POINT/COUNTERPOINT

GENOPHOBIA: WHAT IS WRONG WITH GENETIC DISCRIMINATION?

COLIN S. DIVER[†] & JANE MASLOW COHEN[††]

INTRODUCTION

The decoding of the human genome, announced with great fanfare by President Bill Clinton and Prime Minister Tony Blair in June, 2000,[1] marked a hugely symbolic milestone in the progress of genetic science. Mapping the roughly three billion nucleotide pairs that comprise the human genetic profile is a monumental achievement of human ingenuity and technological sophistication.[2] Yet, before the knowledge unleashed by the Human Genome Project can be widely used to improve human health and welfare, much work remains to be done.[3] Scientists must first locate, along the 23 paired

---

† Charles A. Heimbold, Jr., Professor of Law and Economics, University of Pennsylvania.

†† Professor of Law, Boston University. Professor Cohen wishes to thank the members of the Yale Law and Technology Society who attended her presentation of this paper in workshop format and who engaged its terms with spirited aplomb.

[1] *See* Colin Macilwain, *World Leaders Heap Praise on Human Genome Landmark*, 405 NATURE 983, 983 (2000) ("Clinton hosted an event at the White House . . . joined by video link from London by . . . Blair.").

[2] *See* Nicholas Wade, *Genome Analysis Shows Humans Survive on Low Number of Genes*, N.Y. TIMES, Feb. 11, 2001, at A1. The "genome" is defined as all of the genetic material in the chromosomes of a particular organism. The 3.2 billion letters that represent the chemical composition of the human genome would, if printed in standard newspaper type, comprise 75,490 pages of "news." *Id.* Computer programs vastly increased the speed with which these letters could be separated into approximate sequences so that the actual genes within the genome could be mapped.

Once the rough map was completed, it emerged—contrary to the consensus prediction within the scientific community—that humans make do with only about 30,000 genes—far less than the 100,000 or so that the map had been expected to yield. *Id.* Thus it turns out that we humans have only a third more genes than, for example, worms. *Id.* This startling discovery has led one of the authors to reduce the differences between humans, worms, and other creatures to the great (and optimistic!) folk maxim: "It ain't what you got; it's what you *do* with what you got."

[3] *See* Nicholas Wade, *Now, the Hard Part: Putting the Genome to Work*, N.Y. TIMES,

human chromosomes, the currently estimated 30,000 genes that do all of the real work: that build and repair the body and regulate its functions.[4] Within that universe of genetic material, they must then isolate those specific genetic variations—alleles,[5] mutations, or polymorphisms—that are associated with particular, adverse physical or psychological conditions, such as diseases, functional impairments, and perhaps even socially maladaptive behaviors. Epidemiologists must then study the statistical link between the presence of a particular genetic profile and the manifestation of a particular condition, while proteomics specialists explore the biochemical pathways by which the proteins produced by particular genetic mutations inhibit or otherwise modify normal bodily functioning.[6]

Yet, daunting as the challenge may prove to be, progress is being made at almost breathtaking speed. Every week, breakthroughs are announced in the search for genes, the cataloging of alleles, the identification of their functions, and the estimation of risk factors. Perhaps the most dramatic payoff from this unfolding progress is the development of genetic tests for predisposition to various diseases and functional impairments. Tests already have been developed to identify the presence of over four hundred particular alleles or

---

June 27, 2000, at F1 ("Scientists have nearly finished sequencing the entire human genome, but putting all the bits of DNA in order is only the first phase in the effort to compile a complete operating manual of the human machine.").

[4] The "decoding" of the genome belies the difficulty of understanding what specific functions each gene actually serves; how genes coordinate their functions; whether most of the nucleotides that comprise inactive genes are useless "junk" or perform useful work; how and why some genes fail to reproduce in normal ways; how abnormal genetic variations behave so as to contribute toward processes of illness and disease; how and why genes die; and how their deaths affect the death of the entire being. *See* Rick Weiss, *Life's Blueprint in Less Than an Inch; Research: Little of Genome Makes a Human*, WASH. POST, Feb. 11, 2001, at A1.

For a clear, accessible description of the "work" that genes do in relation to other biological and environmental causes of human development, see Elliott Sober, *The Meaning of Genetic Causation, Appendix One* to ALLEN BUCHANAN ET AL., FROM CHANCE TO CHOICE: GENETICS AND JUSTICE 347 (Allen Buchanan et al. eds., 2000).

[5] Alleles occupy specific loci on a given chromosome, but do so in pairs, one inherited from each parent. *See* THE CODE OF CODES: SCIENTIFIC AND SOCIAL ISSUES IN THE HUMAN GENOME PROJECT 375 (Daniel J. Kevles & Leroy Hood eds., 1992) (providing a glossary definition of "allele"). Each member of such a pair may take one of a number of different forms.

[6] Carol Ezzell, *Beyond the Human Genome*, SCI. AM., July 2000, at 64, 67-69 (describing the techniques involved in proteomics, the study of protein expression). The range of genetic adaptations that can be said to describe the "normal" promises to yield either a more rigorous understanding of the functions that will justify the concept or a rejection of "the normal" as any kind of paradigmatic baseline view.

polymorphisms that are linked to diseases such as Huntington's Disease, cystic fibrosis, sickle-cell trait, Duchenne's muscular dystrophy, and breast and colon cancer.[7] At present, genetic testing is used primarily to diagnose adverse health conditions currently experienced by symptomatic patients or to predict the onset of conditions in persons identified by their family histories to be at risk of genetic disease.[8] But, as the range and accuracy of genetic tests increase and the cost of their administration falls, one can foresee a day when anyone may readily and inexpensively obtain a genetic profile that can identify, or rule out, any of thousands of conditions for which he or she may be at elevated risk.

The prospect of widespread genetic testing has stirred in the popular imagination optimism and anxiety in roughly equal measures. The basis for the optimism is obvious. Accurate, comprehensive, and inexpensive genetic testing, coupled with reliable epidemiological evidence of the probability of expression, promises dramatic improvement in the early detection and prevention of disease. Such knowledge should enable an individual to take preventive steps such as medication, medical monitoring, prophylactic surgery, or behavioral and environmental modifications that may be wholly or partially effective at staving off or even eliminating the onset of disease. Knowledge of this sort can also help people to make discerning educational and career decisions, investment and wealth-transmission plans, work and insurance-related risk assessments, and reproductive choices.[9]

The scientific breakthroughs that make genetic testing possible also promise to spawn dramatic improvements in the treatment of disease, ranging from improved use of the existing pharmacopoeia, to

---

[7] Rick Weiss, *Ignorance Undercuts Gene Tests' Potential*, WASH. POST, Dec. 2, 2000, at A1.

[8] *See generally* RAY MOSELEY ET AL., THE ETHICAL, LEGAL AND SOCIAL IMPLICATIONS OF PREDICTIVE GENETIC TESTING FOR HEALTH, LIFE AND DISABILITY INSURANCE: POLICY ANALYSIS AND RECOMMENDATIONS (1995).

[9] The coupling of prenatal genetic testing as a matter of popular availability with a legal regime that allows for the rights to plan, space, limit, and abjure pregnancy has stirred concern over the potential for large increases in the use of abortion. The motivation for this development is claimed to stem from two highly divergent sources—private efforts to avoid the rearing of significantly health-impaired children and speculation about government efforts to discourage such births on grounds of public cost containment. *See, e.g.*, David T. Morris, *Cost Containment and Reproductive Autonomy: Prenatal Genetic Screening and the American Health Security Act of 1993*, 20 AM. J.L. & MED. 295 (1994) (arguing for prenatal genetic screening service as part of a basic national health plan).

the creation of new pharmaceuticals targeted to persons with particular genetic profiles, to a range of gene therapy interventions designed to neutralize "bad" genes.[10] What is more, the epidemiological findings made possible by the new genetics can aid in the creation of improved environmental, engineering, and behavioral strategies for preventing disease and other functional impairments.

At the same time, the prospect of genetic screening has engendered widespread popular apprehension. One source of this apprehension may be the fear, attributed to some particularly risk-averse individuals, that the new genetics will somehow force upon them unwanted self-awareness. Persons exhibiting this psychological aversion, sometimes called the "nocebo" effect,[11] prefer to remain in a state of medical or genetic ignorance for fear that knowledge will reveal the presence of a predisposition for a condition that is incurable or preventable only by resort to costly and difficult measures.[12]

---

[10] For a description of the potential medical applications of the new genetic technologies, see the essays collected in BIOTECHNOLOGY: SCIENCE, ENGINEERING, AND ETHICAL CHALLENGES FOR THE TWENTY-FIRST CENTURY (Frederick B. Rudolph & Larry V. McIntire eds., 1996).

[11] Troy Duster, *The Social Consequences of Genetic Disclosure, in* BEHAVIORAL GENETICS: THE CLASH OF CULTURE AND BIOLOGY 172, 185-86 (Ronald A. Carson & Mark A. Rothstein eds., 1999).

[12] While certainly plausible, the notion that there is a subpopulation of individuals with a stable preference not to know about their genetic predispositions is an empirical construct with little grounded support. The little factual support offered form this proposition relies on small groups of persons at risk of developing Huntington's Disease, a horrific, late-onset neurological wasting disease that is inevitably fatal and presently incurable. *See, e.g.*, Paul R. Billings et al., *Discrimination as a Consequence of Genetic Testing*, 50 AM. J. HUM. GENETICS 476, 481 (1992) (citing the refusals of individuals to participate in two studies related to the risk of Huntington's Disease). *But see* Sandi Wiggins et al., *The Psychological Consequences of Predictive Testing for Huntington's Disease*, 327 NEW ENG. J. MED. 1401 (1992) (reporting that a study sample of individuals at risk for Huntington's Disease suggested that predictive testing provides psychological benefits for those whose test results demonstrate either increased or decreased risk relative to the baseline). For the earliest report of research that made testing for Huntington's Disease possible, see James F. Gusella et al., *A Polymorphic DNA Marker Genetically Linked to Huntington's Disease*, 306 NATURE 234 (1983).

As more diseases become subject to amelioration and cure, it may become increasingly difficult to predict categorical risk-aversion toward the acquisition of knowledge, at least on the part of individuals with reasonable access to successful modalities for treatment. Because of their small sampling size and the extraordinary severity of the disease, the Canadian researchers who reported in *The New England Journal*, Wiggins et al., *supra*, cautioned in their findings against attempts to generalize from their data, a caution the Billings study, despite its modest sample size, does not contain.

A far more common basis for apprehension stems from a fear that information about one's genetic profile, will be disclosed to others without one's consent and will then be used to one's personal disadvantage.[13] For example, family or friends or co-workers might, as a consequence of knowing about a person's genetic profile, pity or fear or shun him. A prospective marriage partner might break off a relationship. An adoption agency might refuse an application to adopt a child. A divorce court might decline to award custody of a child to a parent considered genetically impaired. A jury or an insurance company might award less compensation to a disabled tort victim whose genetic profile indicated a shorter-than-normal life expectancy. A mortgage lender might decline an application for a loan. An employer might decline to hire a job applicant because of "defective" genes, reassign her to less satisfying work, or subject her to special supervision and monitoring.

The fear of genetic testing's dark side has generated a flood of proposals for the legal protection of genetic privacy,[14] which has, in turn, produced a growing torrent of legislative and administrative enactments at the state and federal levels of government.[15] Although

---

[13] For a suggestive list of contexts in which a third party might seek access to information about a person's genetic profile, see Richard S. Fedder, *To Know or Not To Know: Legal Perspectives on Genetic Privacy and Disclosure of an Individual's Genetic Profile*, 21 J. LEGAL MED. 557, 567 (2000).

