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An Equality Paradigm for Preventing Genetic Discrimination

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INTRODUCTION

On June 26, 2000, scientists announced at a White House news conference that they had completed mapping the human genome sequence, the human race's genetic blueprint.[1] This pronouncement generated tremendous and well-deserved excitement. Genomics, the study and application of genetic information, promises to be an unparalleled tool for improving public health.[2] Genetic testing can identify asymptomatic individuals who are at risk of becoming ill themselves or bestowing illness on their children.[3] As a result, individuals who test positive can take prophylactic measures to slow or stop disease and can also reduce the births of progeny at high risk of compromised health.[4] At the same time, predictive genetic testing

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[1] Nicholas Wade, *Reading the Book of Life: The Overview: Genetic Code of Human Life is Cracked by Scientists*, N.Y. TIMES, June 27, 2000, at A1. For a general overview, see Ari Patrinos & Daniel W. Drell, *Introducing the Human Genome Project: Its Relevance, Triumphs, and Challenges*, 36 JUDGES J. 3 (1997).

[2] *See generally* UNIVERSITY OF KANSAS MEDICAL CENTER, GENETICS EDUCATION CENTER, *at* http://www.kumc.edu/gec/ (last visited Sept. 23, 2002) (providing information on the use of genetic information).

[3] *See id.*

[4] The ability to alter one's genetic material does not yet exist. However, profound ethical issues will be presented when such technology comes to the fore. *See, e.g.*, George J. Annas, *The Man on the Moon, Immortality, and Other Millennial Myths: The Prospects and Perils of Human Genetic Engineering*, 49 EMORY L.J. 753, 779-82 (2000) (urging the adoption of international rules to govern scientific advances that threaten the integrity of the human race); *see also* Michael J. Reiss, *What Sort of People Do We Want? The Ethics of Changing People Through Genetic Engineering*, 13 NOTRE DAME J.L. ETHICS & PUB. POL'Y 63, 76-85 (1999) (evaluating the

threatens unprecedented harm in its potential to engender (and then defend on the grounds of alleged statistical probability) discriminatory treatment in employment.[5] Consequently, scientists most involved in the Human Genome Project[6] and politicians most supportive of it[7] recommend strong legal protections against genetic discrimination.

Nevertheless, while the Constitution[8] and the Privacy Act of 1974[9] provide some protection against the collection, use, and dissemination of genetic information on privacy grounds, effective federal regulations specifically protecting individuals from genetic discrimination in employment are almost nonexistent. Specifically, a single executive order bars federal agencies from discriminating in employment on the basis of "genetic information."[10] Despite repeatedly voiced intentions, Congress has yet to pass legislation specifically prohibiting misuse of genetic information in the area of employment, although a five-year-old bill is once more pending.[11] Notably, the Equal Employment Opportunity Commission ("EEOC") has had mixed initial success in applying the antidiscrimination provisions of the Americans with Disabilities Act ("ADA")[12] to the realm of genetic discrimination.[13] By contrast, the scope of state statutes varies by jurisdiction. About half of the jurisdictions prohibit workplace

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ethical acceptability of somatic gene therapy, germ-line therapy, and somatic or germ-line modification).

[5] While we discuss employment and health care related aspects of these potential harms throughout this Article, it bears noting that the potential harm we describe also extends to other areas sucb as immigration and workmen's compensation.

[6] One such scientist is Dr. Francis Collins, Director of the National Human Genome Research Institute. *See, e.g.*, Gina Kolata, *Using Gene Tests to Customize Medical Treatment*, N.Y. TIMES, Dec. 20, 1999, at A1.

[7] For example, while Dr. Francis Collins "prais[ed] the mapping announcement as having discovered the 'book of life,' " President Clinton cautioned, "[W]e must guarantee that genetic information cannot be used to stigmatize or discriminate against any individual or group." *Reading the Book of Life: White House Remarks on Decoding of Genome*, N.Y. TIMES, June 27, 2000, at F8.

[8] The Fourth, Fifth, and Fourteenth Amendments are particularly applicable. U.S. CONST. amends. IV, V, XIV. *See* discussion *infra* Part II.A.

[9] 5 U.S.C. § 552(a) (2000).

[10] *See* Exec. Order No. 13,145, 65 Fed. Reg. 6,877 (Feb. 8, 2000) [hereinafter Executive Order]. The promulgation's formal title is "To Prohibit Discrimination in Federal Employment Based on Genetic Information." *Id.*

[11] *See* Genetic Nondiscrimination in Health Insurance and Employment Act, H.R. 602, 107th Cong. (2001). The discussion in Part III.E examines how this putative legislation fits within existing theoretical frameworks. *See generally* Jeremy A. Colby, *An Analysis of Genetic Discrimination Legislation Proposed by the 105th Congress*, 24 AM. J.L. & MED. 443 (1998) (explaining that Congress has enacted legislation to prevent abuse of genetic information but that the legislation leaves loopholes for genetic discrimination to occur).

[12] 42 U.S.C. § 12101 (2000).

[13] *See infra* Part III.B-D.

discrimination on the basis of genetic information, and a handful of jurisdictions have established individuals' property rights to their personal DNA information.[14]

What federal protection that does exist or is under consideration—as public law, executive order, or agency guideline—has been developed within theoretical frameworks that fit poorly with the realities of genetic discrimination. These statutes, orders, and guidelines have been designed either to protect against violation of individuals' privacy or to ensure their equal treatment in obtaining social goods, services, and opportunities by prohibiting discriminatory actions.[15] Ethicists and legal scholars divide on whether these harms are properly conceptualized as "discrimination" and whether privacy or equal opportunity is the main right we need to protect.[16]

In this Article we argue for the creation of an equality-based protection similar to the protection that exists for race and sex discrimination. In doing so, we explore the confluence of genetic and disability discrimination and discuss some problems inherent in current approaches to statutory protection in both of these areas.[17] We show that the ADA, as well as current and proposed genetic discrimination laws, bifurcates the population into protected and unprotected groups. The ADA and specialized genetic discrimination law protect different groups that are, essentially, mirror images of each other while leaving an important part of the population unprotected.[18] In practice the ADA applies only to those individuals who are seriously symptomatic,[19] while genetic discrimination law extends only to those who are either nonsymptomatic[20] or asymptomatic.[21] Falling between these two poles and thus lacking

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[14] One example, *infra* note 130 and accompanying text, is the 1996 New Jersey Genetic Privacy Act, N.J. REV. STAT. § 17B:30-12 (1996).

[15] While an analysis of these alternative protection models is set forth in Parts II-III, it bears noting that this duality exists internationally as well. *See generally* Aart C. Hendriks, *Genetics, Data Protection, and Non-Discrimination: Some Reflections from an International (Human Rights) Law Perspective*, Position Paper Prepared for the Public Hearing of the Study Commission on the Law and Ethics of Modern Medicine on 'Consequences of Genetic Diagnostic' (Berlin), Oct. 16, 2000, *available at* http://www.bundestag.de/ftp/pdf_arch/med_hen.pdf.

[16] Assertions that treating people differently based on their genetic makeup is logical rather than discriminatory are set forth and addressed below in Part IV.B.

[17] *See infra* Part III.

[18] *Id.*

[19] "Seriously symptomatic" refers to those individuals whose symptoms substantially limit major life activities.

[20] "Nonsymptomatic" refers to those individuals who have no symptoms.

[21] "Asymptomatic" refers to those who have a disease with a known causative agent but who have not shown symptoms of that condition. One example is an individual, like Sydney Abbott (who we discuss in the context of her Supreme Court case in Part III.C-D), who tests positive for the virus that causes AIDS (HIV) but is asymptomatic.

protection is a large group of presymptomatic individuals with genetic anomalies that may never be expressed or, if expressed, may not manifest as unmitigatable functional impairments.[22] Because excluding this latter category of individuals from labor market participation (and attendant social opportunities) is probabilistically unjustifiable as well as enormously costly to society, we advocate their inclusion in the classification of the group targeted for genetic discrimination protection.[23] We also set to rest fears that broadly extending protection will increase transactional costs for everyone.[24] In making these assertions, we therefore diverge widely from existing legal scholarship. To date, commentators have advocated either greater application of the ADA to cases of genetic discrimination, or else the enactment of new legislation addressed solely to genetic discrimination, without either noting or addressing the exclusion from coverage of an important class of presymptomatic individuals.[25]

Part I describes predictive genetic testing.[26] It then considers genomics' most pertinent potential benefits and costs, those of regulating risks of illness and of discriminating against individuals on the basis of that information.[27] Part II evaluates the privacy model of protection and explains how this framework fails to correspond to the challenges presented by the misuse of genetic information in the workplace.[28] Part III assesses existing and potential disability and genetic antidiscrimination models and their limitations.[29] Part IV begins by examining how these antidiscrimination approaches

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[22] *See infra* Part IV.

[23] *Id.*

[24] *Id.*

[25] An early and well-argued example is Mark A. Rothstein, *Genetic Discrimination in Employment and the Americans with Disabilities Act*, 29 HOUS. L. REV. 23 (1992). For a more recent example, see Eugenia Liu, Bragdon v. Ahbott*: Extending the Americans with Disabilitics Act to Asymptomatic Individuals*, 3 J. HEALTH CARE L. & POL'Y 382 (2000). A lone exception among legal academic treatments is the brief (but astute) "counterpoint" essay, Henry T. Greely, *Genotype Discrimination: The Complex Case for Some Legislative Protection*, 149 U. PA. L. REV. 1483 (2001). Moreover, although we do not explicitly engage their assertions in this Article, commentators have either supported or rejected the doctrine of genetic exceptionalism by arguing that protection against genetic discrimination requires specially targeted legislation because of the unique characteristics of genetic information or that familiar broad approaches to protection will suffice because genetic information introduces no new problems. *See, e.g.*, Sonia M. Suter, *The Allure and Peril of Genetics Exceptionalism: Do We Need Special Genetics Legislation?*, 79 WASH. U. L.Q. 669 (2001). We agree with genetic exceptionalists as to the especially problematic character of genetic information, but believe that advantage is not necessarily gained by specifically targeted employment protections.

[26] *See infra* Part I.A.

[27] *See infra* Part I.B-C.

[28] *See infra* Part II.

[29] *See infra* Part III.

bifurcate the population into protected and unprotected groups while leaving the large group of presymptomatic individuals for whom mitigating measures may be effective against the manifestation of genetic disease unprotected from discrimination.[30] Part IV proceeds to demonstrate how excluding this latter category of individuals from employment opportunities is both probabilistically unjustifiable and enormously costly to society.[31] To ensure that this group of individuals receives equality of opportunity, we develop a new paradigm that safeguards individuals against genetic discrimination on an equality basis similar to the protection extended to race and sex.[32] Part IV concludes by discussing what such paradigm-shifting legislation would entail.[33]

I. BENEFITS AND COSTS OF PREDICTIVE GENETIC TESTING

The potential benefits of predictive genetic testing as a risk regulator are enormous, limited only by the rate at which scientists acquire greater knowledge of the human genome and its applications.[34] Concurrent with these benefits are prospective harms that could arise from misuse of this information to discriminate against individuals on the ground of statistical probability.

A. Predictive Genetic Testing

Predictive genetic testing typically is used to learn whether individuals who do not currently exhibit symptoms of certain diseases are at a higher than usual risk of developing them. The disease may be caused by a variation in a single gene, may be polygenic, or may result from environmental factors that are exacerbated by genetic factors.[35] Predictive genetic testing usually involves examining sample material taken from the individual whose degree of risk is being

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[30] *See infra* Part IV.A.

[31] *See infra* Part IV.B.

[32] *See infra* Part IV.C.

[33] *See infra* Part IV.D.

[34] We focus in this Article on the public health model of genetic policy. For a treatment of two other models, see Lori B. Andrews, *A Conceptual Framework for Genetic Policy: Comparing the Medical, Public Health, and Fundamental Rights Models*, 79 WASH. U. L.Q. 221 (2001).

[35] *See generally* ASSESSING GENETIC RISKS: IMPLICATIONS FOR HEALTH AND SOCIAL POLICY 59-115 (Lori B. Andrews et al. eds., 1994) (providing a general overview of predictive genetic testing).

assessed.[36] Sometimes, however, family members are tested to identify genetic markers that suggest the existence of a heritable anomaly.[37]

Tests used to make predictions about asymptomatic people may also be used as a diagnostic tool after symptoms appear.[38] Genetic testing can indicate that unusual respiratory infections are the result of cystic fibrosis,[39] that elevated cholesterol arises from hypercholestrolemia rather than diet,[40] or that neurological symptoms herald the onset of Huntington's disease.[41]

The degree of probability with which a genetic test predicts the onset of disease depends on many factors, among which are variances in gene expression, accuracy of the test, and the stability of linkage between genetic markers and suspect genes.[42] Only a few diseases are caused by genetic anomalies with one hundred percent penetrance—that is, genes whose presence invariably leads to development of the disease.[43] Some genetic tests suffer from a high occurrence of false positives and/or false negatives.[44] And genetic recombination can interfere with the predictive value of genetic markers.[45] Nevertheless, commentators have observed that "despite these known uncertainties and imprecisions, our aversion to disability is so great that people who receive a positive result for a disabling genetic condition may be stigmatized."[46]

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[36] In a minority of examples, the differential reaction of the eyes of people who have Alzheimer's disease to dilute solutions of Tropicamide can he used as a diagnostic tool. *See Predictive Testing: A Bite of the Apple*, HARV. HEALTH LETTER, June 1, 1995, at 20, *available at* 1995 WL 10430163. A thorough and technical outline is set forth in Neil A. Holtzman et al., *Predictive Genetic Testing: From Basic Research to Clinical Practice*, 278 SCIENCE 602 (1997).

[37] *Sec generally* DORIS TEICHLER-ZALLEN, DOES IT RUN IN THE FAMILY?: A CONSUMER'S GUIDE TO DNA TESTING FOR GENETIC DISORDERS (1997).

[38] *Id.*

[39] Faulty genes can result in excessively salty sweat secretions that adhere to lung coating-mucus, which is part of the clinical picture of cystic fibrosis. *See* Daniel Green, *Testing Ground for Gene Therapy: Cystic Fibrosis is Heavily Researched but Progress has been Faltering*, FIN. TIMES (London), Feb. 27, 1996, at 12.

[40] *See generally* A. Simon et al., *Comparison of Cardiovascular Risk Profile Between Male Employees of Two Automotive Companies in France and Sweden*, 13 EUR. J. EPIDEMIOLOGY 885 (1997) (assessing risk factors).

[41] Among the indicators of Huntington's disease are chorea and dementia. *See generally* STEDMAN'S MEDICAL DICTIONARY 343 (27th ed. 2000).

[42] *See generally* James P. Evans et al., *The Complexities of Predictive Genetic Testing*, 322 BRIT. MED. J. 1052, 1052-56 (2001).

[43] *Id.*

[44] *Id.*

[45] *See infra* Part IV.B (providing a greater exposition of these difficulties).

[46] Ani Satz & Anita Silvers, *Disability and Biotechnology*, *in* ENCYCLOPEDIA OF BIOTECHNOLOGY: ETHICAL, LEGAL AND POLICY ISSUES 173 (Thomas Murray & Maxwell Mehlman eds., 2000).

To mitigate responsibility for an employee's injury or disease, an employer might argue that the individual was pathologically disposed to such an outcome by, for instance, a gene for carpal tunnel syndrome ("CTS")[47] or beryliosis.[48] In this regard, confidence in the accuracy of genetic testing varies greatly, with a tendency to exaggerate in both directions. Neither now nor in the future will someone's genetic makeup forecast that person's future health condition with certainty.[49] On the other hand, it is equally misleading to say that basing health predictions on genetic testing is "little more than medical speculation."[50]

B. Potential Benefits of Predictive Testing

Predictive testing can have several benefits. Predictive genetic testing can reveal individuals' predisposition for genetic conditions associated with disability.[51] When families display a high incidence of an early onset heritable disease, a positive result may enable individuals to prepare for the condition's onset.[52] In some conditions, such as hemochromatosis[53] and Wilson's disease,[54] prophylactic measures to prevent or delay symptoms or therapeutic measures to mitigate or eliminate symptoms may be effective.[55] Detection within a medical setting may confer the indirect benefits of clinical quality controls, genetic counseling, and physician fiduciary obligations.[56]

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[47] *See* Rosalyn S. Carson-DeWitt, *Carpal Tunnel Syndrome*, GALE ENCYCLOPEDIA OF MEDICINE 599-600 (1999) (delineating the possible origins of CTS).

