myopia were not entitled to protection under the ADA because their vision was correctable with the use of glasses); *Murphy v. UPS*, 527 U.S. 516 (1999) (holding that hypertensive mechanic was not "substantially limited" in a major life function because he could control his condition with medication); *Kirkingburg v. Albertson's, Inc.*, 527 U.S. 555 (1999) (suggesting that the human body's ability to compensate for disability should be considered as a mitigating measure).

46. A good overview is provided in Miller, *supra* note 18.

47. 28 U.S.C. § 2000e (1994).

48. We find unconvincing the faith one commentator has in a recent amendment to Massachusetts' antidiscrimination provision. The statute, which prohibits discrimination "because of" the race, sex, and other various characteristics (not including disability) of an individual, and was amended to include "genetic information," fails to protect individuals for the reasons stated. Accordingly, duplicating this enactment on the federal level will equally fail. See P.A. Roche, "The Genetic Revolution at Work: Legislative Efforts to Protect Employees," *American Journal of Law & Medicine*, 28 (2002): 271-84.

49. See, e.g., A. Silvers and M.A. Stein, "Disability, Equal Protection, and the Supreme Court: Standing at the Crossroads of Progressive and Retrogressive Logic in Constitutional Classification," *University of Michigan Journal of Law Reform*, 35 (2001): 81-136.

50. *Goesart v. Cleary*, 335 U.S. 464 (1948).

51. *Cleburne v. Cleburne Living Center*, 473 U.S. 432 (1985).

52. See Silvers and Stein, *supra* note 49.

53. P.J. Giddings, "Lives of the Poets," *New York Times Book Review*, August 18, 2002, at 7.
54. A type of practice approved by the Supreme Court in *Buck v. Bell*, 274 U.S. 200 (1927). See generally R.L. Burgdorf and M. Burgdorf, "The Wicked Witch is Almost Dead: *Buck v. Bell* and the Sterilization of Handicapped Persons," *Temple Law Quarterly*, 50 (1977): 995-1034.
55. 499 U.S. 187 (1991).
56. *Id.* at 200-01, 205.
57. *Id.* at 208-11 (explaining why fear of potential tort liability was an insufficient ground on which to allow the employer's action).
58. 411 U.S. 792 (1973).
59. *Id.* A general overview is available in J.G. Cook and J.L. Sobieski, Jr., *Civil Rights Actions*, Vol. 4, 21-320 to 21-322 (New York, NY: Mathew Bender, 2001).
60. What follows draws from parallel arguments we make elsewhere. See Silvers and Stein, *supra* note 49; see also A. Silvers and M.A. Stein, "From Plessy (1896) and Goesart (1948) to Cleburne (1985) and Garrett (2001): A Chill Wind from the Past Blows Equal Protection Away," forthcoming in Linda Hamilton Krieger, ed., *Backlash Against the Americans with Disabilities Act: Interdisciplinary Perspectives* (Ann Arbor: University of Michigan Press).
61. See Silvers and Stein, *supra* note 49.
62. *Id.* Even in cases where a mutation appears to have 100 percent penetrance, this fact about the mutation is an empirical conclusion. Consequently, it is in principle always subject to disconfirmation.
63. We thank the anonymous reviewer who brought this question to our attention.
64. See Burgdorf, *supra* note 54.
65. A good overall treatment is J.P. Evans et al., "The Complexities of Predictive Genetic Testing," *British Medical Journal*, 622 (2001): 1052. On the issues of expression and penetrance see E.B. Claus, et. al., "The Genetic Attributable Risk of Breast and Ovarian Cancer," *Cancer*, 77 (1996): 2318; S. Thorlacius et. al., "Populations-Based Study of Risk of Breast Cancer in Carriers of BRCA2 Mutation," *Lancet*, 352 (1998): 1337; D. Ford, et. al., "Risks of Cancer in BRCA1-Mutation Carriers," *Lancet*, 343 (1994): 692.
66. See L.B. Andrews et al., eds., *Assessing Genetic Risks: Implications for Health and Social Policy* (Washington, D.C.: National Academy Press, 1994).
67. And, even in cases where a mutation appears to have 100 percent penetrance, this fact about the mutation is an empirical conclusion.
68. See L.F. Ross, "Genetic Exceptionalism vs. Paradigm Shift: Lessons from HIV," *Journal of Law, Medicine & Ethics*, 29, no. 2 (2001): 141-48.
69. See S. Suter, "The Allure and Peril of Genetics Exceptionalism: Do We Need Special Genetics Legislation?," *Washington University Law Quarterly*, 79 (2001): 906-1002.
70. G.J. Annas et al., "Drafting the Genetic Privacy Act: Science, Policy, and Practical Considerations," *Journal of Law, Medicine & Ethics*, 23, no. 4 (1995): 360-66.
71. For an elaboration of these assumptions, which underlie much neoclassical analysis, see R.A. Epstein, *Forbidden Grounds: The Case Against Employment Discrimination Laws* (Cambridge, MA: Harvard University Press, 1992), at 480-94.
72. C.S. Diver and J.M. Cohen, "Genophobia: What is Wrong with Genetic Discrimination?," *University of Pennsylvania Law Review*, 149 (2001): 1439-82.
73. *Id.* For a critique of this model as applied to disabled workers, see M.A. Stein, "Labor Markets, Rationality, and Workers with Disabilities," *Berkeley Journal of Employment & Labor Law* (2000): 314-34; M.A. Stein, "Market Failure and ADA Title I," in L.P. Francis and A. Silvers, eds., *Americans with Disabilities: Exploring Implications of the Law for Individuals and Institutions* (New York, NY: Routledge Press, 2000): 193-208. Of course, how these assessments play out depends on what is factored into the notion of social good. See M.A. Stein, "Empirical Implications of Title I," *Iowa Law Review*, 85 (2000): 1671-90.
74. Diver and Cohen, *supra* note 72.
75. A good overview is set out in Andrews, *supra* note 66, at 59-115.
77. *Id.* at 1642.
78. An early example is D.W. Brock, "The Human Genome Project and Human Identity," *Houston Law Review*, 29 (1992): 7-22 (analyzing the implications of genomics on societal notions of who is "normal.").
79. S.M. Wolf, "Beyond 'Genetic Discrimination': Toward the Broader Harm of Geneticism," *Journal of Law, Medicine & Ethics*, 23, no.4 (1995): 345-53.
80. *Id.* at 347.
81. *Id.* at 348.
82. *Id.*
83. See *id.* at 350.
84. *Id.* at 345-46.
85. *Id.* at 346.
86. *Id.*; see also A. Silvers, "Formal Justice" in A. Silvers, D. Wassermann, and M. Mahowald, *Disability, Difference, Discrimination: Perspectives on Justice in Bioethics and Public Policy* (Lanham, MD: Rowman and Littlefield, 1998): 13-146.