[14] For a sample from the vast literature, see Lori B. Andrews & Ami S. Jaeger, *Confidentiality of Genetic Information in the Workplace*, 17 AM. J.L. & MED. 75 (1991); George J. Annas, *Privacy Rules for DNA Databanks: Protecting Coded 'Future Diaries,'* 270 JAMA 2346 (1993); George J. Annas et al., *Drafting the Genetic Privacy Act: Science, Policy, and Practical Considerations*, 23 J.L. MED. & ETHICS 360 (1995); Lawrence O. Gostin, *Genetic Privacy*, 23 J.L. MED. & ETHICS 320 (1995); Kathy L. Hudson et al., *Genetic Discrimination and Health Insurance: An Urgent Need for Reform*, 270 SCIENCE 391 (1995).

One of the earliest advocates for genetic privacy protection was James Watson, who, with Francis Crick, discovered the structure of DNA. *See* Stephen S. Hall, *James Watson and the Search for Biology's "Holy Grail,"* SMITHSONIAN MAG., Feb. 1990, at 40. By the late 1980s, many research geneticists supported proposals to deny access to genetic screening results without each subject's prior consent. *See* John C. Fletcher, *Where in the World Are We Going with the New Genetics?*, 5 J. CONTEMP. HEALTH L. & POL'Y 33, 40 (1989) ("There was very strong consensus that third parties, such as employers and insurers, should not have access to the results of screening without the patient's consent.").

[15] *See generally* Philip R. Reilly, *Laws To Regulate the Use of Genetic Information*, *in* GENETIC SECRETS: PROTECTING PRIVACY AND CONFIDENTIALITY IN THE GENETIC ERA 369 (Mark A. Rothstein ed., 1997) (surveying current state legislation, federal bills, and model legislation); Karen H. Rothenberg, *Genetic Information and Health Insurance: State Legislative Approaches*, 23 J.L. MED. & ETHICS 312 (1995) (evaluating state legislative strategies to address concerns regarding genetic discrimination in the health insurance context); Karen Rothenberg et al., *Genetic Information and the Workplace: Legislative*

the scope and content of these proposals and enacted measures vary widely, they tend to employ two principal regulatory instruments to protect against feared abuses of genetic information: restrictions on disclosure and restrictions on use. Disclosure restrictions typically forbid the communication or release of genetic information about an identifiable individual to a third person without the individual's prior informed consent. These measures often include ancillary requirements concerning the handling, segregation, updating, or the destruction of genetic information, the counseling of research subjects prior to genetic testing, methods for securing substituted consent for persons unable to give informed consent, and the like.

Use restrictions, by contrast, focus on the uses to which genetic information may be put. By far the most common form of use restriction is a prohibition on so-called "genetic discrimination."[16] The antidiscrimination norm seeks to prevent persons from using information about a subject's genetic profile as a basis for withholding certain privileges or benefits or granting such benefits only on conditions less favorable than would otherwise be imposed.

Of the many contexts in which genetic discrimination has been or might be practiced, the two that have received the most attention and have generated the most urgent calls for regulation are the markets for insurance and employment. The insurance restrictions typically forbid health insurers, and in some cases life or disability insurers, from asking applicants for certain kinds of genetic information or from using that information either to deny or curtail coverage or to assign the applicant to an elevated risk classification.[17] The employment provisions typically restrict the kinds of genetic information that employers may obtain from job applicants and prohibit employers from using such information as a basis for various kinds of actions, such as refusal to hire, refusal to promote, relegation

---

Approaches and Policy Challenges, 275 SCIENCE 1755, 1756 (1997) (urging policymakers to consider the risk that the use of genetic information could result in employment discrimination and a lack of privacy in the workplace).

[16] For a review of the history of the term "genetic discrimination," see Philip R. Reilly, *Genetic Discrimination*, *in* GENETIC TESTING AND THE USE OF INFORMATION 106, 107 (Clarisa Long ed., 1999).

[17] Rothenberg, *supra* note 15, at 313-17. For reasons reflective of the apparent public perception that health insurance is crucial to personal well-being, whereas life and disability insurance coverage is less so, regulatory restrictions on insurance discrimination have not tended to be uniform across these categories. For a British reflection of concern that takes this same uneven form, see Onora O'Neill, *Insurance and Genetics: The Current State of Play*, 61 MOD. L. REV. 716 (1998). *See also* ASS'N OF BRITISH INSURERS, POLICY STATEMENT ON LIFE INSURANCE AND GENETICS (1997).

to unfavorable work assignments, or discharge.[18]

The nondisclosure and nondiscrimination strategies are closely interrelated. One of the primary purposes of protecting a person against the disclosure of genetic information is to limit the danger that it will be used to his or her disadvantage in interpersonal relationships or market transactions. One obviously cannot base discrimination on a person's genetic profile unless one has first obtained information about that profile. Nonetheless, we see the two strategies as analytically and morally distinct. The nondisclosure norm is, we believe, both practically enforceable and morally attractive. It recognizes the fundamental moral value of human autonomy, on the basis of which almost any plausible version of liberal ethics must be founded.[19] Whether one's primary moral desideratum is individual liberty, human equality, or social welfare, one can comfortably conclude that an individual should have a prima facie right to control the dissemination of information about her body, just as she has a prima facie right to oppose unauthorized invasions of her physical integrity. Thus, the law may reasonably forbid third parties from appropriating such information without obtaining an individual's prior informed consent.

A similarly blunt-cut judgment that the nondiscrimination norm should hold sway over regulatory decisions involving the use of genetic information within the markets for employment and insurance is, by contrast, far more problematic. In our view, the attempt to prohibit genetic discrimination *tout simple* is misguided. In this essay, we offer two primary reasons for this view. First, as we argue in Part I, the strategy faces enormous practical difficulties of implementation and enforcement, and is, therefore, almost surely doomed to produce either failure or a massive disappointment of expectations. Second, as we go on to describe in Part II, the strategy is, however well-intentioned, morally unjustified. Here, we make two claims: To begin with, the effort to ban genetic discrimination within insurance and employment markets would, if successful, cause significant welfare losses due to the distortion of allocative efficiency.

---

[18] Paul Steven Miller, *Genetic Discrimination in the Workplace*, 26 J.L. MED. & ETHICS 189, 193 (1998) (citing state statutes addressing the issue of genetic discrimination in the employment context); Rothenberg et al., *supra* note 15, at 1755-56 (discussing New Jersey, New York, and Wisconsin statutes).

[19] For an account of the multiple meanings of, and values protected by, genetic privacy, see Anita L. Allen, *Genetic Privacy: Emerging Concepts and Values*, *in* GENETIC SECRETS: PROTECTING PRIVACY AND CONFIDENTIALITY IN THE GENETIC ERA 31 (Mark A. Rothstein ed., 1997).

Next, the strategy cannot be justified as an appropriate means of achieving the goal that it is most commonly advanced to promote, namely, equality of opportunity. Instead, by selectively favoring a single type of moral "bad luck," while concealing both the extent and the form of its intended cross-subsidies, such a broad-based—that is to say, indiscriminate—use of the nondiscrimination principle may well achieve the opposite result.

I. PRACTICAL RESERVATIONS

A. The Emerging Genetic Privacy Regime

After an early burst of enthusiasm, popular attitudes toward the unfolding genetic revolution have grown steadily more apprehensive in recent years.[20] One can trace this shift in public opinion to at least four interlinked phenomena. First, as the recast artifact of an earlier era's troubled history, the specter of a "new eugenics" began to emerge.[21] The very term "eugenics" invokes a sense of collective guilt for our own history of racist and genetic perfectionism, as well as revulsion at the atrocities committed in the name of Nazi ideology and more recent instances of "ethnic cleansing." In contemporary dress, "new eugenics" conjures up a fear that genetic technologies will be used not so much by governments as by a privileged class of private

---

[20] The transformation of public attitudes is reflected in a series of widely cited public opinion polls. *See, e.g.*, ALAN WESTIN, REPORT ON NATIONAL OPINION SURVEYS RELATING TO GENETIC TESTING, SCREENING AND USES OF GENETIC INFORMATION WITH IMPLICATIONS FOR A NATIONAL SURVEY FOCUSED ON PRIVACY ISSUES AND SAFEGUARDS 1-22 (1997) (discussing a 1986 Harris Organization poll, finding that sixty-six percent of respondents considered genetic engineering a way to improve their lives; a 1992 National Opinion Research Center poll, finding that interviewees, by strong margins, opposed the use of genetic information in hiring, even when directly relevant to employee health; and a 1992 Harris Organization poll, reporting that nearly four out of ten interviewees supported a ban on genetic testing until privacy issues have been resolved); Andrew Sullivan, *Promotion of the Fittest*, N.Y. TIMES, July 23, 2000, § 6 (Magazine), at 16 (describing a 1998 survey in which sixty-three percent of respondents opposed genetic testing if an employer or health insurer could have access to the results). The popular media have fanned the embers of public anxiety with a series of alarmist stories about misuse of genetic information. *See, e.g.*, Geoffrey Cowley, *Flunk the Gene Test and Lose Your Insurance*, NEWSWEEK, Dec. 23, 1996, at 48-50.

[21] *See, e.g.*, 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 13-22 (1993); DANIEL J. KEVLES, IN THE NAME OF EUGENICS: GENETICS AND THE USES OF HUMAN HEREDITY (1985); Robert N. Proctor, *Genomics and Eugenics: How Fair Is the Comparison?* *in* GENE MAPPING: USING LAW AND ETHICS AS GUIDES 57 (George J. Annas & Sherman Elias, eds. 1997).

actors, to engineer a superior race of "perfect" people.[22]

This process of selective genetic enhancement will, it is feared, produce a permanent underclass of the genetically disadvantaged. Feeding this concern is a growing store of largely unverified anecdotes now in circulation about individuals who have been denied insurance, or, more rarely, jobs, loans, or adoptive children, on account of their perceived genetic vulnerabilities. These allegations have reverberated through the popular media,[23] where they inevitably float free of whatever critical commentary might have attached to the research that generated them.[24]

Second, a growing chorus of critics have sounded an alarm against both the risks and the sheer hubris of attempting to transform the natural order through genetic manipulation. Grounded sometimes in naturalist philosophy, sometimes in theological dogma, this sentiment is frequently captured in metaphor, such as the association of modern genetic science with the Frankenstein legend[25] or its characterization as an exercise in "playing God."[26] This theme of genetic engineering gone wrong has baited the imagination of generations of novelists

---

[22] *See, e.g.*, GLENN E. MCGEE, THE PERFECT BABY 111 (1997) ("Many critics of genetic research make reference to a slippery slope that begins with curing illnesses and ends in genetic modifications of appearance, intelligence and character.").

[23] *See, e.g.*, Cowley, *supra* note 20, at 48 (reporting that one insurance company cancelled coverage after discovering a genetic condition); Rachel Nowak, *Genetic Testing Set for Takeoff*, 265 SCIENCE 464, 466 (1994) (reporting that people with the Huntington mutation are often denied insurance).

[24] The most heavily cited empirical study of alleged employment and insurance discrimination is Billings et al., *supra* note 12. For a thoughtful criticism of the Billings study, and other similar empirical studies, see Reilly, *supra* note 16, at 108-17 (arguing that the Billings study produced very little evidence of actual discrimination based on genetics). As Dr. Reilly's review makes clear, there have been very few empirical studies, to date, of discriminatory conduct by health insurers and employers. Further, the studies that have been undertaken thus far employ widely disparate definitions of discrimination. Even under the most expansive definition, scant evidence of discrimination based on genetic testing has been found. *See, e.g.*, E. Virginia Lapham et al., *Genetic Discrimination: Perspectives of Consumers*, 274 SCIENCE 621 (1996).

The unimpressive empirical demonstrations of discrimination that these studies represent may relate to the data-gathering methods employed and the lack of genetic tests for most diseases. *See* Ellen Wright Clayton, *Comments on Philip R. Reilly's "Genetic Discrimination," in* GENETIC TESTING AND THE USE OF INFORMATION 134, 135 (Clarisa Long ed., 1999).

[25] The association is carried forward in the disparaging label, "Frankenfoods," used by critics of genetically modified foods. *See, e.g.*, Margot Roosevelt, *Taking It to Main Street*, TIME, July 31, 2000, at 42.