[48] Beryliosis is "[b]eryllium poisoning . . . from inhalation of beryllium." *See* STEDMAN'S MEDICAL DICTIONARY, *supra* note 41, at 199.

[49] For example, the claim that a particular gene "predicts colon cancer with almost cruel certainty" is probably misleading. Jonathan Bor, *Gene Causing Colon Cancer Found: Discovery at Hopkins Expected to Save Thousands of Lives*, BALT. SUN, May 6, 1993, at A1.

[50] *White House Seeks a Ban on 'Unfair' Genetic Bias*, WASH. POST, June 24, 2001, at A8, *available at* 2001 WL 23176332 (quoting President Bush). The article's title and text are misleading because the President merely voiced support for an existing bill, discussed below in Part III.E, rather than proposing legislation. *Id.* A more accurate appraisal is David E. Sanger, *Bush Supports Federal Law Putting Limits on DNA Tests*, N.Y. TIMES, June 23, 2001, at A10.

[51] *See* ASSESSING GENETIC RISKS: IMPLICATIONS FOR HEALTH AND SOCIAL POLICY, *supra* note 35, at 59-119.

[52] *Id.* at 45 (suggesting that the aims of predictive genetic testing include managing disease progression and providing reproductive options).

[53] Hemochromatosis is an inherited metabolic disorder characterized by the overabsorption of iron. *See* STEDMAN'S MEDICAL DICTIONARY, *supra* note 41, at 801.

[54] Wilson's disease is an autosomal recessively inherited disorder affecting copper metabolism. *See id.* at 522.

[55] For example, hemochromatosis is normally treated through venesection therapy. *See generally* Pierre Brissot et al., *Clinical Aspects of Hemochromatosis*, 23 TRANSFUSION SCI. 193 (2000).

[56] *See* Satz & Silvers, *Disability and Biotechnology*, *supra* note 46, at 173.

Further, when an individual's family medical history demonstrates a propensity toward a particular type of disease, a negative test result may enable that individual to avoid discriminatory treatment.[57] Likewise, if ergonomic,[58] environmental,[59] or other conditions at a work site are likely to bring on pathologies that may have a genetic component, such as beryliosis or carpal tunnel injury,[60] a negative test result may mitigate concern and match individuals in the workforce with jobs they can handle safely. The individual who tests negative may be able to plan a career or expect to have offspring. Learning that one is not genetically disposed to a prevalent familial disease may allow otherwise unavailable opportunities. Individuals who fear themselves to be at high risk of pathology may refrain from pursuing these opportunities, or society may deny them to people believed to be at risk. Proof that they are not at risk will reassure them of their ability to succeed in endeavors aversive for people who develop the disease.

C. Potential Costs of Predictive Testing

Concurrent with the benefits to public health described above, predictive genetic testing also has tremendous potential to precipitate discriminatory treatment in employment-related opportunities and benefits. An example of this potential for harm, and one to which we will return below when assessing the applicability of the ADA to genetic discrimination,[61] is a case settled early last year: *EEOC v. Burlington Northern Santa Fe Railroad.*[62] Claimants in *Burlington Northern*, through their EEOC attorneys, alleged genetic discrimination as the result of the railroad's national policy of

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[57] For example, family screening—mostly focused on siblings—is considered medically imperative based on incidence of hemochromatosis. *See* Brissot, *supra* note 55, at 197-99.

[58] "Ergonomic" refers to the impact upon human physiology caused by the manner in which given employment is physically structured. For a general treatment, see T.S. CLARK & E.N. CORLETT, THE ERGONOMICS OF WORKSPACES AND MACHINES: A DESIGN MANUAL (2d ed. 1995).

[59] An obvious example of an environmentally induced condition is pneumoconiosis, which, when expressed as "Black Lung Disease," is frequently attributable to the inhalation of coal dust by miners. *See Fact Sheet: Occupational Lung Disease*, STATE OF THE AIR (American Lung Ass'n), Sept. 2000, *at* http://www.lungusa.org/diseases/occuptional_factsheet.html.

[60] *See* U.S. DEP'T. OF HEALTH AND HUMAN SERVS., MUSCULOSKELETAL DISORDERS AND WORKPLACE FACTORS: A CRITICAL REVIEW OF EPIDEMIOLOGIC EVIDENCE FOR WORK-RELATED MUSCULOSKELETAL DISORDERS OF THE NECK, UPPER EXTREMITY, AND LOW BACK ch.5 (1997), *available at* http://www.cdc.gov/niosh/pdfs/97-141.pdf.

[61] *See infra* Part III.B-D.

[62] No. C01-4013 (N.D. Iowa) (filed Feb. 9, 2001) [hereinafter Burlington Northern Complaint] (on file with authors).

requiring union members claiming to suffer from CTS to submit to DNA tests to determine whether those workers were predisposed to carpal tunnel injuries.[63]

According to Dr. Francis Collins, Director of the Human Genome Project, possibly one in ten thousand individuals may have such a genetic disposition.[64] In processing claims for compensation by workers who had undergone surgery for CTS, Burlington Northern required the individuals to submit to blood tests without obtaining consent for their use in genetic testing.[65] At least one worker claimed he was threatened with discharge for not permitting the blood to be drawn.[66] Because no federal law specifically prohibited a private employer from genetically discriminating against its workers, the EEOC formulated its charges based upon an expansive reading of the ADA that had been previously encoded in its enforcement guidelines but never directly tested in court.[67] After a flurry of publicity that characterized Burlington Northern as having opened the door to victimizing citizens on the basis of their genetic heritage,[68] defendants settled their claims prior to trial, with the elimination of future genetic testing as part of the remedy.[69]

Regardless of its outcome, this case serves as a beacon illuminating a troubling future.[70] It warns people that they may have to absorb liability for injuries to themselves, if whoever has precipitated those injuries can show that they are less than normally

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[63] *Id.*

[64] *See CBS News: 60 Minutes II, Should Your Boss Know Your Genetic Predispositions,* (CBS television broadcast, Apr. 10, 2001).

[65] This requirement extended both to instances of worker compensation claims, as well as to cases of alleged work-related carpal tunnel injuries. *See* Burlington Northern Complaint, *supra* note 62. Descriptions of the case and its disposition exist in a number of contexts, with one of the more accurate accounts being the EEOC's press release. Press Release, U.S. Equal Employment Opportunity Comm'n, EEOC Settles ADA Suit Against BNSF Genetic Bias (Apr. 18, 2001), *at* http://www.eeoc.gov/press/4-18-01.html [hereinafter EEOC Burlington Northern Press Release]; *see also* Paul Steven Miller, *Genetic Discrimination in the Workplace,* 3 GENETICS MED. 165 (2001), *reprinted in* 3 AAPD NEWS 8 (2001) (both on file with authors) (providing description by an EEOC Commissioner).

[66] *See* Burlington Northern Complaint, *supra* note 62.

[67] *See* discussion *infra* Part III.B-D.

[68] Beyond national print journalism coverage, a Web search conducted in July 2001 reveals at least 842 results, many of which follow this characterization.

[69] *See* EEOC Burlington Northern Press Release, *supra* note 65. Other concessions included the company's agreement to neither analyze or utilize previously collected genetic materials, to refrain from retaliation against employees who had opposed their policy, and to lobby on behalf of pending federal legislation prohibiting genetic discrimination. *Id.*

[70] We discuss the opposite result in *EEOC v. Woodbridge Corp.*, where a district court granted summary judgment to defendants based upon the plaintiffs' failure to satisfy the ADA's "regarded as" criteria for coverage within the context of genetic testing. 124 F. Supp. 2d 1132, 1138-39 (W.D. Mo. 2000); *see also* 19 NAT'L DISABILITY L. REP. 114 (2000); *see infra* Part III.D.

resistant to being injured. The creation of a category of asymptomatic people classified as genetically flawed, who are for that reason left unprotected against the denial of employment opportunities, compensation, and benefits, invites defensive strategies against assignment to this class. The first obvious line of defense is to evade genetic testing. If people adopt this strategy, as they are likely to do, they will impede the realization of genomics' contributions to both personal welfare and social good. Not only will they relinquish well-targeted prophylactic and therapeutic intervention for themselves, they also will obstruct others from obtaining knowledge about their own genes by refusing to participate in procedures that involve family participation (such as the test for Huntington's disease)[71] or in research that requires human-subject participation by individuals with certain familial histories (such as research on genetic dispositions to breast cancer or Alzheimer's disease).[72]

Fear of discrimination thus has the potential to block benefits that otherwise might be gained from genomic knowledge. But how much reality is there in these fears? Undoubtedly, some people are subjected to disadvantageous treatment because they likely have or will develop a genetically based illness or disability. For example, a recent survey by the Eunice Kennedy Shriver Center discovered nearly six hundred cases where, based on beliefs about their predispositions to genetic diseases, individuals lost employment opportunities.[73] In a well-known case in Australia, a young man whose mother had died of Huntington's disease was denied employment in the public sector, in the career for which he had been educated, unless he agreed to a genetic test and the test results were negative.[74] Many other examples can be amassed.[75] Nevertheless, the current extent of genetic discrimination in employment is not known, especially if we restrict the evidence of it to reported legal decisions in which results of

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[71] *See generally* Marleen Decruyenaere et al., *Non-Participation in Predictive Testing for Huntington Disease: Individual Decision-Making, Personality and Avoidant Behaviour in the Family*, 5 EUR. J. HUMAN GENETICS 351 (1997).

[72] *See generally* Katrina Armstrong, *Genetic Susceptibility to Breast Cancer: From the Roll of the Dice to the Hand Women Were Dealt*, 285 JAMA 2907, 2907-09 (2001); SERGE GAUTHIER, CLINICAL DIAGNOSIS AND MANAGEMENT OF ALZHEIMER'S DISEASE (2d ed. 2000).

[73] *See* Julian Borger, *Health Warning as DNA Screening Takes Hold, Americans Find it Can Leave Them Unemployed and Uninsured: Who's Testing our Genes—and Why?*, GUARDIAN (London), Sept. 19, 2000, at 15. These cases also involved the loss of insurance benefits. *Id.* The Shriver Center, which is a division of the University of Massachusetts Medical School, conducts both biobehaviorial and biomedical research and is available online at http://www.shriver.org.

[74] *See* Sandy Taylor, *A Case Study of Genetic Discrimination: Social Work and Advocacy Within a New Context*, AUSTL. SOC. WORK, Dec. 1998, at 52.

[75] *See* Borger, *supra* note 73 and accompanying text.

genetic tests, rather than existing symptoms or family histories, play the decisive role.[76]

The Council for Responsible Genetics has two hundred allegations of genetic discrimination by employers on file.[77] Variations in these cases illustrate how different kinds of information about an individual's genetic condition may play a role. For example, a social worker was dismissed a week after mentioning that her mother had died of Huntington's disease.[78] The worker in another case participated in a research project and tested positive for a mutation of the BRCA1 gene, a mutation that correlates with breast and ovarian cancer in young women.[79] She opted for prophylactic surgery, which appreciably lowered her risk by removing breasts, uterus, and ovaries, the sites of vulnerable tissue.[80] Nevertheless, she subsequently lost her job.[81] Although both cases involve heritable diseases, the former turns on knowledge of familial history and the second on knowledge of molecular medicine. Are they sufficiently similar to qualify as genetic discrimination? We need to clarify whether the target for statutory protection against genetic discrimination includes all individuals at risk for inheritable pathological conditions or just those whose conditions are discovered through predictive genetic testing. We will argue below that, due to the enormous social cost of permitting a large group of individuals to be stripped of labor market productivity, statutory protection against genetic discrimination ought to be very broad.[82]

II. THE PRIVACY MODEL AND ITS LIMITATIONS

In the main, two lines of thought about the grounds for protection against genetic discrimination have been pursued. Initially, the appeal was to citizens' privacy rights. More recently, antidiscrimination safeguards have been invoked. This part analyzes the privacy model and examines some of its limitations.

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[76] *See* Paul Steven Miller, *Is There a Pink Slip in My Genes? Genetic Discrimination in the Workplace*, 3 J. HEALTH CARE L. & POL'Y 225, 234 n.79 (2000).

[77] *See* Borger, *supra* note 73, at 15.

[78] *Id.*

[79] *Id.*

[80] *Id.*

[81] *Id.*

[82] *See infra* Part IV.

A. The Privacy Model

Several areas of U.S. law address privacy rights. One is constitutional law, especially applications of the Fourth, Fifth, and Fourteenth Amendments.[83] Here the emphasis is on preserving individuals' control over that intimate information that affects the core of personal identity. The social and legal space individuals need to develop the emotional, cognitive, and spiritual dimensions essential to autonomous beings is the domain cloaked by the right to privacy. Thus, for example, citizens have the right to affiliate with marriage partners regardless of whether their choice threatens the stability of prevailing social convention,[84] to engage in unregulated sexual practice with a marriage partner,[85] and to avoid becoming a parent.[86] Whether citizens have the concomitant right to decide to become parents with no intrusion by the state is more problematic. *Skinner v. Oklahoma*, a case in which the Supreme Court declared unconstitutional a state statute decreeing the sterilization of three-time convicted offenders, is usually cited in support of the claim to this right.[87] There, however, the Court analyzed *Skinner* as an equal protection case and threw out Oklahoma's statute because the legislative record offered no evidence for preventing thieves' reproduction but not that of embezzlers.[88] As the concurring Justices pointed out, however, the *Skinner* decision did not preclude states from interfering with individuals' reproductive freedom so long as legislatures either construe their socially undesirable characteristics as heritable or associate heritable undesirable characteristics with the individual's class.[89] In the latter instance, individuals might be subject to sterilization based on no more than a showing of their membership in a class with a greater than species-typical probability of transmitting socially undesirable characteristics.[90]

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[83] U.S. CONST. amends. IV, V, XIV.

[84] *See, e.g.*, Loving v. Virginia, 388 U.S. 1 (1967) (overturning Virginia's miscegenation statute).

[85] *See, e.g.*, Bowers v. Hardwick, 478 U.S. 186 (1986) (upholding Georgia's sodomy restriction, while approving similar conduct within the boundaries of heterosexual marriage).

[86] *See, e.g.*, Griswold v. Connecticut, 381 U.S. 479 (1965) (granting access to contraception); Roe v. Wade, 410 U.S. 113 (1973) (upholding right to the abortion procedure).

[87] 316 U.S. 535 (1942).

[88] *Id.* at 538-39.

[89] *Id.* at 544-45.

[90] *Id.*

Tort law also offers individuals some privacy protection.[91] In general, citizens may not intrude upon each other's private affairs by disclosing misleading or embarrassing personal facts, especially those constitutive of personal identity.[92] Such personal information is conceived to have been wrongly appropriated if disclosed for advantage or profit without the person's consent.[93] Here, however, statute and precedent present a complex picture about the ways that various personal facts may or may not be constitutive of personal identity, as well as the conditions under which consent to disclosure may be required or presumed.

Evidentiary privileges, contract and property law, and federal and state statutes also protect privacy rights.[94] Medical patients' privacy is covered by a patchwork of federal and state provisions, including the accrediting standards for hospitals.[95] The Privacy Act of 1974 limits federal agencies' uses of information to those that 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.[96] Another example, 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.[97] Employment discrimination is addressed in these statutes, but it is addressed through a privacy approach. Specifically, employers cannot fail to hire an individual based on the applicant's refusal to submit to genetic tests because those who insist on the privacy of their genetic information cannot be penalized thereby.[98]

Even where not explicitly banned, intrusions into the privacy of an individual's biological condition may be deflected by other protections. The Ninth Circuit's ruling in *Norman-Bloodsaw v. Lawrence Berkeley Laboratory* examined the issue of disparate

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[91] Anita L. Allen, *Genetic Privacy: Emerging Concepts and Values*, *in* GENETIC SECRETS: PROTECTING PRIVACY AND CONFIDENTIALITY IN THE GENETIC ERA 31, 40 (Mark A. Rothstein ed., 1997).