[26] *See, e.g.*, JANE GOODFIELD, PLAYING GOD: GENETIC ENGINEERING AND THE MANIPULATION OF LIFE (1977); TED PETERS, PLAYING GOD? GENETIC DETERMINISM AND HUMAN FREEDOM (1997); JEREMY RIFKIN, WHO SHOULD PLAY GOD? (1977).

and, more recently, screenwriters.[27]

A third contributor to anxieties about the genetic age derives from exaggerated claims of DNA's role in shaping human identity and experience. In their zeal to stir up popular support for their views, biotechnology's boosters and critics alike feed an unfortunate tendency toward genetic essentialism and determinism. Metaphorical descriptors, such as genetic "future diaries,"[28] evoke deep-seated fears that the chemical letters that code for our chromosomes spell out a fate for us that we do not choose and that, short of genetic intervention, we cannot avoid.

Finally, concerns about the preservation of genetic confidentiality have been subsumed within larger anxieties about our loss of control over personal information—particularly medical records—in the digital era. Like our credit, purchasing, educational, legal, and employment histories, our medical histories and diagnostic data are increasingly being reduced to electronic bits that are recorded, packaged, manipulated, transmitted, and even sold.[29] For many Americans, these medical data banks have come to symbolize the ways in which modern technology strips us of our privacy and commodifies our identities.

The power of these genophobic qualms is undeniable: they tap into deep wellsprings of moral intuition and personal vulnerability. The authenticity of these qualms cannot be questioned; but their expression and translation through the public policymaking process can, and must, be questioned. Responding to the emotional force of

---

[27] The modern literature traces from the two classics in the field: MARY SHELLEY, FRANKENSTEIN (1818) and ALDOUS HUXLEY, BRAVE NEW WORLD (1932). The film industry's recent contributions to fears about the genetic revolution include JURASSIC PARK (Universal 1993), GATTACA (Columbia Pictures 1997), and THE 6TH DAY (Columbia Pictures 2000).

[28] Annas, *supra* note 14.

[29] *See* A.M. Capron, *Genetics and Insurance: Accessing and Using Private Information*, 17 SOC. PHIL. & POL'Y 235, 253-54 (2000) (describing the operation of the insurance industry's Medical Information Bureau); Gostin, *supra* note 14, at 320-22 (highlighting several conceptual and technological innovations that are likely to accelerate the "automation" of health records, including genetic testing, screening information, and databases); *see also* Gina Kolata, *When Patients' Records Are Commodities for Sale*, N.Y. TIMES, Nov. 15, 1995, at B1 ("[P]rivate information is being bought and sold freely by companies that have ignored a patchwork of varying state laws that should have made it difficult to transfer those records across state lines."); Sheryl Gay Stolberg & Jeff Gerth, *High-Tech Stealth Being Used To Sway Doctor Prescriptions*, N.Y. TIMES, Nov. 16, 2000, at A1 (discussing the purchasing of "prescriber profiles" of doctors by pharmaceutical marketers in an effort "by drug makers to sway doctors' prescribing habits").

these anxieties, state and federal policymakers have, over the past two decades, enacted into law a tangle of regulatory measures that are all too often inconsistent, poorly coordinated, and ill-conceived.

The state governments have led the way in erecting this jerry-built regulatory structure. Beginning with modest interventions designed to bar the discriminatory use by health insurers of information about specific genetic conditions linked to race, such as sickle-cell trait, state legislatures gradually expanded the range and scope of these prohibitions.[30] By the beginning of the current decade, all states had adopted legislation designed to provide some protection against the unauthorized disclosure of "genetic" information and to prohibit the use of such information in the underwriting of at least some kinds of insurance. A minority of states had extended these restrictions to the use of genetic information in the making of certain kinds of employment decisions as well. The coverage of these enactments varied widely in terms of the kinds of so-called "genetic" information protected and the contexts in which its use was either prohibited, permitted, or even mandated.

The federal government has also addressed the issue of genetic discrimination, albeit somewhat more recently and more obliquely.[31] The federal regulatory intervention that deals most explicitly with genetic discrimination in insurance[32] is the Health Insurance Portability and Accountability Act of 1996 ("HIPAA").[33] The Act restricts the extent to which employment-based group health insurance plans can exclude coverage for "pre-existing conditions," defined to include genetic predispositions.[34] There are, however,

---

[30] For a summary of these developments, see sources cited *supra* note 15.

[31] Bills to prohibit genetic discrimination have been introduced in most recent sessions of Congress. *See, e.g.*, Genetic Nondiscrimination in Health Insurance and Employment Act of 1999, S. 1322, 106th Cong. (1999); Genetic Nondiscrimination in Health Insurance and Employment Act of 1999, H.R. 2457, 106th Cong. (1999). To date, however, Congress has not enacted legislation that addresses the issue squarely.

[32] The McCarran Ferguson Act, 15 U.S.C. §§ 1011-1014 (1994), reserves to the states the primary role in regulating the business of insurance. To date, the federal government has intervened in the health insurance market primarily in its role as regulator of employee benefit plans offered by employers in or affecting interstate commerce and in its role as taxing authority, since such plans are tax-preferred.

[33] Health Insurance Portability and Accountability Act, Pub. L. No. 104-191, 110 Stat. 1936 (1996), *codified as amended in* 29 U.S.C. §§ 1181-1183 (Supp. II 1996); 42 U.S.C. §§ 300gg-300gg-2 (Supp. II 1996).

[34] *See* 29 U.S.C. § 1181(b)(1)(B) (Supp. II 1996); 42 U.S.C. § 300gg(b)(1)(B) (Supp. II 1996).

several conspicuous gaps in the scope of HIPAA's protections,[35] and since the Act applies only to employment-based group health insurance, its provisions do not reach the roughly one-third of American workers unprotected by such plans nor, of course, the unemployed.

The closest approximation to a federal prohibition against genetic discrimination in employment resides within a questionable administrative interpretation of the Americans with Disabilities Act of 1988 ("ADA").[36] By its terms, the ADA affords protection only to persons with a manifested "disability."[37] The Equal Employment Opportunity Commission ("EEOC") issued a guideline in 1995 interpreting the ADA to apply to pre-symptomatic individuals with a genetic predisposition for a disabling condition.[38] This interpretation—which on its face seems dubious[39]—is not binding on the judiciary and has yet to be tested in court.[40] Even to the extent that the ADA might be held to apply to genetic conditions, moreover, it hedges the protections it affords in two crucial respects. First, the Act requires employers to make only "reasonable accommodations" to enable disabled persons to perform a job that they would otherwise not be equipped to perform.[41] Second, employers may, at the "pre-placement" stage of hiring (after a conditional offer of employment has been made), obtain and use information about an employee's

---

[35] *See* Clayton, *supra* note 24, at 135-36.

[36] 42 U.S.C. §§ 12111-12117 (1994).

[37] The Act defines "disability" as: (A) a physical or mental impairment that substantially limits one or more life activities . . .; (B) a record of such an impairment; or (C) being regarded as having such an impairment." 42 U.S.C. § 12102(2); *see also id.* § 12112(a), (d).

[38] 2 EEOC Compl. Man. (BNA) § 902:0045 (Mar. 1995).

[39] *Compare* Mark S. Dichter & Sarah E. Sutor, *The New Genetic Age: Do Our Genes Make Us Disabled Individuals Under the Americans with Disabilities Act?*, 42 VILL. L. REV. 613 (1997) (arguing that courts should not accept the guideline's interpretation of asymptomatic coverage), *with* Frances H. Miller & Philip A. Huvos, *Genetic Blueprints, Employer Cost-Cutting, and the Americans with Disabilities Act*, 46 ADMIN. L. REV. 369 (1994) (arguing in favor of the guideline's construction).

[40] It appears likely that the guideline, if and when it is tested in court, will receive a chilly reception. In one of a trilogy of 1999 decisions narrowing the scope of the ADA, the Supreme Court expressed doubt that any administrative agency, the EEOC included, has authority to issue rules interpreting the general provisions of the ADA, including the definition of "disability." Sutton v. United Air Lines, Inc., 527 U.S. 471, 479 (1999). The other decisions in the trilogy are *Murphy v. United Parcel Service, Inc.*, 527 U.S. 516 (1999), and *Albertson's, Inc. v. Kirkingburg*, 527 U.S. 555 (1999).

[41] 42 U.S.C. § 12112(b)(5).

medical condition and history.[42] Building on the EEOC guideline, President Clinton issued an Executive Order in 2000 prohibiting genetic discrimination in federal employment.[43] Like the ADA, the Order contains several exceptions, including the use of genetic information at the pre-placement stage.[44] Significantly, moreover, it permits employees considerable latitude with respect to information they wish to voluntarily disclose.[45]

A survey of the emerging regulatory regime even as cursory as the foregoing should begin to reveal its numerous short-comings and compromises. These short-comings illustrate the difficulties of erecting a coherent and workable system of protection against "genetic discrimination." First, there is the problem of defining what conditions are embraced within the term "genetic."[46] Genetic conditions can range from certain well-established, clinically defined "diseases," to a wide variety of syndromes and functional incapacities, as well as compulsive, addictive, or even patterned behaviors.[47] Indeed, since much of the story of how genes actually function remains to be discovered, even this extensive catalog may ultimately prove both narrow and unrefined. Do prohibitions on the use of genetic information include restrictions on references to such characteristics as intelligence, or aggressiveness, or obesity that appear to have genetic, as well as environmental, roots?

Any attempt to single out inherited conditions for special treatment immediately encounters the objection that most forms of human misfortune have mixed environmental and genetic pedigrees. Should society provide greater legal protection to a person whose elevated risk of, say, colon cancer happens to be traceable to the presence of a rare genetic mutation and not provide protection to

---

[42] *Id.* § 12112(d)(3).

[43] Exec. Order No. 13,145, 65 Fed. Reg. 6877 (Feb. 8, 2000).

[44] The Order permits federal employers to consider genetic information "to assess whether further medical evaluation is needed to diagnose a current disease, or medical condition or disorder." *Id.* § 1-301(a)(2), at 6879.

[45] The Order permits federal employees to authorize their employers to use genetic information obtained in connection with genetic or health care services provided by the employing agency. *See id.* § 1-301(b)(2), at 6877.

[46] On the difficulty of defining "genetic" for purposes of the genetic privacy laws, see Mark A. Rothstein, *Genetic Privacy and Confidentiality: Why They Are So Hard To Protect*, 26 J.L. MED. & ETHICS 198 (1998); Michael S. Yesley, *Protecting Genetic Difference*, 13 BERKELEY TECH. L.J. 653 (1998).

[47] On the genetic roots of behavior and functional capacities such as intelligence, see DEAN HAMER & PETER COPELAND, LIVING WITH OUR GENES (1998); MATT RIDLEY, GENOME: THE AUTOBIOGRAPHY OF A SPECIES IN 23 CHAPTERS (1999).

another whose elevated risk is traceable to environmental exposure? Furthermore, schemes such as the ADA, HIPAA, and the Clinton Executive Order that permit adverse treatment of symptomatic individuals, but prohibit adverse treatment of asymptomatic individuals, need stronger explanation. Should we not provide greater solicitude, indexed as some form of regulatory protection, toward those with manifested conditions? Measures such as the ADA that utilize the concept of "disability" to define the reach of their jurisdiction have the advantage of focusing attention on the nature, rather than the cause of a person's functional limitations. But the "disability" category, for all its elasticity, is still far too limited to embrace what may be unfair about the constraints that bad luck—genetic or otherwise—can impose on a person.