[92] *Id.*

[93] *See id; see also* June Mary Z. Makdisi, *Genetic Privacy: New Intrusion a New Tort?*, 34 CREIGHTON L. REV. 965, 982-83 (2001).

[94] *See generally* JED RUBENFELD, FREEDOM AND TIME: A THEORY OF CONSTITUTIONAL SELF-GOVERNMENT (2001) (discussing the panoply of factors relevant to privacy law).

[95] *See generally* BARRY R. FURROW ET AL., THE LAW OF HEALTH CARE ORGANIZATION AND FINANCE (4th ed. 2001).

[96] 5 U.S.C. § 552(a) (2000).

[97] N.J. REV. STAT. § 17B:30-12 (1996).

[98] *Id.* A few other states have passed similar provisions. *See, e.g.*, COLO. REV. STAT. ANN. § 10-3-1104.7(1)(a) (West 2001); FLA. STAT. ANN. § 760.40(2)(a) (West 1997 & Supp. 2002); GA. CODE ANN. § 33-54-1(1) (Harrison 1996).

treatment with respect to an employer's invasions of privacy.[99] In *Norman-Bloodsaw*, the employer required employees to provide blood samples and submitted the samples to panels of tests.[100] People of color were tested for syphilis (as was only one Caucasian employee, who happened to be married to an African-American woman).[101] They were retested for syphilis (not a genetic test) regularly.[102] African-Americans were recurrently examined for the sickle-cell gene, despite a single test's sufficiency to identify the presence of the gene.[103] The employer claimed that blood-testing policies were designed to promote the good health of employees. The employer also represented that the tests were simply part of an overall health benefits program that administered EKGs more regularly to men in the age group at high risk for heart disease than to other employees.[104] Employees testified that they received no beneficial information; individuals who knew, from other sources, that they were sickle-cell carriers were never so informed as a result of Lawrence's testing program.[105]

The *Norman-Bloodsaw* court rebuked laboratory administrators for two related failures.[106] First, although notification of the tests that might be run on samples was posted on a wall, the court did not agree that such notification met the standard of disclosure required for informed consent.[107] Second, people of color—especially African-Americans—suffered from a more egregious pattern of testing without their consent than did Caucasian employees.[108]

B. Limitations of the Privacy Model

On the privacy model, a person's genetic information is her property and, consequently, should be under her control. Relatively little litigation has been pursued under genetic privacy statutes.

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[99] 135 F.3d 1260 (9th Cir. 1998).

[100] *Id.* at 1265.

[101] *Id.*

[102] *Id.* at 1265 n.5.

[103] *Id.*

[104] *See id.* at 1265. In dicta, the court stated further that:

> This is not to say that a Title VII action would necessarily lie in a case involving two different but *equivalent* tests administered to men and women. Thus, for example, if test were given to men for testicular cancer and to women for ovarian cancer, there would probably be no cause of action under Title VII. In the case of a pregnancy test for women, however, it is doubtful that an equivalent test *could* be offered to men.

Id. at 1272 n.20.

[105] *Id.* at 1266.

[106] *Id.* at 1267, 1272.

[107] *Id.* at 1267 n.7.

[108] *Id.* at 1272.

Nevertheless, we can identify some issues that are likely to divide the courts.

Given the nonmaterial nature of the possessed object, several difficulties about its control arise. First, whose responsibility is it to identify or safeguard sensitive and easily portable genetic information?[109] In many businesses, individuals who administer health care benefits or manage health and safety programs also have responsibility for some aspects of personnel management.[110] In these circumstances, is it feasible to expect employers to maintain a firewall between health care records that may reveal employees' genetic conditions and information used in personnel decisions? Second, when a proprietor waives a privacy right for one purpose, is the information no longer protected from use for other purposes? Third, where more than one person has a property right in certain information, how are their interests prioritized with respect to maintaining control? Finally, do circumstances in which lack of access to the information threatens public safety, places commercial interests at considerable disadvantage, or deprives the subject of significant benefits, override privacy protections? All these questions have elicited complex and sometimes contradictory answers in litigation over privacy and property rights.[111] The nature of genetic information promises even further complications.[112]

Genetic information about an individual is discovered in several different ways. As in the cases referred to above, a chance remark about family history or response to a formal disclosure requirement may reveal significant data.[113] Data often are accumulated in a medical setting, where informed consent is in principle necessary.[114] In practice, however, patients often are asked to consent only to contributing a specimen or sample or to the use of their body materials for certain panels of tests (as in *Burlington*

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[109] *See generally* Lori B. Andrews & Ami S. Jaeger, *Confidentiality of Genetic Information in the Workplace,* 17 AM. J.L. & MED. 75 (1991); Mark A. Rothstein, *The Law of Medical and Genetic Privacy in the Workplace, in* GENETIC SECRETS: PROTECTING PRIVACY AND CONFIDENTIALITY IN THE GENETIC ERA 281 (Mark A. Rothstein ed., 1997).

[110] *See generally* U.S. DEP'T OF LABOR, HUMAN RESOURCES HANDBOOK, *available at* http://www.bls.gov/oco/ocos021.htm (last visited Sept. 24, 2002).

[111] *See* Rothstein, *supra* note 109, at 285.

[112] While biotechnology companies vie for exclusive rights to genetic information—even to the extent of licensing the genetic information of entire population groups—one commentator has asserted that the intellectual property rights in genetic data are insufficient to "warrant the cost of enforcement by those affected." *See* Michael S. Yesley, *Protecting Genetic Difference,* 13 BERKELEY TECH. L.J. 653, 653 (1998).

[113] *See supra* Part II.A.

[114] *See* JUDITH AREEN ET AL., LAW, SCIENCE, AND MEDICINE 222-34 (2d ed. 1996).

Northern),[115] or they are informed of the tests to be run without specifying what is learned from the tests (as in *Norman-Bloodsaw*).[116] 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 record.[117] In all of these cases, does the patient's consent to be tested imply consent to treat all results of the test as ordinary medical records that are available, under the usual conditions, to employers? Or does genetic privacy assign genetic information an especially secure status?

A different version of the aforementioned problem is created by the rapid expansion of genomic knowledge. A genetic anomaly that is correlated with one condition may, in the future, be correlated with another, or anomalies may cluster so that the presence of one suggests the presence of another.[118] To illustrate, individuals who provided DNA to be tested for susceptibility to heart disease could, years later, find that their physicians have recommended suspension of their drivers' licenses because of new data that the gene has one hundred percent penetrance for a very early onset variation of Alzheimer's disease. Does their earlier consent to the collection of information regarding heart disease entail similar acquiescence to whatever can be further learned from the genetic material they agreed to have tested?

Unlike some other kinds of possessions, genetic information is often the property of more than one individual at the same time. Genetic makeup is shared among close biological relatives, so test results for one person can yield information about another person.[119] Some tests, such as that for Huntington's disease, require samples from biological relatives of the patient to isolate genetic markers.[120] In such cases, should we defer to the individual who will benefit from disclosure or to the one who wishes to preserve privacy? The individual-consent mechanism ill fits a technology that is based on the relational nature of genetic information.[121]

Finally, are there considerations that warrant overriding privacy? Several state genetic privacy statutes prohibit employers from requiring genetic testing during the hiring process but permit it

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[115] *See* discussion *supra* Part I.C.

[116] *See supra* notes 99-108 and accompanying text.

[117] *See* AREEN, *supra* note 114, at 222-34.

[118] *See* discussion *infra* Part IV.B.

[119] *See, e.g.,* Henry T. Greely, *Iceland's Plan for Genomics Research: Facts and Implications*, 40 JURIMETRICS J. 153, 155-57 (2000).

[120] *See generally* Decruyenaere, *supra* note 71.

[121] *See* Anita Silvers, *Primary Care Physicians and the Duty to Inform About Genetic Discrimination*, 1 AM. J. BIOETHICS (forthcoming Summer 2001).

subsequently for occupational safety reasons.[122] In cases in which patients' health conditions endanger others (for instance, where an individual fails to manage her infectious tuberculosis or has a psychiatric condition that makes her a danger to others), courts typically have held that public safety trumps individual rights.[123] What complicates these judgments in the case of genetically occasioned conditions is the looseness of the connection between testing positive for a gene or marker and becoming symptomatic of the correlated disease.[124] How much evidence of correlation between a gene and disease symptoms must there be, and to what degree must a disease gene be expressed, to warrant curtailing the opportunities of individuals who have inherited it? Is Huntington's disease, which we believe to have one hundred percent penetrance, the paradigm?[125] We know that individuals whose relatives developed certain forms of senile dementia are at higher risk of suffering it themselves than individuals with no family history at all.[126] Yet rarely, if ever, do employers demand such family histories or limit the employment of higher risk family members. Does public safety warrant them doing so if genetic testing rather than family history is involved?

Business necessity, which often constitutes an employer's defense against unfavorable treatment of an employee or customer, is also problematic where access to genetic information is concerned. Should necessity be demonstrated prior to obtaining access to information, or only subsequent to acting on it? What counts as a necessity? Should employers be permitted to require employees who file for workers' compensation to undergo genetic testing only if a

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[122] Examples of states adhering to this dual approach include Iowa, New Hampshire, New York, and Wisconsin. *Compare* IOWA CODE ANN. § 729.6.2 (West 1993) *with* § 729.6.7; *compare* N.H. REV. STAT. ANN § 141-H:3I(a) (1996) *with* § 141-H:3V; *compare* N.Y. EXEC. LAW § 296.19(a)(1) (McKinney 2001) *with* § 296.19(c); *compare* WIS. STAT. ANN. § 111.372(1)(a) (West 1997) *with* § 111.372(4).

[123] The defense originated in *School Board of Nassau County v. Arline*, 480 U.S. 273 (1987), a case brought under the Rehabilitation Act by a school teacher with tuberculosis. In *Arline*, the Court held that although an individual with a contagious disease could in fact be excluded from employment while her condition posed a public health danger, she could not be so deprived when that danger abated. *Id.* at 287 n.16. We revisit this concept when describing the ADA defense of direct threat. *See infra* Part III.C.

[124] This question and the ones that follow are discussed in greater detail below in Part IV.B.

[125] In a recent interview on National Public Radio, Karen Wolff, a genetic counselor at the Harvey Institute of Human Genetics in Baltimore, used Huntington's disease as "the best example in the world of genetics" of a predictable but incurable disease. *See All Things Considered* (National Public Radio broadcast, Feb. 13, 2002).

[126] The media have focused extensively on the genetic basis for Alzheimer's disease. *See, e.g.*, Arthur Allen, *Memory Lapse—or Alzheimer's?*, WASH. POST, May 8, 2001, at T10 (discussing a study of the link between family history and the onset of Alzheimer's disease).

contributing genetic condition is relatively prevalent, so that a good deal of money could be saved by declaring it a preexisting or contributory condition? Or may business necessity warrant testing even where savings would be negligible because the genetic conditions are extremely rare?

III. ANTIDISCRIMINATION MODELS AND THEIR LIMITATIONS

As the realities of collecting and protecting genetic information have become clear, enthusiasm for basing protection on privacy rights has waned. Attention has turned to the antidiscrimination model that is already instantiated in federal and state genetic discrimination and disability discrimination law. In this part we describe the antidiscrimination model and explain some of the problems that arise, in both practice and theory, from its application to genetic discrimination

In the United States, discussion has centered on the EEOC's application of the ADA to genetic discrimination.[127] In the United Kingdom and Australia, debate has centered on extending these nations' respective Disability Discrimination Acts.[128] At issue in all these discussions is whether it is appropriate and necessary to develop separate protection for individuals with genetic anomalies. 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.

A. The Genetic Discrimination Model

Although current state laws lean heavily on precedents of privacy, antidiscrimination provisions have been sprinkled among them. For example, the first state to enact a genetic discrimination law, North Carolina, prohibited employment discrimination based on

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[127] While we address this development in depth, the seminal articles by EEOC Commissioner Miller bear noting. *See* Miller, *supra* note 65; Miller, *supra* note 76.

[128] Both the U.K. and Australia have Disability Discrimination Acts; although different in many respects, neither is a civil rights law. For critical overviews, see Mairian Corker, *The U.K. Disability Discrimination Act: Disabling Language, Justifying Inequitable Social Participation*, *in* AMERICANS WITH DISABILITIES: EXPLORING IMPLICATIONS OF THE LAW FOR INDIVIDUALS AND INSTITUTIONS 357 (Leslie Pickering Francis & Anita Silvers eds., 2000); Melinda Jones & Lee Ann Basser Marks, *A Bright New Era of Equality, Independence and Freedom: Casting an Australian Gaze on the ADA*, *in* AMERICANS WITH DISABILITIES: EXPLORING IMPLICATIONS OF THE LAW FOR INDIVIDUALS AND INSTITUTIONS, *supra*, at 371.

the sickle-cell trait.[129] New Jersey's genetic privacy law prohibits certain kinds of decisions from being made about an individual because the person is genetically disposed to develop specified diseases.[130]

Effective federal regulation specifically protecting individuals from genetic discrimination is almost nonexistent. A single, narrowly tailored executive order has barred federal agencies from discriminating in employment on the basis of "genetic information" since February 2000.[131] While the substance of this directive is laudable, it must be noted that the number of federal employees pales in comparison to the combined number of employees in the state and private sectors, where protection is most needed.[132] Further, these regulations do not address the perception that protection from genetic discrimination is a matter for civil rights because unfavorable treatment should no more be based on people's genes than on their genitalia or pigmentation.[133]

B. The Disability Discrimination Model

In addition to measures specifically directed against genetic discrimination, there also exists the potential for application of civil rights legislation—namely the ADA and, more tangentially, Title VII[134]—against such harms. This approach, as seen above in the discussion of *Burlington Northern*,[135] has been championed by the EEOC with some early success.[136] Statements, congressional

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[129] In amended form, the statute now also covers people with hemoglobin C traits, which are related. *See* N.C. GEN. STAT. § 95-28.1 (2001).

[130] *See* 1996 New Jersey Genetic Privacy Act, N.J. REV. STAT. § 17B:30-12(e)-(f) (Supp. 2002).

[131] *See* Executive Order, *supra* note 10. The promulgation's formal title is "To Prohibit Discrimination in Federal Employment Based on Genetic Information." *Id.*

[132] According to the United States Office of Personnel Management, the federal government employed approximately 2,708,100 civilian employees in the year 2000. U.S. OFFICE OF PERS. MGMT., THE FACT BOOK: FEDERAL CIVILIAN WORKFORCE STATISTICS 8 (2001), *available at* http://www.opm.gov/feddata/01factbk.pdf. In December 2001, the U.S. Department of Labor reported 109,768,000 private sector employees and 21,122,000 total government employees (including both federal and state employees). BUREAU OF LABOR STATISTICS DATA, BLS Program and Survey Special Notices, *available at* http://data.bls.gov/cgi-bin/srgate, Series ID EE500500001 & EES90000001 (last visited Sept. 24, 2002).

[133] Fawn H. Johnson, *Discrimination: Jeffords Examining Need for Legislation on Genetic Discrimination; Coalitions Forming*, Daily Lab. Rep. (BNA) No. 48, at C-1 (March 12, 2001).

[134] Such legislation may apply when "a significant correlation to race, national origin, religion, or gender" exists with the particular genetic discrimination, as, for example, sickle-cell disease, which disproportionately impacts African-Americans. Miller, *supra* note 76, at 247.

[135] *See supra* Part I.C.