A second difficulty involves defining the sources of legally protected "genetic information." Most existing state statutes protect only information derived from the testing of a person's genetic material (DNA, RNA, chromosomes, ribosomes, or proteins). The obvious defect of this approach is that "genetic" information may be obtained from many other sources. Indeed, the kind of information revealed by modern genetic testing differs only as a matter of degree from forms of information that have been readily available for a very long time.[48] One can ascertain a great deal about a person's genetic inheritance from direct physical observation, medical examinations and tests, a personal medical history, a family medical history, and the like.[49] Can we justify prohibiting the use of information obtained from one source (genetic tests), but not others? Can we effectively segregate information obtained through the use of prohibited sources from information contained within permitted sources so as to enforce

---

[48] *See* Søren Holm, *There Is Nothing Special About Genetic Information*, *in* GENETIC INFORMATION: ACQUISITION, ACCESS, AND CONTROL 97 (Alison K. Thompson & Ruth F. Chadwick eds., 1999); Thomas H. Murray, *Genetic Exceptionalism and "Future Diaries": Is Genetic Information Different from Other Medical Information?*, *in* GENETIC SECRETS: PROTECTING PRIVACY AND CONFIDENTIALITY IN THE GENETIC ERA 60 (Mark A. Rothstein ed., 1997) (asserting that, while we treat genetic information as "mysterious," it does not differ in any significant way from other sorts of information).

[49] Professor Henry Greely, the author of this volume's Counterpoint, shrewdly offers up the possibility that genetic information will be able to be backwardly inferred from many standard medical diagnoses, thus leading to a conundrum concerning *their* availability to employers and insurers. *See* Henry T. Greely, *Genotype Discrimination: The Complex Case for Some Legislative Protection*, 149 U. PA. L. REV. 1483, 1497 (2001).

Others have observed that since many diseases, conditions, and predispositions are traceable within families, solicitation of family histories may prove the most vulnerable point of entry for market actors who wish to discriminate on genetic grounds.

any such prohibition?

Then, there is the ticklish problem of distinguishing between adverse and favorable genetic information. Should a prohibition on the use of genetic information apply only to uses that disadvantage the subject? What if a person, perhaps previously thought to be at risk of a genetic disease, discovers, thanks to a genetic test, that she is not? Can an insurer use that information to place her in a more favorable risk classification? Should a key individual in a corporate hierarchy *not* be able to provide this kind of reassurance when she is being considered for a move to the top? Virtually all of the extant regulatory measures speak only to the issue of using genetic information to discriminate *against* individuals. They are silent about the use of genetic information to discriminate *in favor of* an individual. Indeed, a few measures affirmatively permit individuals to volunteer favorable genetic information. What, then, is to prevent insurers or employers from inferring that a failure to volunteer favorable information represents the existence of genetic bad news?

Furthermore, it is not always clear whether a bit of information is favorable or unfavorable. What about genetic conditions that elevate a person's probability of both adverse *and* beneficial outcomes, such as a gene that both increases the risk of contracting a particular disease and increases immunity to another disease?[50] Architects of the legal regime face a dilemma. They may attempt the morally and politically dubious feat of prohibiting the use of all genetic information or they must attempt the administratively challenging feat of segregating genetic information into a prohibited negative category and a permitted positive category—categories that, for the foreseeable future, would need to be updated constantly.

Finally, there is the problem of distinguishing prohibited uses of genetic information from permitted, or even compulsory uses. Regulatory prohibitions on the disclosure of genetic test results without the tested individual's consent contain a variety of exceptions, from public health protocols, to criminal prosecutions, to paternity proceedings, to tort suits. The likelihood that such exceptions will expand seems beyond cavil, whether for purposes that are similarly public in nature or for private or quasi-public purposes that we are likely, in time, to approve. Might we not require the disclosure of

---

[50] The gene for sickle-cell trait is an example of such a phenomenon, since it also codes for a protein that is protective against malaria. Graham R. Serjeant, *Sickle-Cell Disease*, LANCET, Sept. 6, 1997, at 725-30.

genetic predispositions relevant to job qualifications where the work involves severe health risks to which some, though not all, people are highly susceptible? What if disclosure is the *only* means by which tragic personal outcomes can be averted? What of jobs involving substantial risks to the public? Might we not want airline pilots or rescue personnel who are at unusually high risk of stroke or heart attack screened off?

B. *The Curse of Unintended Consequences*

As we view it, the emerging regime of genetic privacy is riven with compromises that not only weaken its moral force, as we argue in the following Part, but also cripple its practical function. The principal normative reason for these infirmities is that the regime itself represents the uneasy merger of two conflicting impulses embedded in the regulatory framework. The autonomy-promoting impulse of the privacy regime seeks to encourage individuals to draw on the wealth of genetic information that promises to flow from the current revolution in biological research, and to use it for their physical, psychological, and even financial benefit. Indeed, unless large numbers of people utilize genetic information, the vast investment of public and private resources in genomic research may never be recouped. Yet, the paternalistic impulse that drives the regulatory engine seeks also to envelop market actors in a shroud of enforced genetic ignorance. The attempt to unify these two impulses produces an unstable equilibrium, characterized by a steadily increasing asymmetry of information, motivation, and behavior, that may well prove to be the system's undoing.

One of the most seductive—and insidious—features of the antidiscrimination regime is the fact that its behavioral distortions will manifest themselves only gradually. In the near term—the next few years, perhaps—prohibitions on genetic discrimination in health insurance and employment may cause barely a ripple on the surface of those markets. During this period, the number of people undergoing genetic testing, although growing rapidly in absolute terms, will continue to be small in relative terms. In most cases, individuals will be tested only to help diagnose conditions for which symptoms have already manifested, or to help predict the onset of conditions already indicated by personal or family histories. Testing will rarely produce information about conditions that could not already be discovered from currently available sources. Given the relatively small numbers of persons identified as having any particular

genotype, moreover, the state of epidemiological research will remain too crude to improve very much on the accuracy with which one can forecast the onset of a disease or condition from more traditional sources.[31]

Thus, in the very short run, employers will, despite their protests, manage to function quite acceptably without having access to genetic testing results. They will continue, as at present, to cull from available evidence of physical or psychological symptoms, past job performance, medical tests, family histories, and the like, the information that they consider necessary to screen job applicants and workers. The health insurance market will experience even less disturbance.[32] Most health insurance is provided through groups, usually employer-based, which are experience-rated. Thus, group health insurers—including the large number of employers who self-insure—will, in the short run, have little reason to access the genetic test results of group members. Even in the individual health insurance markets, insurers will continue to rely on existing procedures for risk underwriting to separate applicants into tolerably accurate and stable risk classifications.

The distortions will become more noticeable in the middle term, as the focus of genetic testing shifts from diagnosis to prediction, and as the availability, reliability, and affordability of testing improves. In this stage of the evolutionary process, a much larger proportion of the population will be in possession of what they may surely consider to be negative genetic information. They will be aware of their susceptibility to various diseases or other functional impairments, including many that would not otherwise be indicated by traditional sources of medical information. Epidemiological research will improve to the point that we can establish links between particular genotypes and phenotypes with greater confidence and thus strengthen our ability to estimate the probability, severity, and timing of disease onset.

This second evolutionary period will thus be characterized by a widespread asymmetry of negative genetic information between

---

[31] *See* MOSELEY ET AL., *supra* note 8, at 9-11 (discussing limitations on the expansion of genetic testing).

[32] *See* Mark A. Hall & Stephen S. Rich, *Laws Restricting Health Insurers' Use of Genetic Information: Impact on Genetic Discrimination*, 66 AM. J. HUM. GENETICS 293, 302 (2000) (concluding that most branches of the insurance industry do not inquire about genetic testing results); Joan Stephenson, *Genetic Test Information Fears Unfounded*, 282 JAMA 2197, 2197 (1999) (suggesting that fear about genetic discrimination by insurance companies is "largely unsubstantiated").

individual subjects and those with whom they deal. The consequences will be felt most strongly in the individual health insurance market, which is the segment most susceptible to adverse selection.[53] Customary protections against adverse selection—individual underwriting, combined with preexisting conditions exclusions, deductibles, and coinsurance provisions—will prove less and less effective as a means of sorting applicants into actuarially sound risk classifications.[54] Cross-subsidization between low-risk insureds and high-risk insureds will intensify. Unable to sort high-risks into high-premium risk classifications, insurers will respond by increasing premiums or restricting coverage across the board. Higher premiums will begin to drive many low-income, high-risk insureds and many lower-risk insureds of all income groups from the market.

In the group insurance market, these distortions will be tempered by the homogenizing tendencies of experience rating. Although many group members will possess better information about negative genetic risks and thus have an incentive to overconsume insurance coverage, the lower-risk members of the group will, in most cases, be dissuaded from exiting the pool by a combination of risk aversion, group cohesion, and the fiscal advantages fostered by the tax and group subsidies characteristic of most group insurance plans. Still, many employers—especially small business entities and those in health-sensitive industries—will begin to feel the impact of adverse selection in the escalation of their group insurance premiums or, if they self-insure, their group loss experience, putting pressure on them to cut benefits or to step up efforts to screen out high-risk workers by more aggressive selection or monitoring procedures.

The full extent of market distortions such as these will become manifest in the still longer term, which, given the accelerating rate of scientific progress, will arrive sooner than we think. By that third evolutionary stage, most Americans will have legally protected access to inexpensive "multiplex" genetic tests that provide reliable information about their susceptibility to hundreds of health

---

[53] On adverse selection in insurance markets, see generally KENNETH S. ABRAHAM, DISTRIBUTING RISK: INSURANCE, LEGAL THEORY, AND PUBLIC POLICY 15-16 (1986). The prospect of escalating adverse selection has led the insurance industry to oppose legislative restrictions on the use of genetic information. *See* AM. COUNCIL OF LIFE INS. & THE HEALTH INS. ASS'N OF AM., REPORT OF THE ACLI-HIAA TASK FORCE ON GENETIC TESTING 8 (1991) (detailing the industry's concerns about the potential for adverse selection if insurers were to be denied access to the results of genetic tests already known to the applicant).

[54] See *infra* text accompanying note 79.

conditions and impairments, including both rare and common diseases.[55] What distinguishes this final stage of the genetics revolution is the extent to which not only adverse selection, but "favorable deselection" becomes possible. People will have the informational tools to sort themselves into categories ranging from below-average to above-average health risks. To an extent never before possible, individuals will have the basis for determining where they rank in the genetic lottery of life.

The individual health insurance market will come under intense pressure. According to the "hard-determinist" view of genetics,[56] genetic information will yield predictions so precise and individualized as to destroy the very rationale for insurance.[57] But one need not be a genetic determinist (and we are not) to see how the twin forces of adverse selection and favorable deselection could literally tear the individual health insurance market apart. Armed with reliable evidence of their genetic predispositions, high-risk individuals will rush to obtain increased coverage at standard rates, while their better-endowed neighbors will flee from subsidizing such coverage. To stem the exodus by the latter group, insurers will be forced either to engage in legally evasive tactics, such as "field underwriting,"[58] to exclude high-risk applicants from coverage, or to design low-cost, low-coverage policies designed to capture the lower-risk segments of the market. As several commentators have predicted, the twin forces of adverse selection and favorable deselection may propel the individual health insurance market into a "death spiral" from which it cannot escape.[59] But even if the market is able to

---

[55] *See* Council on Ethical and Judicial Affairs, Am. Med. Ass'n, *Multiplex Genetic Testing*, HASTINGS CENTER REP., July-Aug. 1998, at 15, 15-16 (predicting that, as tests for newly discovered genes are developed, there will be the possibility of administering simultaneously many different "testing packages").

[56] *See generally* P.S. Greenspan, *Free Will and the Genome Project*, 22 PHIL. & PUB. AFF. 31 (1993) (defining determinism and its relationship to free will in the context of the Human Genome Project).

[57] For a plausible rendering of this development that is more fully detailed than ours, see Roberta M. Berry, *The Human Genome Project and the End of Insurance*, 7 U. FLA. J.L. & PUB. POL'Y 205, 231-32 (1996).

[58] For a catalog of such practices, see Timothy Stoltzfus Jost, *Private or Public Approaches to Insuring the Uninsured: Lessons from International Experience with Private Insurance*, 76 N.Y.U. L. REV. 419, 479-81 (2001).

[59] *See* Berry, *supra* note 57, at 231-32 (discussing adverse selection and genetic discrimination); Deborah J. Chollet, *Consumers, Insurers, and Market Behavior*, 25 J. HEALTH POL., POL'Y & L. 27, 37 (2000) (discussing the vulnerability of the individual insurance market to an adverse selection spiral); John V. Jacobi, *The Ends of Health Insurance*, 30 U.C. DAVIS L. REV. 311, 398 (1997) (discussing risk adjustment).

achieve some sort of equilibrium, coverage will be so limited in scope or so expensive as to be practically useless to the vast majority of Americans.

The disturbances occasioned by widespread adverse selection and favorable deselection will not be limited to individual health insurance markets. Even in the more protected preserves of group insurance, the effect of sorting by risk will inevitably be felt. Knowing that their premiums subsidize higher-risk group members, low-risk individuals will reduce the level of their coverage by increasing deductibles or coinsurance, or by selecting less extensive coverage. If such options are not available under their group plan, they will lobby group administrators to offer them. Under any reasonable assumption about the distribution of risk levels within insurance groups, low-risk members will surely exercise sufficient influence to induce compliance with their demands.[60] And if they do not succeed in broadening the range of options available to them, many, especially healthier younger workers in lower paying jobs, may simply opt out of their plans altogether, pulling their premium contributions out of the cross-subsidizing pool.[61]

Faced with the prospect of rising health insurance costs and productivity losses from adverse selection, employers, too, will be pressured to take action to protect their competitive positions. Some will search for legal proxies for forbidden categories of information so that, unimpeded, they can screen out genetically disadvantaged

---

Professor Greely appears dry-eyed in contemplating the death of the individual insurance market, which, by his estimate, affects ten to twenty million Americans. Greely, *supra* note 49, at 1489. Others cheer from the sidelines, based on the assumption that only the complete collapse of the private health insurance market will produce the political will to establish a needed national health insurance system. But the mature liberal democracies whose lead these commentators would have us follow have been forced to rely on a back-up system of private health insurance to ameliorate political discontent with coverage limitations and rationing, which are endemic to national plans. Thus, unless the individual health insurance market were to prove capable of resurrection after death, there seems no ground for optimism about universal health coverage's substitute appeal.

[60] *See* RICHARD A. EPSTEIN, MORTAL PERIL: OUR INALIENABLE RIGHT TO HEALTH CARE? 127 (1997) (attacking government solutions to persistent problems in health care access and delivery).

[61] Evidence of this proposition is provided by recent experience in New York. Enactment of legislation requiring community rating of individual health insurance policies precipitated a massive exodus of younger insureds from the market. *See* Mark A. Hall, *An Evaluation of New York's Reform Law*, 25 J. HEALTH POL. POL'Y & L. 71, 76 (2000) (discussing the effects of reform); Robert Pear, *Pooling Risks and Sharing Costs in Effort To Gain Stable Insurance Rates*, N.Y. TIMES, May 22, 1994, at 22 (discussing risk spreading).

applicants. Many may restrict their hiring to applicants who self-identify as having a clean bill of genetic health, meanwhile presuming that those who do not so identify must be harboring incriminating information. If the legal regime responds by trying to outlaw this practice—a position that will be hard to justify politically and still harder to enforce practically—employers will simply search for lawful means by which to induce the genetically favored to signal their status. For example, employers may restructure compensation policies to increase wages or other nonhealth benefits and correspondingly reduce health insurance benefits.

If these strategies fail, or if the law responds once again, this time by requiring the provision of some minimal level of health insurance coverage, employers might react by substituting part-time for full-time labor. Alternatively, they might reduce labor requirements by automating production, relocating production to regions populated by younger or healthier workers, or moving production facilities offshore.[62] To the extent that health care coverage remains tied to employment, the antidiscrimination strategy will thus have produced the perverse effect of reducing the level of health insurance protection for many people, especially those most in need.

There is, of course, no assurance that the scenario will play out precisely this way. A forecast such as this is too sensitive to unsubstantiated empirical assumptions to be offered on more than a tentative basis. But it is a scenario that seems sufficiently plausible to give pause to enthusiasts for the emerging privacy regime. To their credit, some defenders of the privacy regime acknowledge these problems and point toward possible reforms.[63] But beyond the search for regulatory fixes, the rather grim prognosis sketched above ought to motivate a much more searching examination of the underlying normative justifications for the current regime. That is the

---

[62] *See* Richard A. Epstein, *The Legal Regulation of Genetic Discrimination: Old Responses to New Technology*, 74 B.U. L. REV. 1, 16-17 (1994) (describing some of the strategies firms will adopt "to cut their losses in a world that regards concealment . . . [as an] employee['s] birthright").

[63] *See generally* Rothstein, *supra* note 46 (discussing why the protection of genetic privacy and confidentiality is so elusive).

Discussants at the Yale Law and Technology workshop offered the hope that consumers of genetic testing might gain sufficient reassurance from the current regime to effectuate personal information-gathering norms that might then survive the regime's collapse, a silver-lining approach to the dark cloud of regulatory failure. The point is debatable, for certain, though the authors worry that since the current regime cannot deliver on its promises, the dark cloud of failure will reveal a second dark cloud: popular disillusionment and despair.

examination we begin in the following Part of this essay.

II. NORMATIVE RESERVATIONS

A. *Allocative Efficiency*

Voluntary exchange between two willing and informed individuals is the paradigm of efficiency-enhancing transactions. Each party experiences a net increase in utility by surrendering something that she values in exchange for something that she values even more. Thus, according to most versions of utilitarian or social welfarist ethics, society should not only permit, but indeed encourage, its members to engage in voluntary transactions. Any form of government regulation, such as a prohibition on "genetic discrimination," that interferes with the terms on which individuals may contract, is thus presumptively efficiency-reducing.

The presumption is, of course, rebuttable. "Market failures" such as coercion, information asymmetries, or harmful externalities may cause individuals to enter into transactions that reduce their own welfare or that of third parties.[64] But government regulation—especially regulation that denies to one contracting party information in the possession of the other—is rarely an efficient response to such market failures. In view of the inevitable distortions and costs of government regulation, its advocates always bear a heavy burden of persuasion. We argue in this Part that advocates for a ban on genetic discrimination in employment and insurance cannot bear that burden. Prima facie, such a prohibition imposes significant efficiency losses on those markets and those losses cannot be justified by the claimed offsetting benefits.

1. Employment

Information derived from genetic testing can improve the productivity of labor—and therefore the efficiency of labor markets—in two ways. First, it can improve the match between the qualifications of individual workers and the requirements of particular jobs. Second, it can facilitate more cost-effective investments in human capital. Employers currently invest vast resources in the screening and

---

[64] For thoughtful analyses of these and other conditions, see generally Matthew D. Adler & Eric A. Posner, *Rethinking Cost-Benefit Analysis*, 109 YALE L.J. 165 (1999); Howard F. Chang, *A Liberal Theory of Social Welfare: Fairness, Utility, and the Pareto Principle*, 110 YALE L.J. 173 (2000).

selection of workers. For many, medical screening, based on information gleaned from questionnaires, personal histories, and medical examinations, is an indispensable part of that process.[65] The new era of genetic information holds the promise of improving significantly on the reliability and accuracy of such information. Armed with genetic test results and corresponding epidemiological data on the correlation between genotype and phenotype, employers may be able to improve the quality of the predictions they can make about the two determinants of job performance: intensity and quality of effort.

Some advocates for genetic privacy question the incremental value of genetic testing information in screening and evaluating employees. They argue that existing sources of information already enable employers to make such predictions at an acceptable level of accuracy. The best predictor of future performance, they claim, is past performance (where such information is available). Employers can monitor and measure employee performance and discharge or retrain underperforming workers. A related argument stresses the distinction between symptomatic and asymptomatic conditions. Workers, the argument goes, should not be evaluated until a condition manifests itself. At that time, the employer can determine the appropriate course of action, including sick leave, treatment, reassignment, and, if output declines excessively, removal.

These arguments fail adequately to account for transaction costs. Hiring or promoting an underqualified or underproductive worker is inevitably costly to the employer. Reliance on ex post monitoring of performance is costly. In some situations, the quality and quantity of a worker's output can be easily observed and verified, and remedial action readily taken. But in most situations, that is not the case. Monitoring and corrective action require investment in supervision, and often require changes in production design or scheduling. In the meantime, the underperforming worker inflicts on the organization both demoralization costs and the opportunity costs of foregone output. For these reasons, it is almost always in the employer's interest to establish better ex ante screening mechanisms so as to select workers who will require less supervision and corrective action.

In making the optimal tradeoff between ex ante screening and ex

---

[65] *See* MARK A. ROTHSTEIN, MEDICAL SCREENING AND THE EMPLOYEE HEALTH COST CRISIS 1 (1989) (discussing the growing importance of medical screening); MARK A. ROTHSTEIN, MEDICAL SCREENING OF WORKERS 15-18 (1984) (discussing the various methods for assessing a patient's current health status).

post monitoring, the distinction between asymptomatic conditions and symptomatic conditions is not controlling and may be irrelevant. All employment decisions are predictive in nature and all evidence used in making such decisions—whether based on job performance, personal habits, manifested medical conditions, or genetic predispositions—is probabilistic. What matters, from an allocative point of view, is not whether specific symptoms of a disposition have manifested, but the confidence with which one can predict that the disposition will adversely affect job performance within the period of the employee's predicted job tenure.

The efficiency gains of a transparency regime do not stop with improved employee selection. Genetic information surely holds the promise of improving the productivity of the existing workforce, as well. By identifying particular health risks, such information could enable employers to design fitness or wellness programs to reduce behaviors that may aggravate risk, to monitor indicators of employees' health at regular intervals, to redesign production processes or the workplace environment so as to reduce health risks, or to reassign workers to tasks or work locations that reduce their exposure to such hazards.[66] Likewise, genetic information may someday provide a more reliable basis for measuring deficits in job-relevant skills that can be corrected by the design of training programs.

Defenders of the privacy regime tend to be dismissive of this category of efficiency improvements. Part of their skepticism may be based on an empirical assumption that few employers in fact offer fitness or wellness programs, or even training programs tailored to the needs of particular workers. To the extent that this is the case, the reason is often that employers lack information sufficient to identify programs that would be cost-effective. By hypothesis, genetic information may well fill that gap by permitting more accurate diagnoses of conditions that affect worker productivity, as well as the basis for more reliable predictions about the relationship between genotype and job performance.

Critics also argue that giving employers the option of reassigning workers with low tolerances to workplace hazards diminishes the

---

[66] *See, e.g., Gene-Environment Research Could Spur Increased Workplace Testing, Experts Predict*, 69 U.S.L.W. 2500 (Feb. 27, 2001). Indeed, employers may be forced to conduct genetic testing to protect themselves from liability for exposing workers to hazards to which they are genetically susceptible. For a survey of possible applications of genetic testing to tort liability, see Gary E. Marchant, *Genetic Susceptibility and Biomarkers in Toxic Injury Litigation*, 41 JURIMETRICS 67 (2001).

employer's incentive to remove those hazards from the workplace altogether. That is undoubtedly true. But there is no reason to suppose that all workplace hazards can be ameliorated more cost effectively by engineering changes in the production process or working environment than by personnel reassignments. Some people are less tolerant of particular workplace conditions than others. No one seriously claims that forklifts should be designed so that they can be driven by sight-impaired persons or that buildings should be designed so that steel frames could be erected by people with vertigo.

Most advocates for a privacy regime are willing to concede that genetic information could be appropriately used in screening employees for jobs that involve safety risks to the public or to fellow employees.[67] But, from an allocative perspective, there is no justification for this limitation. Unqualified workers can probably impose much larger aggregate costs on society by wasting resources and diminishing output than by causing personal injury or death. Drawing a distinction between safety-related jobs and non-safety-related jobs for purposes of permitting the use of genetic information merely invites endless line-drawing, evasion, and litigation, without serving a convincing efficiency-promoting purpose.