[136] *Id.*

testimony, and scholarship by EEOC Commissioner Paul Steven Miller indicate that the agency will continue to pursue this line of legal argument.[137]

Federal courts have required 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."[138] The ADA does not specify application to genetic conditions. There are, however, several reasons for thinking that it may be applicable, at least to some extent.[139]

First, the congressional record offers some evidence of legislative intent. Congressman Major Owens stated that

> [t]hese protections of the ADA will also benefit individuals who are identified through genetic tests as being carriers of a disease-associated gene . . . Under the ADA, such individuals may not be discriminated against simply because they may not be qualified for a job sometime in the future. The determination as to whether an individual is qualified . . . may not be based on speculation regarding the future.[140]

Other Congressmen echoed these expectations about the scope of the ADA.[141] In sum, Congressmen characterized genetic discrimination as exhibiting the myths, fears, and stereotypes that historically have prevented people perceived as biologically anomalous from enjoying fair equality of opportunity.[142]

Second, the ADA clearly protects individuals with inherited impairments such as muscular dystrophy, retinitis pigmentosa, osteogenesis imperfecta, achondroplasia, Williams syndrome, and schizophrenia.[143] Regardless of the degree to which they are symptomatic, individuals with these genes clearly have the inherited conditions. Some conditions encompass a range of limitations. For instance, the skills of people with Williams syndrome vary from

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[137] *See* Part III.B.

[138] 42 U.S.C. § 12102(2)(A)-(C) (2000).

[139] *See infra* Part III.C.

[140] 136 CONG. REC. H4614-02 (1990), *available at* 1990 WL 97270.

[141] *See id.*

[142] *See id.*

[143] *See* Bultmeyer v. Fort Wayne Cmty. Schs., 100 F.3d 1281, 1284 (7th Cir. 1996) (holding that paranoid schizophrenia is a covered disability under the ADA); Johnson v. Equicom, Inc., 2001 U.S. Dist. LEXIS 18032, *10-11 (N.D. Tex. 2001) (holding that the plaintiff with retinitis pigmentosa had a disability but failed to demonstrate that he was discharged because of his disability); EEOC v. MCI Telecomms. Corp., 993 F. Supp. 726, 728-29 (D. Ariz. 1998) (addressing muscular dystrophy); Duprey v. Conn. Dep't of Motor Vehicles, 28 F. Supp. 2d 702, 703 (D. Conn. 1998) (finding that plaintiff with osteogenesis imperfecta was "limited in the major life activity of walking").

individual to individual.[144] Almost all are exceptionally good at music and bad at math.[145] Some are so seriously limited intellectually as to be classified as mentally retarded, while others attain college and postgraduate degrees.[146] A state that proposed to sterilize all its citizens with Williams syndrome (as some states did in the past)[147] very likely would be charged with disability discrimination under the ADA. In that event, it would be exceedingly disturbing if a court ruled that the ADA protected only the people with Williams syndrome whose condition limits them from finishing elementary or high school, leaving the individuals with Williams syndrome who have finished college with no defense against being sterilized.

Some of the genetic conditions referenced above—for instance, muscular dystrophy and retinitis pigmentosa—are progressive.[148] Individuals who test positive for these genes may be asymptomatic at the time yet face substantial limitation in the future. Whether such individuals are protected while they are asymptomatic remains unclear.[149] Suppose an employer believes, mistakenly, that visually impaired individuals cannot perform a particular job. It would be disquieting if the employer were prohibited from excluding, on the basis of genetic information about the employee's retinitis, an individual who had already lost his sight due to retinitis but could exclude from employment qualified individuals with the retinitis gene who could see perfectly well.

Third, citing the congressional record, the EEOC has offered guidance that brings actions arising from genetic information relating to genetic disease or disabling conditions under the regulation of the ADA's "regarded as" criteria. Initially, in March 1995, the EEOC issued an ADA Compliance Manual guideline that instructed that the "regarded as" part of the definition of "disability" "applies to individuals who are subjected to discrimination on the basis of genetic information relating to illness, disease, or other disorders."[150] Two subsequent policy and enforcement guidance statements reiterate this

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[144] *See generally* Howard M. Lenhoff et al., *Williams Syndrome and the Brain*, SCI. AM., Dec. 1997, at 68.

[145] *Id.*

[146] *See generally* Satz & Silvers, *supra* note 46.

[147] A comprehensive treatment of this topic is provided in Robert L. Burgdorf & Marcia Burgdorf, *The Wicked Witch is Almost Dead:* Buck v. Bell *and the Sterilization of Handicapped Persons*, 50 TEMP. L.Q. 995 (1977).

[148] *See* STEDMAN'S MEDICAL DICTIONARY, *supra* note 41, at 558, 1560.

[149] *See* MICHAEL FAILLACE, DISABILITY LAW DESKBOOK: THE AMERICANS WITH DISABILITIES ACT IN THE WORKPLACE 2-13 (2000).

[150] U.S. EQUAL EMPLOYMENT OPPORTUNITY COMM'N, 2 EEOC COMPLIANCE MANUAL § 902.8 (2000). The "regarded as" prong is analyzed in greater detail below in Part III.D.

position. The first, issued on July 26, 2000 (on the ADA's tenth anniversary), reiterated the previous position that discrimination against individuals with disabilities falls under the "regarded as" prong of the ADA pursuant to the EEOC's enforcement of the executive order.[151] The second, issued a day later, specifically states that blood tests to detect genetic markers or diseases are medical examinations within the ADA's purview.[152] These pronouncements have been followed in EEOC opinion letters.[153] In sum, the EEOC's position 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.[154]

Although presymptomatic people may reject the idea that they should be assigned to the disability classification, disability discrimination has been practiced against certain groups of presymptomatic people. Moreover, the "logic" of disability discrimination invites this practice. Therefore, the group of presymptomatic people who are vulnerable to disability discrimination could expand enormously as predictive genetic testing becomes more widespread.

A number of legal commentators strongly support application of the ADA to the realm of genetic discrimination precisely on this ground.[155] To date, however, only a handful of cases clearly charging genetic discrimination have been filed by the EEOC, the most prominent (and only successful) one of which was the settlement

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[151] *See* U.S. EQUAL EMPLOYMENT OPPORTUNITY COMM'N, 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.

[152] *See* U.S. EQUAL EMPLOYMENT OPPORTUNITY COMM'N, ENFORCEMENT GUIDANCE ON 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.

[153] *See, e.g., Letter re: Genetic Discrimination*, 7 NAT'L. DISABILITY L. REP. 362 (1995).

[154] Miller, *supra* note 76, at 246. Although the article was written in his personal capacity, see *id.* at 225 n.*, his view of the agency's position has also been reiterated in statements made in his authorized capacity. *See EEOC Settles ADA Suit Against BNSF for Genetic Bias*, EEOC NEWS RELEASE (U.S. Equal Employment Opportunity Comm'n) Apr. 18, 2001. For example, Miller has stated that the EEOC "will continue to respond aggressively to any evidence that employers" misuse genetic information. *Id.*; Report Letter, EEOC Compliance Manual Report No. 157 (U.S. Equal Employment Opportunity Comm'n) April 27, 2001, *available at* http://www.hr.cch.com/primesrc/bin/higbwire.dll; *see also* Prepared Statement of Paul Steven Miller, Commissioner U.S. Equal Employment Opportunity Commission, Before the Senate Committee on Health, Education, Labor and Pensions, FEDERAL NEWS SERVICE, July 20, 2000.

[155] *See* sources cited *supra* note 25.

discussed above, in *Burlington Northern*.[156] A second suit alleging genetic discrimination on the ground of adverse employment decisions grounded in predisposition to carpal tunnel injury, *EEOC v. Woodbridge Corp.*,[157] was dismissed at the summary judgment stage.[158] A claim by Terri Sergeant, a woman allegedly dismissed by her employer after she was identified as a carrier of the Alpha-1 gene, which can express itself as a progressive lung disorder, has received a permission-to-sue letter from the EEOC.[159]

The ADA appears to have potential for protecting against genetic discrimination in employment.[160] Dr. Francis Collins, director of the Human Genome Project, has remarked that "it is estimated that all of us carry dozens of glitches in our DNA . . . . As a nation, we have stated unequivocally" in the ADA "that one's ability to do a job should be judged on just that—the ability to do the job."[161] Collins has testified that citizens are already declining to serve as subjects in genetic research out of fear that they could be denied a job or a promotion based simply on their participation.[162] Clearly Congress intended to protect citizens who are discriminated against here and now because other people may fear the future effects of the disease for which they are at high risk, but the propriety and effectiveness of doing so by calling these citizens "disabled" is questionable.

C. Limitations of the Disability Discrimination Model

Courts have interpreted the ADA so as to limit the number of people who fall under its protection. In *Sutton v. United Air Lines, Inc.*, one of the Supreme Court's reasons for refusing protection to plaintiffs rejected from employment on the basis of their myopia was that the number of disabled people in the country would far exceed

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[156] *See supra* Part II.C.

[157] 263 F.3d 812 (8th Cir. 2001); 19 NAT'L. DISABILITY L. REP. 114 (2000).

[158] 263 F.3d at 813. The rationale offered by the court is discussed below in Part III.D.

[159] *See* Alpha-1 Association, *Update on Terri Sergeant's Genetic Discrimination Case, at* http://web.archive.org/web/20010208195556/www.alpha1.org/newsmakers/index.htm (last visited Aug. 21, 2002) (Sergeant's story was first covered by Scientific American following her testimony before the Senate Health, Education, Labor and Pension Committee.). *See also* National Partnership for Women & Families, *Genetic Discrimination is a Real Problem, With Real Victims, at* http://www.nationalpartnership.org/content.cfm?L1=5&L2=2.0&L3=2 (last visited Aug. 21, 2002).

[160] The difficulties are discussed *infra* Part IV.C.

[161] *See Genetic Information in the Workplace: Hearing Before the Senate Comm. on Health, Educ., Labor and Pensions*, 106th Cong. (2000) (relaying prepared testimony of Francis S. Collins, M.D., Ph.D., Director of the National Human Genome Research Institute).

[162] *See id.*

Congress's projections if myopics were included.[163] Nonetheless, in *Bragdon v. Abbott*, the Supreme Court agreed in principle that asymptomatic individuals might merit disability protection.[164] The *Bragdon* decision can be interpreted as suggesting that this conclusion holds only when, despite being asymptomatic, the individual nevertheless is limited in respect to major life activities.[165] Were the *Bragdon* precedent to be taken literally, individuals whose Huntington's disease has not yet manifested would be protected against employment discrimination if they refrained from major life activities such as reproducing, but not otherwise. In addition, Chief Justice Rehnquist's *Bragdon* dissent that "[r]espondent's argument, taken to its logical extreme, would render every individual with a genetic marker for some debilitating disease 'disabled' here and now because of some possible future effects"[166] has met with approbation in some of the lower courts.[167] Last, in both *Albertson's, Inc. v. Kirkingburg* and *Sutton*, the Supreme Court gave clear warning that the deference traditionally granted to federal regulatory agencies may not be extended to the EEOC's understanding of the ADA (which by inference includes its guidelines on genetic discrimination).[168]

Notwithstanding the Court's cautionary language, it is precisely this last theory—that a person can be disabled although asymptomatic or presymptomatic—that has been the basis upon which the EEOC has initiated application of the ADA to genetic discrimination.[169] This legal application invites potential difficulties. Among the most significant is the potential for courts to view asymptomatic individuals as failing to satisfy criteria for protection under the ADA, which would eliminate the legal basis of plaintiff's argument.[170] There also are several defenses that have been successful under the ADA and that can be raised in response to allegations of genetic discrimination. For instance, employers could assert that potentially disabling conditions preclude workers from fulfilling "essential" job functions, thus disqualifying them from ADA protection.[171] Thus, the efficacy of duplicating the EEOC's single

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[163] 527 U.S. at 471, 484-85. Especially on point are the opinions of Justices O'Connor and Ginsburg. *Id.* at 494.

[164] 524 U.S. 624, 647 (1998).

[165] *Id.*

[166] *Id.* at 661 (Rehnquist, C.J., dissenting).

[167] *See, e.g.*, Onishea v. Hopper, 171 F.3d 1289, 1307 (11th Cir. 1999).

[168] 527 U.S. 555, 563 n.10, 569 n.15 (1999); 527 U.S. 471, 480 (1999).

[169] *See supra* notes 150-54 and accompanying text.

[170] *See infra* notes 209-53 and accompanying text.

[171] *See* FAILLACE, *supra* note 149, at 3-14 to 3-55.

success in applying the ADA to the private employer in *Burlington Northern* is unknown.[172]

Once an individual is hired, the ADA does not prevent employers from obtaining medical information about employees.[173] Indeed, employers are obligated to make reasonable accommodations for workers with known disabilities, and they bear some responsibility for determining whether an individual actually requires an accommodation.[174] To protect themselves from the charge of failing to accommodate a worker, employers might reasonably pursue and act upon genetic information.[175] For example, an employer might seek to learn whether an employee's vision problems are symptoms of a progressive genetic disease in order to equip that employee's workstation with business software applications compatible with the screenreading programs that the employee eventually may need to use. What would then prevent the same employer from passing over the still sighted individual for training opportunities and promotions thought to be unsuitable for a person who is blind? It would be extremely difficult to prove that the genetic information caused the employer's disregard.[176]

The ADA also permits employers to limit disabled people's opportunities if their condition prevents them from executing the essential functions of the job,[177] because such individuals would fail to satisfy the statutory prerequisite of being "qualified" for that particular employment.[178] Although the determination of which job functions are essential in any given dispute may seem at first blush the proper province for a jury determination as fact finder,[179] a vast majority of courts have instead deferred to employers' assertions of essentiality,[180] and have thus ruled as a matter of law that plaintiffs

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[172] *See* discussion *supra* Part II.D.

[173] 42 U.S.C. § 12112(d) (2000).

[174] § 12112(b)(5)(A) (requiring this interactive process).

[175] *See* FAILLACE, *supra* note 149, at 4-95 to 4-102.

[176] This task is difficult in any context. *See generally* Susan Sturm, *Second Generation Employment Discrimination: A Structural Approach,* 101 COLUM. L. REV. 458 (2001) (detailing many of the individual ways in which employment discrimination can manifest and describing the difficulties involved in proving them).

[177] *See* § 12111(8).

[178] *Id.*

[179] Summary judgment requires that there be "no genuine issue as to any material fact and that the moving party is entitled to judgment as a matter of law." FED. R. CIV. P. 56.

[180] This reinforces much of Sturm's assertion of subtle discrimination in other contexts. *See* Sturm, *supra* note 176. Professors Linda Krieger and Lauren Edelman are currently engaged in an empirical study examining the relative weight accorded employers' stipulations as to essentiality in the respective areas of disability, race, and sex. Linda Krieger & Lauren Edelman (unpublished manuscript on file with the authors).

were unqualified for their positions.[181] Accordingly, workers with genetic vulnerabilities to materials found in the workplace or to injuries provoked by characteristic workplace tasks seem especially susceptible to rejection on the ground of inability to perform essential functions.

Moreover, employers have gradually extended another existing defense to employment opportunity exclusion under the ADA—that of workers posing a "direct threat."[182] Traditionally, this defense referenced workers either creating a public health risk (paradigmatically, as food handlers) or endangering other employees (for instance, by transmitting communicable diseases).[183] The EEOC's regulation refers to the health and safety of "self" as well as that of "others."[184] Utilizing genetic and other medical information, employers may now be authorized to treat presently or potentially disabled employees adversely on the ground that those workers' own disabilities directly create risks to themselves.

Until recently, a direct intercircuit conflict existed between the Eleventh Circuit, which recognized this defense, and the Ninth Circuit, which did not.[185] In *Echazabal v. Chevron USA, Inc.*, a worker employed by various independent contractors at an oil refinery during

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[181] Detailed analyses are provided in Ruth Colker, *Winning and Losing Under the Americans with Disabilities Act*, 62 OHIO ST. L.J. 239 (2001) and Ruth Colker, *The Americans with Disabilities Act: A Windfall for Defendants*, 34 HARV. C.R.-C.L. L. REV. 99 (1999).

[182] § 12113(b). The standard is the same as that of "significant risk" under the Rehabilitation Act. H.R. REP. NO. 101-485, pt. 3, at 45 (1990), *reprinted in* 1990 U.S.C.C.A.N. 445, 468; Sch. Bd. of Nassau County v. Arline, 480 U.S. 273, 274 (1987) (issuing guidance on how to assess risk factors).