Advocates for a ban on genetic discrimination might concede that genetic test data can, if properly used, enhance the efficiency of labor markets, for the reasons discussed above. But they argue that employers are just as likely—perhaps more likely—to misuse such information by irrationally screening out productive workers merely because they have a genetic predisposition for some feared disease or condition. To the extent that such economically irrational behavior persists, a ban on genetic discrimination could actually improve social welfare.

In support of this claim, privacy advocates cite studies that purport to provide empirical evidence that employers are beginning to use genetic information to screen out workers with particular genotypes. As we discuss elsewhere,[68] however, this literature is too anecdotal to establish the extent or nature of genetic discrimination in the workplace. Few claims of such discrimination have in fact been systematically investigated, verified, or documented.[69] Furthermore,

---

[67] *See, e.g.*, David Orentlicher, *Genetic Screening by Employers*, 263 JAMA 1005, 1008 (1990) (admitting that genetic testing for jobs bearing on public safety poses "[a] more difficult question").

[68] *See supra* note 24 and accompanying text.

[69] One well-publicized instance of alleged improper genetic testing in

to the extent that employers have used genotypic evidence to screen out certain persons from the workplace, we have no empirical evidence to indicate whether these acts of discrimination were "irrational" in the sense of being unrelated to bona fide occupational criteria.

Perhaps the most straightforward refutation of the "irrational" discrimination claim is that it flies in the face of economic logic. In a competitive labor market, employers who persistently engage in irrational behavior by excluding productive workers who happen to have some genetic predisposition should be punished by market forces.[70] It is true, of course, that group-based discrimination can persist in competitive labor markets, as the history of race-based and gender-based employment discrimination vividly demonstrates. But that undeniable—and undeniably deplorable—fact does not furnish a basis for predicting a similar pattern of irrational discrimination by genotype.

Commentators have advanced two theories to explain the persistence of group-based discrimination in competitive labor markets. The "statistical discrimination" theory posits that some employers use observable traits, such as race, as proxies for unobservable differences in individual productivity.[71] Even to the extent that statistical discrimination adequately explains racial or gender discrimination, however, it has no obvious application to genetic discrimination. Unlike race or gender, genetic predisposition for disease is not usually a readily identifiable group proxy for individual characteristics. Indeed, genetic test information holds the promise of providing the very form of individualized prediction that

---

employment was brought to light in a recent complaint brought by the EEOC against the Burlington Northern Santa Fe Railroad. The EEOC alleged that the railroad was violating the ADA by conducting genetic tests of workers complaining of carpal tunnel syndrome, without informing the workers of the purpose of the tests. *Railroad Agrees To End Genetic Testing, After Disability Discrimination Suit by EEOC*, 69 U.S.L.W. 2490, 2490-91 (Feb. 20, 2001) (reporting on EEOC v. Burlington N. Santa Fe R.R., No. C01-4013 (N.D. Iowa filed Feb. 9, 2001)). In response, the railroad agreed to terminate the testing program, while denying any wrongdoing. *Id.*

[70] *See* GARY BECKER, THE ECONOMICS OF DISCRIMINATION 14-15 (2d ed. 1971) (analyzing the payment of forfeiture of income for the privilege to discriminate in the marketplace).

[71] *E.g.*, Edmund S. Phelps, *The Statistical Theory of Racism and Sexism*, 62 AM. ECON. REV. 659, 659 (1972) (introducing "the statistical theory of racial (and sexual) discrimination in the labor market"); Stewart Schwab, *Is Statistical Discrimination Efficient?*, 76 AM. ECON. REV. 228, 228 (1986) (concluding that statistical discrimination may be inefficient under certain conditions).

the statistical discrimination theory posits as unavailable.

Another set of theories offered to explain the persistence of group-based employment discrimination focuses on a posited "taste" for discrimination. According to this family of theories, an employer discriminates against members of certain groups as a way of satisfying a personal preference for discrimination,[72] achieving higher status within his group,[73] or minimizing the costs of employee diversity and divisiveness.[74] As we argue below,[75] by contrast, there is no reason to believe that people have a widespread aversion to most diseases or other conditions that might be predicted by genetic information. Genotype per se is not a basis for "invidious" discrimination, even if some conditions linked to genotype (such as race) are. Given the enormous diversity of genetic characteristics and the hidden nature of most genotypes, one cannot plausibly assert that genetic aversion is an argument in the preference functions of most people. Therefore, we see no basis for applying these theories to the field of genetic discrimination.

2. Insurance

Information from genetic testing can improve the efficiency of health insurance markets by enabling insurers to classify risks more accurately and thus equate the price of coverage to its value. Confronted by an actuarially fair premium, the prospective insured can, in turn, more accurately determine whether the utility gained from coverage exceeds the utility sacrificed by the payment of the premium. She can thereby make better decisions concerning the amount and kind of insurance coverage to buy as well as the optimal level of investment in other health-promoting activities.[76]

---

[72] *See* BECKER, *supra* note 70, at 14-15 (describing rational discrimination when in the form of nepotism).

[73] *See* Richard H. McAdams, *Cooperation and Conflict: The Economics of Group Status Production and Race Discrimination*, 108 HARV. L. REV. 1005, 1007 (1995).

[74] *See* RICHARD A. EPSTEIN, FORBIDDEN GROUNDS: THE CASE AGAINST EMPLOYMENT DISCRIMINATION LAWS 60-72 (1992).

[75] *See infra* Part II.B.2.

[76] Like other forms of insurance, health insurance creates an incentive to overconsume health care services and to underconsume various preventive measures, such as exercise, diet change, and avoidance of risky activities. *See* Martin Gaynor et al., *Are Invisible Hands Good Hands? Moral Hazard, Competition, and the Second-Best in Health Care Markets*, 108 J. POL. ECON. 992, 993 (2000) (discussing moral hazard effects on consumption due to health insurance); Richard Zeckhauser, *Medical Insurance: A Case Study of the Tradeoff Between Risk Spreading and Appropriate Incentives*, 2 J. ECON. THEORY

Genetic privacy advocates argue that insurers can achieve a tolerable level of allocative efficiency without recourse to genetic testing information. Their argument has two parts. First, to the extent that private health insurers do engage in individual rating (in the sale of nongroup, individual insurance policies), there are other means available to them to achieve economically efficient risk classification. Second, most private health insurance is sold to groups (primarily employment groups), achieving higher levels of efficiency, at least from the insurer's perspective, by basing premiums on the collective loss experience of the group and not on the individual characteristics of its members.

It is true, as the privacy advocates claim, that the presence of adverse selection does not necessarily impair the efficient operation of individual health insurance markets. Heretofore, insurers have protected themselves against the distortions produced by information asymmetry by using such techniques as medical underwriting, exclusion of preexisting conditions, and the structure of deductibles and coinsurance provisions.[77] Widespread private availability of genetic information, however, will severely test the effectiveness of these techniques. Genetic testing will give individuals access to vastly more complete information about not only the presence of otherwise invisible risk factors, but also the probabilities regarding the timing and severity of their expression. Armed with such information, they may be able to make much more accurate estimates of their insurance risks than will those who underwrite those risks. Persons who know that they are in an elevated risk category will thus have an even stronger incentive than at present to increase their insurance coverage, so long as insurers are unable to identify them in advance as high-risk and are therefore unable to place them in appropriate risk classifications.[78]

Likewise, preexisting condition exclusions and coinsurance provisions will prove increasingly impotent as weapons to combat the

---

10, 10 (1970) (arguing for a compromise featuring some risk-spreading and some incentive). Any policy that causes people to overconsume health insurance (by underpricing coverage) exacerbates these deadweight losses.

[77] The classic theoretical demonstration of this point can be found in Michael Rothschild & Joseph Stiglitz, *Equilibrium in Competitive Insurance Markets: An Essay on the Economics of Imperfect Information*, 90 Q. J. ECON. 629 (1976).

[78] *See* Robert J. Pokorski, *Use of Genetic Information by Private Insurers*, *in* JUSTICE AND THE HUMAN GENOME PROJECT 91, 91 (Thomas F. Murphy & Marc A. Lappé eds., 1994) (arguing that "genetic information must be made available to insurers as a matter of equity").

allocative distortions caused by adverse selection. Even if preexisting exclusions could be legally applied to asymptomatic genetic predispositions, they would be difficult to enforce in a regime of legally protected genetic privacy. And, at the extreme, their widespread adoption would virtually destroy the utility of health insurance, effectively converting it into accident insurance. Similarly, in the coming genetic era, coinsurance provisions will prove to be ineffectual to induce applicants to sort themselves into actuarially sound risk classifications. By themselves, coinsurance provisions and deductibles are simply too crude an instrument to handle the expanded range of healthcare risks revealed by the new forms of genetic information.[79]

As a consequence, the asymmetrical treatment of genetic information by the incoming privacy regime almost surely diminishes the allocative efficiency of individual health insurance markets. The precise magnitude and direction of this effect are difficult to predict, but one of two scenarios seems inevitable. In one, the individual health insurance market will settle into a fragile equilibrium characterized by massive misclassification and mispricing of risk, with attendant invisible cross-subsidies and deadweight losses. In the other, the market will spin out of control and disappear altogether, thereby denying a large segment of the population access to a utility-enhancing source of financial protection.

As compared to individually rated health insurance, group health insurance achieves allocative efficiency, from the point of view of the insurer, but sacrifices efficiency from the point of view of the insured. Insurers are able to make a competitive profit to the extent that experience rating provides a reliable basis for predicting the group's future loss experience. Because the individual premiums are uniform in most group policies, however, most individuals in a group pay either too much or too little for the coverage that they receive. The high-risk members of the group tend to overconsume health insurance and the low-risk members underconsume health insurance. Overconsumers have an incentive to invest too little in alternative

---

[79] *See* Michael Smart, *Competitive Insurance Markets with Two Unobservables*, 41 INT'L ECON. REV. 153, 153 (2000) (demonstrating that coinsurance can achieve an efficient separation of insureds by relative risk only if insureds vary along only one dimension of private information); *cf.* M. Susan Marquis, *Adverse Selection with a Multiple Choice Among Health Insurance Plans: A Simulation Analysis*, 11 J. HEALTH ECON. 129, 131 (1992) (arguing that in a competitive market, high-option health insurance plans will be driven out of the market by adverse selection).

means of reducing health risk, such as changing diet, physical exercise, and abstinence from risky behaviors, while underconsumers have the opposite incentive.

The advent of genetic testing information, if available to both parties, would almost surely increase the overall efficiency of group insurance markets. Initially, such information would have no impact on the behavior of insurers, since group insurance is not individually underwritten. But such information would have an impact on the behavior of group members. As genetic information enables individuals to sort themselves more accurately by relative risk, the high-risk group will, at the margin, increase their demand for insurance coverage, while lower-risk individuals will, at the margin, decrease their demand. To the extent that the group administrator offers choices of coverage, or can be induced to do so by pressure from the low-risks, the uniformity of the current group insurance regime will gradually break down. Insureds will sort themselves by risk levels, defined by differential coverage and premium levels. From the perspective of insureds, then, the overall allocative efficiency of the group insurance system will increase as the group insurance market comes to resemble more closely the individual health insurance market.

A prohibition on the use of genetic information by group insurers might, therefore, have efficiency-reducing effects for the same reasons that such a prohibition would distort efficiency in individual insurance markets. The growing asymmetry in information between insureds and insurers might hamper efforts of insurers to classify individuals accurately by risk and to price insurance products appropriately. Unlike the individual health insurance market, the group market is much less likely to collapse because tax and employer subsidies, combined perhaps with group solidarity, will prevent a mass exodus by the low-risk. The resulting equilibrium will, however, surely be less efficient than a market premised on full transparency of genetic information.

3. Discouraging Genetic Testing

Many privacy advocates argue that welfare losses caused by distortion of employment and insurance markets will be offset by welfare gains produced by removing an impediment to genetic testing. They claim that many people are likely to be discouraged

from seeking genetic testing for fear that adverse results will be disclosed to, or demanded by, prospective employers and insurers.[80] By removing this fear, a legal prohibition on the use of genetic test data in insurance and employment would thus unleash the therapeutic and ameliorative benefits that could flow from widespread use of predictive genetic testing.

Whether overall utility would be enhanced by such a prohibition is, however, debatable. When a person decides not to undergo genetic testing, she is presumably deciding that her net utility would be reduced: that is, that the costs (including not only the direct cost of undergoing the testing, but also the expected adverse impact that the resulting knowledge would produce on both her economic prospects and her psychological state) outweigh the benefits (in terms of the improvement in her, and perhaps her offspring's, health that could result from ameliorative actions). By protecting individuals from adverse employment and insurance consequences, the antidiscrimination strategy eliminates two components of the economic cost of testing from the individual's cost-benefit calculus. In so doing, the government in effect encourages overconsumption of genetic testing.

Suppose, by analogy, that the government required property insurers to provide flood damage insurance at deeply subsidized rates. In so doing, the government would encourage people to overbuild on flood plains. It is no answer to say that genetic testing is a good thing, and building on flood plains is not. Whether genetic testing should be undertaken depends on its costs and benefits. These costs and benefits will vary widely from individual to individual. For many risk-averse people, testing is psychologically very costly.[81] Presumptively, those people—not the state acting on their behalf—should make the decision whether to incur the costs. As with any comparable decision, the goal of allocative efficiency will be served only if, in making that decision, they address the true social costs and true social benefits of their actions.

One answer to this argument might be that individuals lack

---

[80] *See* Capron, *supra* note 29, at 248 ("The chief concern is that health insurance companies will, by policy or chance, accumulate genetic test data regarding specific patients, which will then be available to these companies . . . when these patients apply for new . . . insurance policies."); Kimberly A. Quaid & Michael Morris, *Reluctance To Undergo Predictive Testing: The Case of Huntington Disease*, 45 AM. J. MED. GENETICS 41, 43-44 (1993) (listing the potential loss of health insurance as one of the main reasons people choose not to be tested).

[81] *See supra* notes 11-12 and accompanying text (discussing the nocebo effect).

sufficient knowledge to determine what is in their best interest. For example, an individual may be misinformed about the probability that she will be found to have a particular genetic condition, or she may overestimate the adverse health or economic consequences of having such a condition, or she may overestimate the difficulty of preventing or ameliorating the condition. To the extent that this is the problem, however, the appropriate regulatory response should be to provide better information by mandating or subsidizing genetic counseling, for example, so that the individual can make a more informed decision about whether to undergo genetic testing.

A plausibly better answer is to say that genetic testing can produce positive externalities. By obtaining confirmation of a genetic predisposition, a person may be able to protect her offspring from inheriting that condition. Ordinarily, however, we leave it up to individuals to decide what is in the best interests of their children. We give parents wide latitude in deciding where and how to live, what to feed their children, what type and level of health care to provide them, and so forth. Public policy steps in, as in the context of mandatory inoculation against certain diseases, only when the benefits clearly and consistently outweigh the costs. On this rationale, most states already mandate prenatal genetic screening for such conditions as PKU or sickle-cell trait.[82] To the extent that we identify other genetic conditions for which prospective parents clearly ought to test, the appropriate policy response is either to mandate testing or to subsidize testing for those conditions.

Whatever the source of the "market failure" that might prevent people from making optimal decisions about whether to undergo genetic testing, in short, the antidiscrimination strategy is surely one of the least attractive policy instruments for curing that defect. Unlike the provision of additional information, or the subsidizing or mandating of particularly beneficial forms of testing, the prohibitory strategy provides at best only a partial and uncertain incentive for testing and, in the process, distorts the efficiency of two additional markets: employment and insurance. For these reasons, we conclude that the encouragement of genetic testing does not provide a convincing welfare-based argument to prohibit the use of genetic test results in employment or insurance.

---

[82] *See, e.g.*, MASS. GEN. LAWS ANN. ch. 76, § 15B (1991) (dealing with screening programs, testing, and limiting disclosure for sickle-cell trait and related genetically linked diseases).

B. *Equality of Opportunity*

Few advocates for the emerging regime of genetic privacy ground their position on the principle of allocative efficiency.[83] Rather, they base their policy recommendation on a principle of distributive justice deriving from egalitarian ethics. The most widely accepted version of egalitarianism posits that every human being deserves an equal opportunity to achieve her potential or her life's goals and that a just society, therefore, has a moral obligation to redress barriers to equal opportunity.[84] Ethicists have distinguished several versions of the equal opportunity principle, ranging from a simple prohibition on the erection of unequal legal barriers, all the way to a requirement of affirmative action to correct inequalities.[85] Virtually all theories of equal opportunity posit that individuals should not suffer social disadvantages as a result of factors beyond their control. A person's success in the "race of life" should be determined, not by the "brute luck" of the natural or social lottery, but only by the extent to which she uses her talents and opportunities. One deserves, by this account, only what one chooses.[86] One does not morally deserve unchosen and uncontrollable attributes, nor the adverse consequences that flow from possessing such attributes.

Being born with a genetic predisposition for disease or some other severely dysfunctional condition is a paradigmatic example of bad moral luck. Thus, the brute luck theory clearly implies that the

---

[83] *But see* Paul M. Schwartz, *Privacy and the Economics of Personal Health Care Information*, 76 TEX. L. REV. 1 (1997) (arguing that regulation of health care information privacy is an efficient response to transaction costs and other market failures).

[84] *See, e.g.*, JOHN RAWLS, A THEORY OF JUSTICE 73-78 (rev. ed. 1999) (discussing "fair equality of opportunity"); JOHN E. ROEMER, EQUALITY OF OPPORTUNITY 5 (1998) (noting that "the purpose of an equal-opportunity policy is to level the playing field"); AMARTYA SEN, INEQUALITY REEXAMINED 4-5 (1992) (arguing for equality of a "person's capability to achieve functionings that he or she has reason to value"). The principal contemporary rival to the theory of equal opportunity is Ronald Dworkin's theory of "equality of resources." RONALD M. DWORKIN, SOVEREIGN VIRTUE: THE THEORY AND PRACTICE OF EQUALITY 65-119 (2000). Since Dworkin includes mental and physical powers among the "resources" that a just society should equalize, his theory has similar implications for the treatment of genetic disadvantages. *See id.* at 433-36 (asserting that a national health care system is the only proper way to deal with the inherent inequality of genetics).

[85] *See* ALLEN BUCHANAN ET AL., FROM CHANCE TO CHOICE: GENETICS AND JUSTICE 65-67 (2000); Allen Buchanan, *Equal Opportunity and Genetic Intervention*, 12 SOC. PHIL. & POL'Y 105, 109-10 (1995) (analyzing theories of equality and equal opportunity).

[86] *See, e.g.*, DWORKIN, *supra* note 84 at 73, 287, 341 (distinguishing deliberate gambles from chance without choice).

genetically unlucky should have a claim to some sort of compensatory treatment to offset their innate disadvantage. But what sort of compensatory treatment? And against whom can they make such a claim? Without more, the brute luck version of egalitarianism does not provide answers. The mere fact that a person has suffered a misfortune, even a grievous misfortune, does not, by itself, entitle her to demand whatever form of remedy she likes from any person or institution of her choosing.

A policy that forbids the use of information relevant to an individual's employability or insurability selectively conscripts private parties into the process of subsidizing that individual. Those conscripted parties, moreover, include not only impersonal economic organizations, but real people as well. Suppose, for example, that a job applicant obtains a job despite knowing—and, indeed, concealing—information that would reveal limitations on productivity. The advantage gained by such a person comes at the expense of not only the employer, but also another disappointed job applicant who is presumably better qualified for the job. Indeed, if a ban on using genetic information makes it more difficult for employers to verify the accuracy of the health-related questions that they *are* permitted by law to ask, then the policy may have the consequence of benefiting the dishonest at the expense of the honest.[87] Likewise, adverse selection in insurance penalizes not only the insurance company, but also other insured persons, a portion of whose premiums must contribute to the subsidy.

Ordinarily in our moral order, a victim of misfortune can make a claim only against a private party who can fairly be said to have either caused her plight or consented in fact to bear responsibility for her protection.[88] How, then, can a victim of genetic misfortune be considered morally entitled to demand employment or insurance, at the cost of corporations or individuals who have, by hypothesis, neither caused her genetic impairment nor consented to bear responsibility for its alleviation? The prohibitionist literature suggests

---

[87] *See* Epstein, *supra* note 62, at 8-13 (arguing that genetic privacy protection can be a means of facilitating, and indeed, encouraging fraud).

[88] Richard Epstein has made this point in many of his writings. *See, e.g.*, EPSTEIN, *supra* note 60 (arguing against a legal requirement that private employers or insurers provide subsidized coverage for those without health insurance); Richard A. Epstein, *A Theory of Strict Liability*, 2 J. LEGAL STUD. 151 (1973). In particular, Epstein's criticism of the emerging regime of genetic privacy prefigures several of the arguments we make in this piece, including the ways in which such a policy distorts markets and interferes with individual liberty in the name of collective duty. *See* Epstein, *supra* note 62.

two answers: the argument that health insurance and employment are "necessities" and the argument that genetic discrimination is closely akin to other forms of morally condemned invidious discrimination. We find neither claim to be persuasive. The fact that a particular good is a "necessity" does not, by itself, alter the presumption against selective coerced altruism. Even if it did, the antidiscrimination rule is a singularly inappropriate mechanism for matching the remedy to the need. As for the "invidious discrimination" argument, we find the analogy between, say, racial discrimination and genetic discrimination unconvincing. The historical and social realities that justify moral condemnation of the former simply do not apply with comparable moral force to the latter.

1. Necessity

The brute luck version of equal opportunity argues that a just society should readjust the point from which the genetically unlucky begin the race. One plausible way to accomplish this objective is to provide to every individual at least a minimal allotment of goods and services deemed indispensable to the pursuit of life's goals. Among such goods and services, so it could be argued, are health insurance and employment.[89] Whether health insurance and employment are truly "necessities" is, of course, debatable.[90] Their importance is a matter not so much of biological necessity as social or cultural contingency. Still, a credible argument can be made that in the context of contemporary America, health insurance and employment should be considered as essential ingredients of a decent life. In a world of unpredictable health risks and highly specialized, expensive health care, health insurance should be understood as an essential

---

[89] The "necessity" argument has been made most often in the context of health insurance. *See, e.g.*, Martin Johnston, *Selling Souls: Ethical Theory and Commercialisation of Genetic Information*, *in* GENETIC INFORMATION: ACQUISITION, ACCESS, AND CONTROL 79 (Alison K. Thompson & Ruth F. Chadwick, eds., 1999).

[90] *See* Trudo Lemmens, *Private Parties, Public Duties? The Shifting Role of Insurance Companies in the Genetics Era*, *in* GENETIC INFORMATION: ACQUISITION, ACCESS, AND CONTROL 31 (Alison K. Thompson & Ruth F. Chadwick eds., 1999) (arguing that health insurance has not yet completed the transition from private market good to social necessity). It is difficult to maintain that health insurance is regarded as a necessity in a nation, such as the United States, in which over 44 million people are uninsured. U.S. CENSUS BUREAU, HEALTH INSURANCE COVERAGE 1998, at 1 (1999). Even less can it plausibly be argued that a job is a necessity, given the persistence of unemployment (albeit at historically low levels in recent years) and the lack of public job programs or subsidies to assure private employment of the unemployed and the underemployed.

means of protecting people against crippling financial losses—including losses occasioned by the very sorts of conditions for which the brute luck theory seeks to compensate. Likewise, in a postagrarian, postartisanal economy dominated by large productive enterprises, employment is the primary means by which people can achieve not only financial independence, but also personal dignity and self-fulfillment.