[183] *See* H.R. REP. NO. 101-485, pt. 2 (1990), *reprinted in* 1990 U.S.C.C.A.N. 303, 358-59. Some recent litigation offers clear examples. Borgialli v. Thunder Basin Coal Co., 235 F.3d 1284 (10th Cir. 2000) (involving a psychiatrically impaired employee in charge of explosives); Robertson v. Neuromedical Center, 983 F. Supp. 669 (M.D. La. 1997), *aff'd*, 161 F.3d 292 (5th Cir. 1998) (focusing attention on a deficient neurologist); Newman v. Chevron USA, Inc., 979 F. Supp. 1085 (S.D. Tex. 1997) (involving an employee in position of filling trucks with gasoline who suffered from post-traumatic stress disorder).

[184] 29 C.F.R. app. § 1630.2(r) (2001). Section 1630.2 also advises that "the employer must determine whether a reasonable accommodation would . . . eliminate" this direct threat.

[185] *Compare* Moses v. Am. Nonwovens, Inc., 97 F.3d 446 (11th Cir. 1996) (holding that an employee with epilepsy was properly dismissed from his job in a production plant because of the employer's fear that he would come to harm if he suffered a seizure in proximity to the fast-moving and/or extremely hot machinery near which he was required to work), *with* Echazabal v. Chevron USA, Inc., 226 F.3d 1063, 1066 (9th Cir. 2000), *rev'd*, 122 S. Ct. 2045 (2002) (limiting the defense to posing a threat to "other individuals"). Indirect treatments, through dicta, occurred in four other cases, wherein the courts sided with the Eleventh Circuit's view that direct threats do include threats to one's self. *See* LaChance v. Duffy's Draft House, Inc., 146 F.3d 832 (11th Cir. 1998) (involving an epileptic line cook); EEOC v. Amego, Inc., 110 F.3d 135 (1st Cir. 1997) (involving a depressed employee who worked at a group residence for severely disabled individuals); Daugherty v. City of El Paso, 56 F.3d 695 (5th Cir. 1995) (involving an insulin dependent diabetic bus driver).

the previous twenty years applied directly to Chevron for a position in the same unit.[186] Postoffer, preemployment physical examination by Chevron's physician revealed that Echazabal's liver was secreting higher than normal levels of certain enzymes.[187] As a result, Chevron rescinded its job offer on the ground that Echazabal's liver might be damaged by further exposure to chemicals emanating in the plant.[188] Echazabal's subsequent consultation with several doctors revealed that he had asymptomatic hepatitis C.[189] Because none of these latter physicians advised him to stop working in that environment, Echazabal continued working in the plant for contractors.[190] Three years later a similar fact pattern was repeated.[191] Echazabal applied to Chevron for employment, was extended a job offer contingent on passing a medical exam, was discovered to have hepatitis C as a result of the examination, and had his job offer withdrawn.[192] This time, however, Chevron did not allow Echazabal to remain employed at its refinery.[193] Subsequently, Echazabal brought an action against Chevron[194] asserting, among other claims, that the defendant did not have an affirmative defense under the ADA's direct threat provision to deny him employment on the ground of his being a danger to himself.[195] The district court granted summary judgment in favor of Chevron, and Echazabal appealed.[196]

A three-judge panel of the Eleventh Circuit held two-to-one that the ADA's "language is dispositive" in limiting the defense to employment decisions designed to avoid a direct threat to "other individuals," that the EEOC's interpretation was therefore overly expansive, and that no other interpretation was plausible.[197] In support of the ruling, Judge Reinhardt presented numerous examples from the ADA's legislative history.[198] Writing for the dissent, Judge

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[186] 226 F.3d at 1065.

[187] *Id.*

[188] *Id.*

[189] *Id.*

[190] *Id.*

[191] *Id.*

[192] *Id.*

[193] *Id.*

[194] *Id.* The action was brought in state court and subsequently removed by defendant to federal court. *Id.*

[195] *Id.*

[196] *Id.* at 1063.

[197] *Id.* at 1066-67. "The fact that the statute consistently defines the direct threat defense to include only threats to others eliminates any possibility that Congress committed a drafting error when it omitted from the defense threats to the disabled individual himself." *Id.*

[198] *Id.* at 1066-72.

Trott noted that the panel had "fortunately" created an intercircuit conflict that "will compel the Supreme Court or Congress to resolve this dispute."[199] The plea was prescient, as certiorari was subsequently granted, and a decision was handed down on June 10, 2002.[200]

Reversing the Eleventh Circuit's ruling, a unanimous Supreme Court held that the EEOC regulation authorized an employer to exclude a disabled employee whose job performance would "endanger his own health."[201] The Court did not, however, expatiate the standard employers had to meet to justify such exclusion or establish whether Echazabal's liver condition actually posed a danger to himself.[202] The possible, although not mandated, revisiting of both the procedural and factual questions was left on remand to the Ninth Circuit.[203] Given the Court's broad approbation of the defense, it seems likely that employers will continue to assert that current or future workers ought to be excluded from employment opportunities because their genetic dispositions present threats to their own well-being.

The ADA also contains a partial exemption for insurance coverage. Pursuant to a safe harbor provision in Title V, insurers may offer coverage that adversely impacts individuals with disabilities, so long as the differential treatment is based upon actuarially sound evidence that these individuals pose an expensive risk and is not a "subterfuge to evade" the ADA's antidiscrimination purpose.[204] As a result, courts have held that employers are not required to offer any particular coverage to disabled individuals so long as the coverage offered is equal to that offered to nondisabled people.[205] Some courts have interpreted the "safe harbor" provision to require proof by disabled plaintiffs of intentional stratagems;[206] others have allowed

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[199] *Id.* at 1075 (Trott, J., dissenting).

[200] Chevron USA, Inc. v. Echazahal, 122 S. Ct. 2045 (2002).

[201] *Id.* at 2047.

[202] *Id.* It bears noting, however, that when describing the harms that Echazahal might cause, Justice Souter did so only in terms of the potential costs (such as tort liability) that would be borne by the employer and did not mention those which might harm Echazabal's own health. *Id.* at 2052. We discuss the implications in a companion piece, Anita Silvers & Michael Ashley Stein, *Disability, Paternalism, and the Supreme Court* (unpublished manuscript on file with authors).

[203] *Echazabal*, 122 S. Ct. at 2053.

[204] 42 U.S.C. § 12201(c) (2000); *see also* 29 C.F.R. § 1630.16(f) (2001). For international perspective, see Trudo Lemmens, *Selective Justice, Genetic Discrimination, and Insurance: Should We Single Out Genes in Our Laws?*, 45 MCGILL L.J. 347 (2000).

[205] *See, e.g.*, 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).

[206] *See, e.g.*, *Ford*, 145 F.3d at 601; Krauel v. Iowa Methodist Med. Ctr., 95 F.3d 674, 678-79 (8th Cir. 1996).

actuarial support to rebut allegations of discrimination,[207] a position not inconsistent with that of the EEOC.[208]

D. The "Regarded As" Classification

Disability discrimination law has followed a trajectory targeted at defining who shall be protected against disability discrimination and who shall not be.[209] Seven ADA cases the Supreme Court has heard relate, in one way or another, to this question. *Bragdon* concerned whether an individual with an asymptomatic HIV infection was protected.[210] In *Sutton*,[211] *Kirkingberg*,[212] *Murphy v. United Parcel Service*,[213] and *Toyota v. Williams*,[214] the Court addressed whether people with certain physical limitations—severe myopia, blindness in one eye, extremely elevated blood pressure, and repetitive stress syndrome, respectively—are protected. In *Cleveland v. Policy Management Systems*, the protection of an employee who claimed eligibility for Social Security Disability Insurance ("SSDI") under the ADA was concurrently protected by the ADA.[215] And in *University of Alabama v. Garrett*, the protection of state employees was at issue.[216]

In all but one of these cases, defendants prevailed. Subsequently, a larger proportion of plaintiffs have proceeded under the "regarded as" prong of the ADA.[217] Predictive genetic testing typically is done before the individual's genetic condition becomes symptomatic and causes substantial limitations of major life

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[207] *See, e.g.*, Winslow v. IDS Life Ins. Co., 29 F. Supp. 2d 557 (D. Minn. 1998); Morgenthal v. AT & T Co., 97 Civ. 6443 (DAB), 1991 U.S. Dist. LEXIS 4294 (S.D.N.Y. Apr. 6, 1999).

[208] *See* U.S. EQUAL EMPLOYMENT OPPORTUNITY COMM'N, EEOC INTERIM ENFORCEMENT GUIDELINES 12 (1993).

[209] In some cases, state law is more embracing than federal law. For instance, recent amendments to California's Fair Employment and Housing legislation specify that employees be protected without regard to the degree of substantiality of their impairments. *See* CAL. GOV'T CODE § 12940(e)(1), (f)(1) (West 2001).

[210] 524 U.S. 624, 628 (1998).

[211] 527 U.S. 471 (1999).

[212] 527 U.S. 555 (1999).

[213] 527 U.S. 516 (1999).

[214] 534 U.S. 184 (2002).

[215] 526 U.S. 795, 797 (1999).

[216] 276 F.3d 1227 (11th Cir. 2001).

[217] Referring to this prong of the ADA via the nomenclature of "perceived as" disabled, Michelle Travis offers comprehensive treatments. *See* Michelle Travis, *Leveling the Playing Field or Stacking the Deck? The "Unfair Advantage" Critique of Perceived Disability Claims*, 78 N.C. L. REV. 901 (2000) [hereinafter Travis, *Leveling the Playing Field*]; Michelle Travis, *Perceived Disabilities, Social Cognition, and "Innocent Mistakes"*, 55 Vand. L. Rev. 481 (2002).

activities.[218] Therefore, we may expect that individuals who seek remedies for protection against genetic discrimination through the ADA often will claim that they have been treated unfavorably because they are regarded as disabled rather than because they are disabled.[219]

For example, Terri Sergeant, an individual with a family history of Alpha-1 antitrypsin, an often fatal deterioration of the lungs, has filed under the "regarded as" prong.[220] When presymptomatic, Sergeant tested positive for the genetic disposition for this disease, which had killed her brother at age thirty-seven.[221] As a result of the test, her physician initiated preventive therapy that deters the development of the disease and protects against lung infection.[222] This treatment costs more than $45,000 annually but permits her to work and engage in all other life activities without limitations.[223] Sergeant worked for a firm that partially self-insured for employees' health insurance.[224] During her employment, she had repeatedly received outstanding performance evaluations and merit salary increases.[225] In November 1999, seven months after her costly preventive treatment began, she received another excellent review and increase.[226] One month later, her employment was terminated.[227]

Although there is no certainty that Sergeant would have become symptomatic even without the preventive therapy, the prophylactic measures appear to have been effective.[228] Sergeant remains able to perform activities like walking and breathing, major life activities that are severely compromised in symptomatic cases of Alpha-1 antitrypsin.[229] There is no reason to believe that her employers, who observed her daily, regarded her as currently unable to perform these activities, for the medical information indicates that there is no medical question about her work capability provided she has access to expensive medical interventions.[230] The record of

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[218] ASSESSING GENETIC RISKS: IMPLICATIONS FOR HEALTH AND SOCIAL POLICY, *supra* note 35, at 59-115.

[219] Arguments in support of this assertion are set out in Miller, *supra* note 76, at 240-41.

[220] Alpha-1, *supra* note 159; National Partnership, *supra* note 159.

[221] National Partnership, *supra* note 159.

[222] *Id.*

[223] Alpha-1, *supra* note 159.

[224] *Id.*

[225] *Id.*

[226] *Id.*

[227] *Id.*

[228] National Partnership, *supra* note 159.

[229] *Id.*

[230] *See id.*

litigation under the "regarded as" clause, however, is insufficiently clear to know whether she will succeed under this theory.[231]

To establish a claim of being "regarded as" disabled under the ADA,[232] the statute requires a plaintiff to demonstrate that her employer mistakenly believed she had a physical or mental impairment that limited a major life activity, when she in fact had no such impairment.[233] An example of such a mistaken belief would be an individual who utilizes a lower leg prosthetic device to ameliorate an amputation, but whose functional ability has not actually been impaired.[234] 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 such as walking or standing. Congress extended the ADA's definition of disability to this group of functionally nondisabled individuals in order to combat erroneous but widespread cultural assumptions about people with "disabilities"—what the EEOC eloquently terms the "perception of disability based on myth, fear, or stereotype."[235]

The current Supreme Court addressed the "regarded as" prong in *Sutton v. United Air Lines, Inc.*, a case involving myopic twins denied employment as pilots by United Air Lines.[236] The Court acknowledged the goals underlying the protection of individuals misperceived as having disabilities that were articulated in *Arline*.[237] Nevertheless, the *Sutton* Court held that to be regarded as disabled under the ADA a defendant would have to entertain stereotypical misperceptions about a plaintiff's ability to carry out a broad range of jobs because of the mistaken belief that a nonexistent disability substantially limited her from performing certain major life activities.[238] In other words, an employer has to believe that the individual is ecumenically disabled—that she cannot perform an entire range of jobs in addition to the one from which she claims she has been unjustly excluded.[239] The Court's attendant decisions in *Albertson's, Inc. v. Kirkingburg*[240] and *Murphy v. United Parcel*

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[231] *See supra* Part III.B.

[232] 42 U.S.C. § 12102(2)(C) (2000).

[233] 29 C.F.R. app. § 1630.2(*l*) (2001) (providing the EEOC interpretive guideline).

[234] One well-known example is cross-country runner Terry Fox. *See* Michael Ashley Stein, *From Crippled to Disabled: The Legal Empowerment of Americans With Disabilities*, 43 EMORY L.J. 245 (1994).

[235] 29 C.F.R. app. § 1630.2(*l*) (2001) (providing the EEOC interpretive guideline).

[236] 527 U.S. 471, 475 (1999).

[237] *Id.* at 489-90.

[238] *Id.* at 489.

[239] *Id.*

[240] 527 U.S. 555 (1999).

Service[241] upheld this ruling without much adumbration. Lower courts have subsequently viewed employers' misperceptions as "innocent mistakes," requiring that group-based animus (i.e., believing that plaintiffs are socially incompetent in a generic sense) be ascribed to defendants as a prerequisite to satisfying the "regarded as" criteria.[242]

The single recorded federal decision to adjudicate a claim of genetic discrimination on the merits, *EEOC v. Woodbridge Corp.*,[243] followed the current Supreme Court's ADA rulings in granting defendant summary judgment (despite the similarity of the case to claims asserted by the EEOC in *Burlington Northern).*[244] In *Woodbridge*, the EEOC brought an action on behalf of nineteen job applicants who had successfully applied to work in Woodbridge's polyurethane foam-producing factory.[245] As part of their postoffer, preemployment medical examinations, the plaintiffs were subjected to a neurometry test specially developed to screen for the existence or "significant likelihood" of developing CTS.[246] As the result of the plaintiffs having scored above a certain level on that test, they were each denied employment at the defendant's factory.[247]

Plaintiffs through their EEOC attorneys asserted that applicants for other jobs in the factory—including electricians and tool technicians who also placed stress upon their wrist joints—had not been subjected to the test.[248] They also claimed that because of the neurometry screening, Woodbridge regarded them as disabled and therefore illegally discriminated against them.[249] Citing *Sutton*, the district court granted summary judgment to defendant on the ground that to prevail under the "regarded as" prong the employer must have not only subjectively believed that the employees had a disability but also "regard[ed] the employee as disabled as defined" under the ADA.[250] The court ruled that Woodbridge believed that the applicants' predisposition to CTS, although not definitively evidenced by the neurometry screening, rendered them unqualified only for the specific factory positions.[251] Under these circumstances, the court held that

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[241] 527 U.S. 516 (1999).

[242] *See, e.g.*, Taylor v. Pathmark Stores, Inc., 177 F.3d 180, 193 (3d Cir. 1999); Deane v. Pocono Med. Ctr., 142 F.3d 138, 143-44 (3d Cir. 1998) (en banc).

[243] 124 F. Supp. 2d 1132 (W.D. Mo. 2000), *aff'd*, 263 F.3d 812 (8th Cir. 2001).

[244] *Id.* at 1133.

[245] *Id.* at 1134-35.

[246] *Id.*

[247] *Id.* at 1135.

[248] *Id.*

[249] *Id.* at 1133.

[250] *Id.* at 1136.

[251] *Id.* at 1137.

Woodbridge could not have regarded the nineteen applicants as disabled in the general sense.[252]

Thus, whether Terri Sergeant—or any other claimant under the ADA's "regarded as" prong—can establish that her employer regarded her as disabled and fired her for this reason is unclear. (To date, the EEOC has invited the parties to arbitrate their claims.)[253] The circular nature of her dilemma, however, is clear. Positive genetic testing permits Sergeant to take preventive measures against the substantial limitations of major life activities that could occur as a result of her genetic condition. The success of these measures may have left her unprotected against losing her job, however. Ironically, people may have to forgo the medical benefits genetic information can bring if they are to be protected by the ADA from discrimination based on that information. This catch-22 situation, which so adversely affects asymptomatic and presymptomatic individuals such as Sergeant, is not addressed by either existing or proposed statutory provisions.

E. Putative Federal Protection

A bill intended to address genetic discrimination independently of the ADA, House Bill 602, is currently pending before Congress.[254] Cosponsored by Representative Louise Slaughter (a microbiologist),[255] the Genetic Nondiscrimination in Health Insurance and Employment Act[256] would, in pertinent part, prohibit employment discrimination in hiring and terms of employment on the basis of genetic information.[257] The proposed legislation addresses predictive genetic information, acquired from the analysis of human DNA, RNA, chromosomes, proteins, and certain metabolites in order to detect genotypes,

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[252] *Id.*

[253] Letter from U.S. Equal Employment Opportunity Comm'n on Charge No. 14AA00039, (Nov. 21, 2001) (on file with authors).

[254] *See* H.R. 602, 107th Cong. (2001). The Subcommittee on Commerce, Trade, and Consumer Protection held a brief hearing on July 11, 2001, at which the measure's cosponsors and five other supporters, including Dr. Craig Venter of Celera Genomics, advocated its passage. *The Potential for Discrimination in Health Insurance Based on Predictive Genetic Tests: Hearing Before the House Subcomm. on Commerce, Trade, and Consumer Protection of the House Comm. on Energy and Commerce*, 107th Cong. (2001), *available at* http://energycommerce.house.gov/107/action/107-46.pdf [hereinafter *Subcomm. on Commerce Hearing*] (last visited Sept. 24, 2002).

[255] Representative Slaughter has commented that "every single human being is born with genetic flaws. As a result, we are potentially uninsurable and potentially unemployable." *Subcomm. on Commerce Hearing*, *supra* note 254, at 8.

[256] H.R. 602, 107th Cong. § 1 (2001).

[257] § 202.

mutations, or chromosomal anomalies or from information about genetic test results or occurrences of genetic disease in family members.[258] It excludes data about any other aspect of an individual's health and thus does not cover information about individuals who already are symptomatic.[259] This legislative approach focuses on the special nature of genetic information and invokes the theory of "genetic exceptionalism."[260]

Under the terms of House Bill 602, employers may not use predictive genetic information or information about requests for genetic testing or counseling to fail to hire, discharge, discriminate in working conditions or compensation, or segregate or limit employees in disadvantageous ways.[261] Nor may employment agencies, labor unions, or training programs treat anyone unfavorably on the basis of predictive genetic information.[262] Employers may collect predictive genetic information about employees only within the strictures of narrow programs for monitoring toxic substance risks and only with the employee's consent.[263] Similarly, any information acquired through such programs may be disclosed only with the employee's consent or for certain federally approved purposes.[264]

Senate Majority Leader Tom Daschle promised early action on the bill,[265] which has more than 250 bipartisan cosponsors and the President's promised support.[266] Whether the measure will pass and, in the end, prove effective remains unclear. House Republicans have declined to hold hearings on earlier versions of this proposed bill for the previous five years,[267] insisting even on the day after the human genome code's mapping was announced that there had "been no incidence of genetic discrimination that anyone can point to at this period of time."[268]

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[258] § 201.

[259] *Id.*

[260] *See* Suter, *supra* note 25, at 671.

[261] *See* § 202.

[262] §§ 203-05.

[263] § 202.

[264] § 206.

[265] *See* Dave Boyer & Audrey Hudson, *Lieberman Assumes Bush Watchdog Post Promises Oversight of Energy Policy*, WASH. TIMES (D.C.), June 8, 2001, at A1. "It's time for our laws to catch up with our science. We can't take one step forward in science, but two steps backwards in civil rights." *Id.*

[266] *See* Ed Timms, *'Genetic Discrimination' Condemned: Bush, Lawmakers Favor Protection in Employment, Health Insurance*, DALLAS MORNING NEWS, June 24, 2001, at 4A.

[267] The current sponsor has lamented that "we have had so much trouble getting hearings on this." Sanger, *supra* note 50.

[268] *Genetic Data: Genetie Privacy Laws Unlikely This Year*, AMERICAN HEALTH LINE, June 28, 2000, *available at* http://www.americanhealthline.com.

Some participants in the debate about genetic discrimination have questioned the need for new federal legislation. For example, Senator Jim Jeffords has suggested that the ADA may offer adequate protection against genetic discrimination.[269] We do not enter this debate directly here, except to note that new federal legislation would face difficulties of interpretation and application similar to those the ADA has encountered.

There is, first, a question about how efficaciously federal antidiscrimination regulations can constrain states from discriminating against prospective and present employees on the basis of predictive genetic information. The Supreme Court has struck down the application of certain provisions of both the ADA (in *Board of Trustees v. Garrett*[270]) and the Age Discrimination in Employment Act (in *Kimel v. Florida Board of Regents*[271]) to states in view of their Eleventh Amendment immunity.[272] In both these cases, the Court declared that Congress did not have sufficient evidence of pervasive historical discrimination on the proscribed basis by the states, which is the sole condition under which a civil rights approach can constrain state sovereignty.[273] There is less historical evidence, not more, that states have discriminated on the basis of predictive genetic information.[274]

Second, there is the matter of workers' ability to carry out the essential functions of the job. Employers often claim to be protecting workers who are at higher than usual risk of workplace-induced illnesses or injuries by excluding them from jobs that may harm them.[275] Are workers who are regarded as needing such protection unable to execute functions essential to the job because proximity to necessary work is a personal hazard? If so, should employers be required to continue their employment?

Third, will it be effective to forbid employers to be influenced by protected genetic information when making employment decisions?

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[269] *See Discrimination: Jeffords Examining Need for Legislation on Genetic Discrimination; Coalitions Forming*, *supra* note 133.

[270] 531 U.S. 356 (2001).

[271] 528 U.S. 62 (2000).

[272] *Id.* at 66.

[273] *See id.* at 90-91; Garrett, 531 U.S. at 374.

[274] The sterilization of individuals with certain kinds of biological and behavioral characteristics could be cited as an early form of genetic discrimination. *See* David Pfeiffer, *Eugenics and Disability Discrimination*, 9 DISABILITY SOC'Y 481 (1994); Burgdorf & Burgdorf, *supra* note 147. However, this evidence, cited in congressional hearings during the debate on the ADA and in briefs filed in *Garrett*, was deemed insufficient proof of historical discrimination by states despite Justice Breyer's vociferous dissent. *Garrett*, 531 U.S. at 369-70.

[275] *See supra* notes 185-86 and accompanying text.

We believe it will not. The legislation's protection does not extend to important kinds of information. Terri Sergeant's case 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 House Bill 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 bills for $45,000 annually for preventive treatment.[276] House Bill 602 would prohibit Sergeant's employer from basing an employment decision on the first and third items on this list, but not on the second and fourth.[277] Indeed, all the information the employer needs to identify her genetic condition is manifested in the record of her prophylactic treatment. An Internet search will quickly identify the conditions for which the treatment is prescribed.[278] Granted, knowing her family history might also offer a clue, but the employee would have difficulty establishing that this protected information was crucial.

Thus, the ban on using predictive genetic information does not protect against unfavorable personnel actions that are prompted by beliefs about employees' dispositions to genetic illness. One of the main benefits an individual obtains from predictive genetic information about herself is the foreknowledge to take preventive or mitigating measures.[279] Information that the employee is taking such measures is not protected. An employer concerned with eliminating workers with genetic susceptibility to asbestosis or mesothelioma from contact with asbestos fibers could identify behaviors that frequently occur when individuals learn of their susceptibility: ceasing to smoke, meticulous use of masks, and so on. On the basis of this information, which would not be protected under the provisions of House Bill 602, the employer could take action. Here the employer could claim to be responding to the threat the workplace poses to the worker and, in fact, could claim that relieving the employee of her assignment

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[276] *See* Alpha-1, *supra* note 159.

[277] *See* H.R. 602, 107th Cong. (2001). Many of the state laws that address genetic discrimination are similar to House Bill 602 in this respect. *See* National Human Genome Research Institute, *Genetic Information and Health Insurance Enacted Legislation, at* http://www.nhgri.nih.gov/Policy_and_public_affairs/Legislation/insure.htm (last visited Aug. 26, 2002) (charting enacted state legislation that addresses genetic information and health insurance as of April 29, 2002).

[278] Tamoxifen, for instance, is quickly identified as a medication used to reduce the incidence of breast cancer simply by typing the name of the drug into any major Internet search engine.

[279] *See supra* Part I.B.

safeguards a worker who already has signaled her desire not to become ill.

Analysis of Terri Sergeant's claim raises another difficult question common to genetic antidiscrimination law, regardless of whether the law is provided by the ADA or specialized legislation. This is the problem of determining who will be protected and who will not, when no bright line separates vulnerable from safe and deserving from undeserving populations.

In an attempt to limit the population protected by the ADA, courts have constructed a high threshold for protection under the "disabled" prong, while there currently is uncertainty and a lack of clarity about who is eligible for protection under the "regarded as" prong.[280] A similar problem would occur for individuals seeking protection under the provisions of House Bill 602. Whether an individual is presymptomatic or 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 not a strict indicator of Alzheimer's disease, as demonstrated by the young parents who lock their cars on sweltering summer days, forgetting that their infants are inside.) Knowing that this patient's family has a history of early onset Alzheimer's disease, the physician orders genetic testing, which gives a positive result for a gene associated with Alzheimer's disease. An examination of the patient's cognitive functioning, with attention to the cognitive deficits diagnostic of Alzheimer's disease, is inconclusive. Although no diagnosis of Alzheimer's disease can be made on the existing evidence, the physician starts the patient on Aricept as a prophylactic to delay cognitive impairment just in case the patient's memory problems signal the development of Alzheimer's.[281] 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 Aricept) 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

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[280] *See* Travis, *Leveling the Playing Field*, *supra* note 217.

[281] Aricept is relatively nontoxic, and clinical studies suggest that very early administration can delay symptom development by approximately two years. *See generally* David S. Knopman, *Management of Cognition and Function: New Results from the Clinical Trials Programme Of Aricept® (Donepezil Hcl)*, INT'L J. NEUROPSYCHOPHARMACOLOGY, July 2000, at 13; David G. Wilkinson, *The Pharmacology of Donepezil: A New Treatment of Alzheimer's Disease*, 1 EXPERT OPIN. PHARMACOTHERAPY 121 (1999).

off onset of disease in individuals whom genetic tests show to be at risk may be as revealing as the test results themselves.

Individuals claiming harm from genetic discrimination may have to establish that the harm occurred prior to any sign of their condition and indeed, prior to the employer's imagining such a sign. With respect to relief under the ADA, questions about the extent of plaintiffs' overall limitations often seem to preempt questions about plaintiffs' competence to perform the requirements of the job. Similarly, 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 family history, may preempt questions about whether a genetic condition makes an employee unable to perform the requirements of the job. Because prophylactic prescriptions are separate from the protected record, individuals who use genetic information to pursue preventive measures to benefit their health may, in doing so, lose their legal recourse against genetic discrimination. Thus, the purpose of genetic antidiscrimination law, namely, to free citizens to improve their health through applications of genomic knowledge, may not be realized.

IV. DECIDING WHO SHOULD BE PROTECTED

The ADA, as well as current and proposed genetic discrimination laws, bifurcates the population into protected and unprotected groups. Both approaches leave the large group of presymptomatic individuals who take steps to delay potential genetic disease unprotected from discrimination. Excluding this latter category of individuals from social opportunities is unjustifiable on probabilistic grounds and enormously costly to society. To ensure that this group of individuals receives equality of opportunity, we advocate their inclusion in the classification of the population safeguarded from genetic discrimination, along the lines of protection extended to race and sex. Last, we discuss what such paradigm-shifting legislation would entail.

A. Bifurcating the Population

No matter what their race and sex, regardless of whether they are identified with a dominant or a minority group, all citizens may, in principle, seek recourse through the law if they are harmed by race or sex discrimination.[282] In contrast, courts have seen federal legislation that protects against disability discrimination as bifurcating the population.[283] Many state statutes that protect against genetic discrimination, as well as prospective federal legislation to protect against genetic discrimination, invite the same interpretation.[284] Each might be understood to create two classes, one that benefits from the law's protection and one that is bereft of it.

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,[285] but giving no protection to individuals who can adapt to or mitigate their impairments sufficiently to engage substantially in such activities.[286] On the other hand, proposed specialized legislation that targets genetic discrimination will protect individuals until they evidence limitation of life activities or some other readily observable sign of their propensity for, or manifestation of, genetic disease.[287] The protected population is thus almost a reverse mirror image of the population protected by the ADA, but once again, individuals who take mitigating measures are unprotected.[288]

Ironically, neither the disability discrimination approach nor the attempt to provide separate protection from genetic discrimination shields people who take mitigating measures to escape dysfunction.[289] Further, the lines drawn between protected and unprotected groups do not reflect the difference between people who can and cannot function successfully. Thus, the ADA fails to protect a significant group of people who have impairments but nevertheless can do the job. For example, in *Kirkingburg*, the Supreme Court ruled that an individual, fired as a truck driver because he was blind in one eye, was not protected under the ADA.[290] Kirkingburg's brain forfeited his ADA protection when, in a process still not understood by cognitive science, it enabled him to judge depth accurately with only one eye.[291] The

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[282] *See generally* LAURENCE H. TRIBE, AMERICAN CONSTITUTIONAL LAW 1436-1672 (2d ed. 1988).

[283] *See supra* Part III.D.

[284] *Id.*

[285] *See* Travis, *supra* note 217.

[286] *See, e.g.*, Sutton v. United Air Lines, Inc., 527 U.S. 471, 475 (1999).

[287] *See* National Human Genome Research Institute, *supra* note 277.

[288] *See id.*

[289] *See id.*

[290] Albertson's, Inc. v. Kirkingburg, 527 U.S. 555, 565-67 (1999).

[291] *Id.* at 565. Depth perception usually is binocular, but some individuals apparently adapt to being monocular by correlating visual cues of light and darkness, and perspectives created by tiny head movements, so as to make accurate visual judgments about depth. *See* Wolfgang

bottom line here is that, although Kirkingburg's monocular performance satisfied the standards set for binocular individuals, the Court's reading of the law denied him the opportunity binocular people enjoy and, in doing so, decreased his scope of productivity.[292] Analogously, an individual who, on the basis of a positive genetic test result, takes measures to block a genetic condition from producing dysfunction likely forfeits protection against discrimination when he takes preventive action to preserve his productivity. Thus, existing approaches to both disability discrimination and genetic discrimination fail in large part to reduce the costs of excluding otherwise productive citizens from equal opportunity.

B. Statistical Probability and Social Cost

Some people believe that genetic discrimination accurately targets real biological inferiorities.[293] Under this view, to which many ascribe,[294] genetic variations are perceived as important differences that may warrant assignment to inferior social status and justify inequality of protection.[295] Is this discrimination? And if so, who should be protected against genetic discrimination? Although everyone is equally protected against race or sex discrimination, courts have bridled at protecting everyone equally against disability discrimination. Should everyone be protected equally against genetic discrimination? Congresswoman Slaughter, the author and cosponsor of House Bill 602, has correctly remarked that everyone has some "bad genes."[296] Nonetheless, is it justifiable—either economically or morally—to extend to everyone the protection that everyone needs?[297]

Skrandies, *The Processing of Stereoscopie Information in Human Visual Cortex: Psychophysical and Electrophysiological Evidence*, CLINICAL ELECTROENCEPHALOGRAPHY, July 2001, at 152; Christopher W. Tyler & Leonid L. Kontsevich, *Stereoprocessing of Cyclopean Depth Images: Horizontally Elongated Summation Fields*, 41 VISION RESEARCH 2235 (2001).

[292] *Kirkingburg*, 527 U.S. at 565-67.

[293] *See, e.g.*, RICHARD A. EPSTEIN, FORBIDDEN GROUNDS: THE CASE AGAINST EMPLOYMENT DISCRIMINATION LAWS (1992).

[294] For example, two prominent media columnists subscribe to this view. *See* Andrew Sullivan, *Ban on Use of Genetic Data by Employers, Insurers is Irrational*, SEATTLE POST-INTELLIGENCER, Aug. 6, 2000, at G-I. (decrying the analogy between genetic discrimination and racial discrimination as "bogus" and averring that "the sooner we get over our handwringing, the better"); Michael Kinsley, *Genetic Correctness*, WASH. POST, Apr. 18, 2000, at A29 (maintaining that divergent treatment based upon genetics is "discrimination that makes perfect sense").

[295] *See supra* note 294.

[296] *Subcomm. on Commerce Hearing*, *supra* note 254.

[297] The question of group membership, especially as it pertains to disability, is an especially pertinent and difficult one that goes beyond the boundaries of this Article, but is one that we have begun to address elsewhere. *See* Anita Silvers & Michael Ashley Stein, *Disability, Equal Protection, and the Supreme Court: Standing at the Crossroads of Progressive and*

Excluding instances of purposeful prejudice (or "distaste"),[298] discrimination may occur when a decisionmaker, lacking perfect information about the characteristics of the members of a given group, bases her assessment on inaccurate "indicators" that she believes can evaluate those individuals' present or future performance.[299] Some of these assessments may be irrational.[300]

Genetic discrimination targets a DNA anomaly, real or imagined, and assigns individuals with that anomaly to the "abnormal" group.[301] Some members of the group will eventually express symptoms of particular illnesses (with varying degrees of functional limitations), while others will not.[302] As the result of genetic discrimination, however, all members of the group must accept inferior employment opportunities on the presumption that society has an acceptable interest in excluding them.[303] This result transpires mainly because as a culture we do not yet understand that predictive genetic testing's usefulness as a basis for preventive health care does not make it an equally useful basis for predicting personal performance. Although reliable scientific knowledge is growing exponentially in the field of genomics, there also exists huge potential

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Retrogressive Logic in Constitutional Classification, 35 MICH. L. REV. 81 (2002); Anita Silvers & Michael Ashley Stein, *Disability, Race, Social Construction, and Group Identity* (unpublished manuscript on file with authors); Anita Silvers & Michael Ashley Stein, *From Plessy (1896) and Goesart (1948) to Cleburne (1985) and Garrett (2001): A Chill Wind From the Past Blows Equal Protection Away*, *in* BACKLASH AGAINST THE AMERICANS WITH DISABILITIES ACT: INTERDISCIPLINARY PERSPECTIVES (forthcoming 2002). Other noteworthy treatments are Mark Kelman, *Market Discrimination and Groups*, 53 STAN. L. REV. 833 (2001) and Samuel A. Bagenstos, *Subordination, Stigma, and Disability*, 86 VA. L. REV. 397 (2000).

[298] The seminal writing on "distaste" is by Nobel Prize–winning economist (and journalist) GARY S. BECKER, THE ECONOMICS OF DISCRIMINATION 39-45 (2d ed. 1971).

[299] For an appraisal of how this phenomenon affects the labor market participation of disabled workers, see Michael Ashley Stein, *Labor Markets, Rationality, and Workers with Disabilities*, 21 BERKELEY J. EMP. & LAB. L. 314 (2000). Additionally, general policy misassessments are described in Silvers & Stein, *Disability, Equal Protection, and the Supreme Court: Standing at the Crossroads of Progressive and Retrogressive Logic in Constitutional Classification*, *supra* note 297.

[300] *See* Dennis J. Aigner & Glen G. Cain, *Statistical Theories of Discrimination in Labor Markets*, 30 INDUS. & LAB. REL. REV. 175 (1977). As to the efficiency of these types of determinations, see Richard A. Posner, *The Efficiency and the Efficacy of Title VII*, 136 U. PA. L. REV. 513, 516 (1987); Stewart Schwab, *Is Statistical Discrimination Efficient?*, 76 AM. ECON. REV. 228 (1986).

[301] *See* ASSESSING GENETIC RISKS: IMPLICATIONS FOR HEALTH AND SOCIAL POLICY, *supra* note 35, at 59-115.

[302] *See infra* notes 320-25 and accompanying text.

[303] *See* EPSTEIN, *supra* note 293.

for erroneous predictive decisionmaking. This inaccuracy can be traced to two causes—one social, the other scientific.[304]

The values of individuals who conduct genetic tests can influence their interpretation of the results.[305] For example, research by Dr. Paul Billings and his colleagues indicates that people commit base-rate judgment errors in overassessing the chances of contracting illnesses produced by genetic factors relative to nongenetically induced conditions.[306] Another study, this time by state insurance commissioners, found that respondents consistently ignored base-rate conditions relative to genetic manifestations.[307] Statistically, students and staff at Harvard Medical School fared even worse in a study of interpretive base rates.[308] When asked, "[I]f a test to detect a disease whose prevalence is 1/1000 has a false positive rate of [five percent], what is the chance that a person found to have a positive result actually has the disease, assuming you know nothing about the person's symptoms or signs?", almost half responded ninety-five percent, with only about one-fifth answering correctly (two percent).[309] If sophisticated professionals can make systematic mistakes when interpreting genetic information, then the decisions of businesses utilizing that information may not be accurate.

Furthermore, actual predictive genetic testing itself manifests a wide range of clinical utility (i.e., precision) and therefore may not be a likely indicator of productivity.[310] As mentioned above,[311] the accuracy with which a genetic test predicts the onset of disease depends on many factors, including variances in gene expression, a test's technical

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[304] Although it is not our view, some individuals claim that these errors are purposefully linked. *See* RUTH HUBBARD & ELIJAH WALD, EXPLODING THE GENE MYTH: HOW GENETIC INFORMATION IS PRODUCED AND MANIPULATED BY SCIENTISTS, PHYSICIANS, EMPLOYERS, INSURANCE COMPANIES, EDUCATORS AND LAW ENFORCERS (1993).

[305] *See* Peter David Blanck & Mollie Weighner Marti, *Genetic Discrimination and the Employment Provisions of the Americans with Disabilities Act: Emerging Legal, Empirical, and Policy Implications*, 14 BEHAV. SCI. & L. 411 (1996) (providing the sources cited *infra* notes 306-09).

[306] *See* Paul R. Billings et al., *Discrimination as a Consequence of Genetic Testing*, 50 AM. J. HUMAN GENETICS 476, 480 (1992).

[307] *See* Jean E. McEwan et al., *A Survey of State Insurance Commissioners Concerning Genetic Testing and Life Insurance*, 51 AM. J. HUM. GENETICS 785 (1992).

[308] *See* Ward Casscells et al., *Interpretation by Physicians of Clinical Laboratory Results*, 299 NEW ENG. J. MED. 999, 1000 (1978).

[309] *Id.*

[310] *See* National Institutes of Health, Secretary's Advisory Committee on Genetic Testing, *A Public Consultation on Oversight of Genetic Tests*, at 9 (1999-2000), *available at* http://www.edc.org/SACGT/id48.htm [hereinafter NIH-SACGT] (on file with author). "Clinical utility refers to the degree to which benefits are provided by positive and negative test results." *Id.*

[311] *See supra* Part I.A.

precision, and the stability of linkage between genetic markers and suspect genes.[312] Some genetic tests suffer from a high occurrence of false positives and/or false negatives.[313] Moreover, genetic recombination can interfere with the predictive value of genomics.[314] Consequently, predictive genetic testing "contains a substantial component of uncertainty," not only as to whether a given condition will express itself, but also when and how severely this expression will appear.[315]

In addition, the predictive value of a test depends heavily upon the nature of the disease for which it tests.[316] First, only a few diseases are caused by genetic anomalies with one hundred percent expression—that is, genes whose presence invariably leads to development of the disease.[317] One such example is multiple endocrine neoplasia type 2, a rare disorder resulting from mutations in the RET protooncogene that is nearly certain to develop into medullary thyroid carcinoma.[318] By contrast, perhaps fifty to sixty 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.[319] Accordingly, interpreting the presence of any particular gene as meaning that an individual will categorically manifest a correlated health condition is not statistically supportable.

Second, while predictive genetic testing *can* be useful in identifying which individuals from the population are at increased risk, estimates of penetrance—the proportion of individuals with a particular genetic susceptibility who will in fact develop the associated condition[320]—vary tremendously. In circumstances involving defective BRCA1 or BRCA2 genes, penetrance estimates for breast cancer range from thirty-six to eighty-five percent and for ovarian cancer from ten

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[312] An excellent treatment is James P. Evans et al., *The Complexities of Predictive Genetic Testing*, 322 BRIT. MED. J. 1052 (April 28, 2001).

[313] *Id.* at 1053.

[314] *Id.* at 1054.

[315] *Id.* at 1053.

[316] *Id.* at 1053-54.

[317] *See* ASSESSING GENETIC RISKS: IMPLICATIONS FOR HEALTH AND SOCIAL POLICY, *supra* note 35, at 59-115.

[318] *See* A.O. Hoff et al., *Multiple Endocrine Neoplasias*, 62 ANN. REV. PHYSIOLOGY 377 (2000); C.A. Stratakis & D.W. Ball, *A Concise Genetic and Clinical Guide to Multiple Endocrine Neoplasias and Relatcd Syndromes*, 13 J. PEDIATRIC ENDOCRINOLOGY METABOLISM 457 (2000).

[319] *See* Elizabeth B. Claus et al., *The Genetic Attributable Risk of Breast and Ovarian Cancer*, 77 CANCER 2318 (1996).

[320] *See* Paolo Vineis et al., *Misconceptions About the Use of Genetic Tests in Populations*, 357 LANCET 709 (2001); *see also* Howard Hughes Medical Center, *Blazing a Genetic Trail: Glossary*, *at* http://www.hhmi.org/genetictrail/glossary/glossary.htm (last visited Sept. 4, 2002).

to forty-four percent.[321] 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, if at all, is unclear.[322] Thus, with few exceptions, extrapolating from the presence of given genetic anomalies to a prediction that the individual will develop the associated disabilities is not statistically provable.

Additionally, a single gene can carry many different mutations, and a disease can be associated with mutations of many genes. Over eight hundred different mutations of genes associated with cystic fibrosis have been identified.[323] Some of these will cause the disease to manifest in varying degrees of severity, and some will have no effect at all.[324] Furthermore, identical mutations in such genes will affect individuals from different populations to different degrees because of variations in environmental factors.[325] A particular genetic mutation may also have effects different from the one that is being investigated. For instance, in the future, scientists could discover that having a particular breast cancer gene mutation correlates with immunity from AIDS (as sickle-cell trait correlates with heightened immunity to malaria). Thus, an employer screening for and then discriminating against individuals with a genetic predisposition to breast cancer because of the costs associated with that illness might end up excluding employees with immunity to higher-cost illnesses. To do so would not only be illogical, it would also increase individual costs.

Nevertheless, the view that not all people warrant protection appears to emerge from concern about the costs of covering everyone alike. For example, a recent article by prominent law professors Colin Diver and Jane Cohen maintains that banning genetic discrimination within the employment market would "cause significant welfare losses due to the distortion of allocative efficiency."[326] In sum, Diver and Cohen begin from a neoclassical model of the labor market, one that presumes that voluntary exchanges between willing and informed

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[321] *See* Steinunn Thorlacius et al., *Population-Based Study of Risk of Breast Cancer in Carriers of BRCA2 Mutation*, 352 LANCET 1337 (1998); D. Ford et al., *Risks of Cancer in BRCA1-Mutation Carriers*, 343 LANCET 692 (1994).

[322] *Id.*

[323] *See* NIH-SACGT, *supra* note 310, at 7.

[324] *Id.*

[325] *Id.*

[326] Colin S. Diver & Jane Maslow Cohen, *Genophobia: What is Wrong with Genetic Discrimination?*, 149 U. PA. L. REV. 1439, 1445 (2001). They also erroneously assert that a ban on genetic testing would harm equality of opportunity. *See* discussion *infra* Part IV.C.

individuals are "the paradigm of efficiency-enhancing transaction."[327] Consequently, the withholding of genetic information from employers by individuals with genetic anomalies causes unjustified "significant efficiency losses."[328] This loss occurs because rendering that information exclusive to its owners prevents employers from properly assessing (and penalizing) the presumed lower productivity and higher costs associated with those conditions.[329]

Diver and Cohen's assessment fails for three main reasons. The first is that they make the same presumptive errors detailed above regarding the accuracy of (and accordingly the justification for relying upon) predictive testing.[330] Their argument stands up only if genetic screening can accurately predict whether a debilitating condition will be expressed by an anomalous gene *and* can correctly assess whether and to what extent a given individual will be functionally impaired. As we have argued, available scientific evidence demonstrates that this level of precision has not yet been achieved.[331]

Yet, even if predictive testing could make these prognostications, Diver and Cohen also err in their assertion that economic efficiency therefore mandates the allowance of genetic discrimination within the employment market.[332] Strong policy reasons, in fact, militate against such a conclusion. To begin with, everyone is vulnerable to genetic discrimination because we each have some atypical or anomalous genes that may, in the future, become suspect as new scientific knowledge expands the pool of individuals believed to be at heightened risk for genetic dysfunction.[333]

Permitting the exclusion of a larger number of individuals on the basis of their genetic susceptibilities may be an exercise in rational exclusion from an individual employer's personal point of view because it reduces the chance that these individuals will manifest symptoms and require a disability-related accommodation or

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[327] Diver & Cohen, *supra* note 326, at 1460. For a critique of this model as applied to disabled workers, see Stein, *supra* note 299; Micbael Ashley Stein, *Market Failure and ADA Title I*, *in* AMERICANS WITH DISABILITIES: EXPLORING IMPLICATIONS OF THE LAW FOR INDIVIDUALS AND INSTITUTIONS 193 (2000).

[328] Diver & Cohen, *supra* note 326, at 1460.

[329] *Id.*

[330] *Id.*

[331] *See supra* Part III.B.

[332] Diver & Coben, *supra* note 326, at 1460. Of course, much of the assessment depends on what one factors into the notion of social good. An extremely articulate treatment (also acknowledged by Diver and Cohen) is provided by Howard F. Chang, *A Liberal Theory of Social Welfare: Fairness, Utility, and the Pareto Principle*, 110 YALE L.J. 173 (2000). *See also* Michael Ashley Stein, *Empirical Implications of Title I*, 85 IOWA L. REV. 1671 (2000).

[333] *See* ASSESSING GENETIC RISKS: IMPLICATIONS FOR HEALTH AND SOCIAL POLICY, *supra* note 35, at 59-115.

increase group-based insurance costs.[334] Nevertheless, it is neither economically efficient nor in the interests of the general society and the collective good to keep productive individuals out of the economy and thereby require that resources be devoted to them while they themselves do not generate productive goods.

This last point can be illustrated in concrete terms. Studies show that hiring people with disabilities generally lowers taxpayers' burdens[335] and benefits the national economy.[336] In large part, this is due to reducing expenditures on disability-related public assistance obligations, currently estimated at $120 billion annually.[337] Pertinently, one report estimates that for every one million disabled people employed, there would be as much as a $21.2 billion annual increase in earned income, a $2.1 billion decrease in means-tested cash income payments, a $286 million annual decrease in the use of food stamps, a $1.8 billion decrease in Supplemental Security Income payments, 284,000 fewer people using Medicaid, and 166,000 fewer people using Medicare.[338]

Consequently, society's interests in achieving the most productive overall arrangement of its citizens overrides the individual employer's interests in reducing the risk that their particular cohorts of workers will be less net-productive.[339] Moreover, leaving asymptomatic or presymptomatic individuals unprotected impedes the realization of the precise public health benefits and related savings in health-care costs that genomics was supposed to achieve.

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[334] Many of the same arguments used to be rolled out to defend excluding people of color or women from desirable workplaces. *See* EPSTEIN, *supra* note 293; Tribe, *supra* note 282.

[335] *See, e.g., The JWOD Program: Providing Cost Savings to the Federal Government by Employing People with Disabilities* (Feb. 6, 1998) (listing survey results and reporting tbat the federal government saved $1,963,206 over the course of the study by employing 270 people with disabilities) (on file with Iowa Law Review); *Taxpayer Return Study California Department of Rehabilitation Mental Health Cooperative Programs* (Oct. 1995) (finding that for every disabled person employed, California taxpayers saved an average of $629 per month in costs) (on file with Iowa Law Review).

[336] *See generally* Thomas N. Chirakos, *Aggregate Economic Losses from Disability in the United States: A Preliminary Assay*, 67 MILBANK Q. 59 (Supp. 2, pt. 1 1989).

[337] *See* David I. Levine, *Reinventing Disability Policy 1* (Inst. of Indus. Relations, Working Paper No. 65, 1997), *at* http://socrates.berkeley.edu/niir/wpapers/pdf/65.pdf.

[338] *See* Patricia Digh, *People with Disabilities Show What They Can Do*, HR MAG., June 1998, at 141 (citing Rutgers University economist Douglas Kruse).

[339] *See* Lawrence O. Gotsin, *Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers*, 17 AM. J.L. & MED. 109 (1991).

C. The Equality Model

Underlying much of the concern regarding costs voiced by commentators such as Diver and Cohen is a mistaken notion about what is required in order to guarantee individuals' equality of opportunity within the context of genetic difference.[340] They are correct in their formulation of the general premise that egalitarianism "posits that every human being deserves an equal opportunity to achieve her potential or her life's goals" so that a just society is under "a moral obligation to redress barriers to equal opportunity."[341] Nonetheless, when Diver and Cohen apply this notion of equality to the area of genetic discrimination, they do so incorrectly.

First, they argue that protection against genetic discrimination privileges individuals on the basis of their "brute luck" in having inherited propensities for genetic disease.[342] This contention errs because it relies on the mistaken idea that to refrain from disadvantaging an individual is to privilege that individual. Incorrectly assuming that the individuals in question will be less productive, Diver and Cohen imagine that protection against genetic discrimination means that less-qualified individuals will be preferred to more qualified individuals through mechanisms of "coerced altruism."[343] This assumption is misguided, however. To have the misfortune to inherit anomalous genes through no fault of one's own in no way equates with being less productive.

Second, they mistakenly reformulate their premise about equal opportunity as a principle that an individual's success in the "race of life" should not be determined by "the 'brute luck' of the natural or social lottery."[344] To the contrary, most proponents of equality of opportunity do not propose to address natural differences. Instead, they seek the elimination of artificial—that is, socially imposed—barriers to the exercise of natural talents.[345] Some equal opportunity theorists—for instance, the bioethicist Norman Daniels—argue that we must provide medical care to people disadvantaged by poor health,

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[340] Because it is well-written and recent, we utilize Diver and Cohen's article as a proxy for other commentators but stress that our criticisms are not limited to the aforementioned.

[341] Diver & Cohen, *supra* note 326, at 1471. Variations abound as to what exactly the opportunity to achieve equality requires. A primer on equality theory would include RONALD M. DWORKIN, SOVEREIGN VIRTUE: THE THEORY AND PRACTICE OF EQUALITY (2000), JOHN RAWLS, A THEORY OF JUSTICE (1999), and AMARTYA SEN, INEQUALITY REEXAMINED (1992).

[342] Diver & Cohen, *supra* note 326, at 1471.

[343] *See id.* at 1473.

[344] *Id.* at 1480.

[345] *See* Anita Silvers, *Formal Justice, in* DISABILITY, DIFFERENCE, DISCRIMINATION: PERSPECTIVES ON JUSTICE IN BIOETHICS AND PUBLIC POLICY 13 (1998).

but only in cases and to the extent that there are treatments to restore them to a physical state in which equality of opportunity becomes meaningful for them.[346] Apparently Diver and Cohen have confused equality of opportunity with a view often thought to be its strong opponent, namely, the principle adopted by welfarists that justice requires equality of outcomes, not just equality of opportunity.[347]

In doing so, they also suggest that employers will be statistically correct in promoting biological species–typicality in their employees, for instance, by offering fitness and wellness programs.[348] In general, Diver and Cohen underestimate the force with which promoting species-typicality creates aversion to genetic anomaly. For example, they insist that genetic aversion does not affect "the preference function of most people."[349] Diver and Cohen make this claim primarily based upon the assumption that genetic anomalies are "hidden."[350] They therefore suppose that most people do not consider genetic anomalies in dealing with one another.[351] In doing so, they apparently overlook the fact that most genetic anomalies have observable manifestations, and that the history of eugenics programs fully demonstrates how averse society has been toward individuals believed to carry inherited anomalies.[352]

A central problem for many commentators who consider the implications of genetic difference is that they label genetic differences as diseases rather than acknowledging that those differences sometimes also indicate when certain individuals may be at greater risk of disease. In so doing, they import a criterion of genetic normality which, in a thoughtful and prescient article published in 1995, Susan M. Wolf termed "Geneticism."[353] 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

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[346] Daniels asserts this thesis in many places, including his chapter in HEALTH CARE ETHICS: AN INTRODUCTION 290 (1987).

[347] *See generally* NEAL DEVINS & DAVISON M. DOUGLAS, REDEFINING EQUALITY (1998) (providing different visions of what constitutes equality).

[348] *See* Diver & Cohen, *supra* note 326, at 1477.

[349] *Id.* at 1465.

[350] *Id.*

[351] *Id.*

[352] For example, they ignore Justice Holmes's infamous justification of state-imposed sterilization on the ground that "[t]hree generations of imbeciles are enough." Buck v. Bell, 274 U.S. 200, 207 (1927).

[353] *See* Susan M. Wolf, *Beyond "Genetic Discrimination": Toward the Broader Harm of Geneticism*, 23 J.L. MED. ETHICS 345, 346 (1995).

into those categories, and harboring attitudes and prejudices that motivate such behavior."[354] She believed that formal equality theory requires groups manifesting differences to be treated as if they had none of these differences.[355] 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."[356] In reality, however, there is no natural biological underclass, for "[t]here is nothing neutral or scientifically 'real' about identifying a genetic norm" for as "no one actually possesses this fictive 'normal' genotype, it is completely unclear what it means to treat someone as if they did have it."[357]

Wolf argued that as a society we must not be misled into thinking that a strategy that failed in regard to sex discrimination—namely, attempting to assimilate members of a subordinated group to the dominant group—will work for genetic discrimination.[358] By reifying the properties of the dominant group into "a norm that does not exist," assimilation serves to "merely entrench genetic bias."[359] Such an approach "instantiates a norm that does not exist" and serves to "merely entrench genetic bias."[360] Wolf also argued that as a society we must go beyond an approach to genetics paralleling early sex antidiscrimination theory that seeks to treat members of the subordinate group (women/those with known genetic anomalies) like members of the dominant group (men/those without known genetic anomalies)."[361] We must abandon the stereotype that individuals with genetic variations are deviant, abnormal, or defective rather than simply variant. Instead, policymakers and theorists ought to learn from work done in the areas of race and sex[362] to understand that the

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[354] *Id.* at 347.

[355] *Id.*

[356] *Id.* at 348.

[357] *Id.*

[358] *Id.* at 350.

[359] *Id.* at 345-46.

[360] *Id.*

[361] *Id.*

[362] Representative literature includes the following: CATHERINE A. MACKINNON, FEMINISM UNMODIFIED: DISCOURSES ON LIFE AND LAW (1987); Kimberle Crenshaw, *Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory, and Antiracist Politics*, 1989 U. CHI. LEGAL F. 139 (1989); Kimberle Crensbaw, *Race, Reform, and Retrenchment: Transformation and Legitimation in Antidiscrimination Law*, 101 HARV. L. REV. 1331 (1988); Charles R. Lawrence III, *The Id, the Ego, and Equal Protection: Reckoning with Unconscious Racism*, 39 STAN. L. REV. 317 (1987).

practice of treating people differently based on their different genome type must be discontinued.[363]

We agree with many of Wolf's assertions and take notice of her concerns. We are, however, 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 shall argue, equality invites a methodology that acknowledges the differences between groups but eschews unfounded inferences based on these differences.[364] In sum, we do not object as strongly as Wolf to "seeing people as their genes"[365] because we think it possible for formal justice to acknowledge differences in genetic identity without using "genetic notions to privilege some individuals and subordinate others."[366]

Effective protection against genetic discrimination is not easy to achieve. Because protecting against genetic discrimination also requires promoting the important social and cultural change of rejecting "species-typicality," approaches to genetic discrimination that are analogous to formal equality protections against racial and sex discrimination may have limited efficacy absent a concurrent shift in attitudinal perception[367] and in the legal concepts framing prevention of genetic discrimination. We now turn to this matter.

D. Reconceptualizing the Protected Class

Neither current protection against disability discrimination, nor current or proposed protection against genetic discrimination, adequately shields the large group of presymptomatic individuals using measures to prevent or mitigate potential genetic anomalies that may never be expressed or that, if expressed, may not manifest as functional impairments.[368] Moreover, this class of people is one for

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[363] Literature that pushes this front within the realms of race and sex jurisprudence includes: Adrienne Asch & Gail Geller, *Feminism, Bioethics, and Genetics*, *in* FEMINISM & BIOETHICS: BEYOND REPRODUCTION (1996); Dorothy E. Roherts, *The Genetic Tie,* 62 U. CHI. L. REV. 209 (1995); Rochelle Cooper Dreyfuss & Dorothy Nelkin, *The Jurisprudence of Genetics*, 45 VAND. L. REV. 313 (1992).

[364] *See infra* Part IV.D.

[365] Wolf, *supra* note 353, at 346.

[366] *Id.*; *see also* Silvers, *supra* note 345, at 13-146.

[367] Or, as Wolf puts it, "Too much discussion of genetic disadvantage proceeds as if scholars of race and gender had not spent decades critiquing and developing antidiscrimination theory." Wolf, *supra* note 353, at 345.

[368] *See supra* Part III.

whom opportunity will be productive and whose productivity otherwise might be lost to the community.[369]

We therefore propose extending genetic discrimination protection to the general population by prohibiting discrimination towards individuals "on the basis of their genetic identity." Such a proscription, with language borrowed from Title VII of the Civil Rights Act of 1964[370]—the central protection against race or sex discrimination[371]—would tailor genetic antidiscrimination protection to those instances when employers utilize genetic information as the grounds for inequitably reducing opportunities because of stereotypic beliefs about the significance of the individuals' genetic identity.

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.[372] This initial presumption will either be borne out or disproved by empirical evidence when particular actions are challenged.[373] In line with our current treatment of racial minorities and women, 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 are not.[374]

For purposes of the law, the population of the legal classification of genetically anomalous people would be characterized not in terms of stereotypes but, instead, through empirical study of the relevant biological groups. We would cease to use genetic anomalies as proxies for performance limitations. People with higher than typical risk of genetic disease as a class would be presumed to remain viable employees, even though some will not be so. Except perhaps in cases of genes with perfect (one hundred percent)

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[369] *See supra* Part IV.A-C.

[370] 42 U.S.C. § 2000e (2000).

[371] *Id.*

[372] The following discussion draws from parallel arguments we make in two forthcoming pieces: *Disability, Equal Protection, and the Supreme Court: Standing at the Crossroads of Progressive and Retrogressive Logic in Constitutional Classification*, *supra* note 297; *From Plessy (1896) and Goesart (1948) to Cleburne (1985) and Garrett (2001): A Chill Wind From the Past Blows Equal Protection Away*, *supra* note 297.

[373] *See supra* note 372.

[374] *Id.*

penetrance,[375] the presumption would be that members of the class of genetically anomalous people will remain competent and productive, although a subclass will not be so, rather than that class membership means future deficiency.[376]

Here we borrow from contemporary constructions of the legal classifications of race and sex. For example, half a century ago, equal protection did not reach women because, as a class, they were characterized as unable to defend themselves and others, even though only a subclass of women actually was too weak to do so.[377] Today, the class of women generally is thought capable in this regard,[378] although presumably the existence of a subclass too weak to do so remains the same.[379] 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.[380] Thus, for instance, we think 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 defend themselves.[381]

Broadly, constructing classifications on an equality basis means that no one may be treated with less favorable presumptions, nor 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 Wolf's concern that characteristics associated with one genetic class become a standard for members of other classes. According to 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.

On the whole, the law has little patience with legal classifications construed in probabilistic terms. On the other hand, the nature of genetic information is such that attributions of genetic

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[375] *See supra* notes 316-20 and accompanying text (discussing varying degrees of penetrance for diseases such as breast cancer and Huntington's disease).

[376] *See Disability, Equal Protection, and the Supreme Court: Standing at the Crossroads of Progressive and Retrogressive Logic in Constitutional Classification*, *supra* note 297.

[377] *See* Goesart v. Cleary, 335 U.S. 464, 465 (1948) (upholding a Michigan statute that prohibited women from being licensed as bartenders except where the bars were owned by their husbands or fathers).

[378] *See* Cleburne v. Cleburne Living Ctr., Inc., 473 U.S. 432, 441 (1985).

[379] *See Disability, Equal Protection, and the Supreme Court: Standing at the Crossroads of Progressive and Retrogressive Logic in Constitutional Classification*, *supra* note 297.

[380] *Id.*

[381] *Id.*

identity are inescapably probabilistic.[382] How, then, can legal classifications do justice to the nature of genetic identity?

Constructing the class of genetically anomalous people as we have proposed appropriately acknowledges that genomic knowledge supports judgments that are probable at best. This approach recognizes that in most cases genes associated with genetic diseases have less than one hundred percent penetrance and also that many genetic diseases are multivariant, meaning that several factors must combine to induce the onset of symptoms.[383] Individuals who are at higher than species-typical risk for onset are nevertheless very often unlikely to become symptomatic.[384] Further, even individuals who are symptomatic may maintain their competence and productivity, especially if mitigating measures for their disease can be found.[385]

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 be far more difficult than a mere showing that their propensity to a genetic disease is more than species-typical.

The requisite standard of proof must serve the liberty and opportunity interests of individuals and also satisfy collective social interests. The latter interests include both the reasonable desire of citizens to be self-supporting and the reasonable desire of employers to maintain productive enterprises. We propose a high standard of protection to align the law with current realities regarding genetic knowledge. With few exceptions, employers (and society at large) cannot predict accurately the effect DNA anomalies have on particular individuals.[386] 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.

Increasingly, medical information will have a genetic component. We do not argue for the abolition of any use of medical information in employment decisions. Instead, we take issue with the selection of proxy characteristics based upon empirically unfounded stereotypes that lead to the general exclusion of people with genetic differences regardless of competence or qualification.

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[382] A balanced treatment of this issue is found in Stewart J. Schwab, *Is Statistical Discrimination Efficient?*, AM. ECON. REV., Mar. 1986, at 228, 228-34.

[383] *See* discussion *supra* Part I.A.

[384] *See* ASSESSING GENETIC RISKS: IMPLICATIONS FOR HEALTH AND SOCIAL POLICY, *supra* note 35, at 59-115.

[385] *Id.*

[386] *See supra* Part I.A.

CONCLUSION

We have argued for the creation of an equality-based protection for genetic discrimination similar to that of race and sex discrimination. We pointed out that, like race and sex, everyone is genetically anomalous in some way. That is, everyone exhibits some differences from genetic species-typicality because species-typicality is as much an idealized construction as the idea of the "average person." We showed that, although everyone is genetically anomalous in some way, the practical and theoretical problems inherent in current approaches to statutory protection leave many people exposed to genetic discrimination. In this regard, we explained how the ADA and genetic discrimination laws both bifurcate the population into protected and unprotected groups that leave unprotected the group of presymptomatic individuals who utilize mitigating measures.

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 learns 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 rapidly.

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 genetic discrimination that would protect the people who have the most to lose and to gain from genomics. Finally, to indicate how implementation of our proposal can be initiated, we discussed some features of what such a paradigm-shifting approach would necessitate.