There are three objections to this argument. First, the classification of health care and employment as "necessities" does not, by itself, alter our general moral skepticism about compelled altruism.[91] After all, if a drowning man cannot demand that a passer-by save his life—the ultimate "necessity"—why can a genetically, disfavored person demand that a particular insurer offer him subsidized insurance or a particular employer offer him a subsidized job? Second, the necessity argument suffers from the general theoretical objection to social provision of "merit goods."[92] Individuals—even genetically disadvantaged individuals—attach differing values to goods such as health insurance coverage or employment, or for that matter, other necessities such as food, shelter, and health care itself. Those who are severely genetically disadvantaged, for example, might place an especially high value on access to high-limits health, disability, or even life insurance. Those who are mildly disadvantaged might place a higher value on access to a high-paying or particularly secure job. Given the diversity of preferences in any population, the ethically superior means of providing even "necessities" is a cash subsidy, not merit goods.

Third, even if one accepts that society has an obligation to provide employment and health insurance protection, the antidiscrimination strategy is particularly ill-suited to serving that goal. It is not enough for society to classify a good as a "necessity"; it must also specify the quantity or quality of that good to which individuals are minimally

---

[91] On the justifications for the "no-duty-to-rescue" rule of tort law, see Epstein, *supra* note 88, at 198-200; James A. Henderson, Jr., *Process Constraints in Tort*, 67 CORNELL L. REV. 901, 928-43 (1982). Some theorists have called for creation of a limited duty to rescue. *See, e.g.*, Ernest J. Weinrib, *The Case for a Duty To Rescue*, 90 YALE L.J. 247, 251 (1980) (calling for recognition of a duty of "easy rescue").

[92] *See* Richard A. Musgrave, *Merit Goods*, *in* 3 THE NEW PALGRAVE: A DICTIONARY OF ECONOMICS 452 (John Eatwell et al. eds., 1987) (discussing multiple meanings of the term "merit goods" and the extent to which most of them involve overriding individual consumer preferences); *see also* RICHARD A. POSNER, ECONOMIC ANALYSIS OF LAW 511-13 (5th ed. 1998) (discussing the relative advantages of cash transfers and in-kind benefits).

entitled. Food may be a necessity but a six-course meal at Le Bernardin is not. The minimum-benefits approach to equal opportunity has been worked out most fully in the context of health insurance, where egalitarians have argued that the state should provide every citizen protection against the consequences of the most common and devastating of health risks.[93] We are fully sympathetic with such a position. But we do not believe that the unrefined application of an antidiscrimination policy is the appropriate means for achieving that result. Assuming that some minimal level of health insurance coverage is a necessity, the government should provide the benefit directly, as it does (albeit imperfectly) in the Medicare or Medicaid programs, or indirectly through some form of subsidy or tax benefit. In this way, the government can target the benefit to those who need it, in the precise amount or level they need, and only for as long as they need it.

The prohibitionist strategy, by contrast, is indiscriminate. It provides a (hidden) subsidy to any person who might be discriminated against for genetic reasons, regardless of financial or other need. More importantly, the antidiscrimination policy subsidizes the purchase of any level of insurance that the beneficiary might choose to obtain, not merely some basic minimum level of coverage. Because the value of the implicit subsidy surely increases as the level of coverage increases, such a policy gives beneficiaries an incentive to consume far more than the level of coverage that any plausible egalitarian theory would deem minimally necessary. It is as though the government sought to combat malnutrition by requiring all food-service establishments, from the neighborhood soup kitchen to the Michelin three-star restaurant, to give the malnourished a fifty percent discount on the price of every meal.

2. Invidious Discrimination

The principle invoked most persistently to justify the prohibitionist strategy is the argument from invidious discrimination. Discrimination on genetic grounds, it is claimed, is morally indistinguishable from other forms of discrimination, such as racial or gender discrimination, that are widely condemned.[94] These latter

---

[93] *See, e.g.*, NORMAN DANIELS, JUST HEALTH CARE (1985) (arguing that health care has a crucial effect on equality of opportunity).

[94] *See* Susan M. Wolf, *Beyond "Genetic Discrimination": Toward the Broader Harm of Geneticism*, 23 J.L. MED. & ETHICS 345 (1995) (applying analysis of race and gender

forms of discrimination are, after all, based on genetic attributes. Therefore, proponents argue, discrimination based on genetic attributes must also warrant moral condemnation. It is true that most forms of invidious discrimination, such as racial or sexual discrimination, are grounded in genetic differences. To the extent that certain genetic characteristics—such as sickle-cell trait[95]—are strongly correlated with groups that have been the target of invidious discrimination, their use as a proxy or marker for race ought equally to be prohibited. But the link between a few genetic traits and legitimately regulated suspect classifications hardly justifies an across-the-board prohibition on the use of all genetic traits. It may, of course, turn out that the genetics revolution will spawn new, as yet unforeseen, forms of invidious discrimination. If and when this happens, prohibitions on those forms of discrimination may be justified. But the mere possibility that new forms of discrimination may someday emerge cannot justify the present costs to welfare and liberty of a blanket prohibition.

The immutability of race or sex is often identified as a basis for the judgment that these forms of discrimination are morally offensive. But immutability is not the touchstone for determining the immorality of discrimination. Prohibitions against racial and gender-based discrimination seek to remedy a very long and sorry history of systemic subordination and oppression of readily (although imperfectly) identifiable groups within our society. Immutability may be important because victims of these particular forms of discrimination cannot readily escape from the attribute that singles them out for subordination. But the basis for moral condemnation is not the biological fact of immutability: it is the social fact of oppression. There is no corresponding history of discrimination against the "genetically disadvantaged." Indeed, there cannot be. The science that could permit the construction of such a class is still

---

antidiscrimination norms to genetics).

[95] A frequently cited example is the use of sickle-cell screening programs to discriminate against individuals of African descent. JAMES E. BOWMAN & ROBERT F. MURRAY, JR., GENETIC VARIATION AND DISORDERS IN PEOPLES OF AFRICAN ORIGIN 365-66 (1990) (detailing briefly the results of the discovery of sickle-cell trait); *see also* Arthur L. Caplan, *Handle with Care: Race, Class and Genetics, in* JUSTICE AND THE HUMAN GENOME PROJECT 30 (Timothy F. Murphy & Marc A. Lappé eds., 1994) (discussing hypothetical situations regarding race and genetics); Patricia A. King, *The Past as Prologue: Race, Class, and Gene Discrimination, in* GENE MAPPING: USING LAW AND ETHICS AS GUIDES 94, 98-99 (George J. Annas & Sherman Elias eds., 1992) (describing the historical uses of sickle-cell screening).

in its infancy.

If biology, or immutability, were the morally relevant factor, our society would condemn the use of countless other criteria for making differentiated judgments about people. But it does not. Consider intelligence—a trait, or rather a congeries of cognitive information storage and processing abilities, with undeniable genetic roots.[96] If genetic discrimination were per se immoral, how could we possibly condone the nearly universal use of intelligence measures in education, employment, and other settings? The same could be said for other attributes such as aggressiveness, stature, obesity, or physical beauty.[97]

At this point in the argument, the concept of "stigmatization" typically makes an appearance. Privacy advocates may concede that we do not morally condemn every form of discrimination, not even every form of discrimination based on inherited attributes. But, they argue, we should, and in fact do, condemn discrimination based on inherited attributes that involve social "stigma." Just as people have historically been stigmatized for their race, it is said, so they are stigmatized for possessing "bad" genes. An ironclad regime of genetic privacy is thus justified to protect people from this form of undeserved social blemish.

It is difficult to know what to make of this argument, because the concept of stigma is so protean. Some writers seem to use the concept of stigma in a perfectly circular fashion: a trait is stigmatizing because it is used as a basis for differentially adverse treatment.[98] Others invoke the specter of past eugenics movements, as though one can simply abstract from the particular social conditions and stereotypes that gave rise to those horrific abuses.[99] Still others cite the results of public opinion polls expressing popular concern about invasions of genetic privacy, as though fear of misuse of information necessarily reflected aversion to the underlying condition revealed by such information.[100]

---

[96] On the genetic basis for intelligence, see HAMER & COPELAND, *supra* note 47, at 218-19.

[97] *See id.* at 39-47, 73-80, 99-102, 245 (describing the genetic basis of "thrill-seeking," depression, antisocial behavior, addiction, and obesity respectively).

[98] *See, e.g.*, Fedder, *supra* note 13, at 561, 565 (providing examples of stigmatization linked with genetics).

[99] *See supra* notes 21-22 and accompanying text.

[100] *See* Sullivan, *supra* note 20, at 16 (noting that Americans tend to oppose genetic testing if the results can be accessed by a health insurer).

It is undeniable that disease can elicit fear and ostracism. The most egregious contemporary example—one invoked frequently in the genetic discrimination literature—is HIV/AIDS. But the popular aversion to HIV-positive persons and AIDS victims has nothing to do with genetics and very little to do with biology. It derives from an incendiary combination of widespread phobias relating to sex, homosexuality, licentiousness, and illicit drug use, coupled with, at least in the early years of the AIDS epidemic, exaggerated fears of communicability and, unfortunately, more accurate perceptions of incurability.[101]

By no means can one say that all genetic conditions, or even all diseases of genetic origin, generate social stigma remotely comparable to that visited on carriers of the AIDS virus. The most common genetically influenced diseases, such as heart disease or cancer, elicit reactions of sympathy and solicitude far more than fear and aversion. Indeed, the labeling of a condition as a "disease" often reduces the stigma attached to a condition or pattern of behavior. Consider the characterization of alcoholism as a disease, the relabeling of "senility" as Alzheimer's disease, or the emerging consensus that obesity has a strong genetic component. While surely there are genetic conditions that do produce the reactions one might fairly describe as "stigmatization," one can hardly justify a blanket prohibition on genetic discrimination on that ground.[102]

Those who would analogize genetic discrimination to other forms of invidious discrimination frequently invoke the example of discrimination against persons with disabilities. After all, they argue, if an employer is forbidden from discriminating against an applicant or jobholder because of a manifested disabling condition, surely that employer should also be precluded from treating adversely an asymptomatic person who merely possesses a genetic predisposition for that condition. The analogy is superficially attractive, but, on closer inspection, unconvincing.

The moral justification for prohibiting disability discrimination is comparable to that used to justify prohibitions on racial or gender

---

[101] *See* Nancy Perkins, *Prohibiting the Use of the Human Immunodeficiency Virus Antibody Test by Employers and Insurers*, 25 HARV. J. ON LEGIS. 275, 276-78 (1988) (discussing the history and nature of AIDS and HIV).

[102] Alexander Capron argues that the stigma of "bad genes" will decline as the "widespread and basically random nature of genetic risks becomes more apparent." Alexander Morgan Capron, *Which Ills To Bear?: Reevaluating the "Threat" of Modern Genetics*, 39 EMORY L.J. 665, 690 (1990).

discrimination. Our society has, due to irrational prejudice and fear, excluded a class of persons with certain readily identifiable conditions, fairly described as "disabilities," from activities, such as employment, which they are otherwise qualified to perform. Thus, an employer who excludes a person from an otherwise suitable job solely because of her disability actively perpetuates that history of oppression and subordination. In that sense, the employer implicates herself sufficiently in the applicant's misfortune to become morally responsible for its perpetuation.

It is true that the primary legal embodiment of this moral intuition, the Americans with Disabilities Act, requires that the employer go beyond a purely negative prohibition against using the suspect classification as a basis for adverse treatment.[103] By affirmatively obliging employers to make "reasonable accommodations" for the disabled, the Act conscripts private actors to subsidize the disadvantaged.[104] But the reasonable accommodations requirement can be viewed as a rather modest remedial measure, much like the obligation of affirmative action in the racial context, to effectuate an essentially prohibitory policy. As in the context of racial discrimination, the long history of unjust discrimination against the disabled had led to the hardening of certain exclusionary hiring procedures, selection criteria, training routines, and job designs. The Act obliges employers to examine those practices and, at least where "reasonable," change them to facilitate the law's negative command. So interpreted, the ADA does not provide a convincing precedent for enacting a far more sweeping prohibition on the use of all genetic factors, or even all genetic test data, in insurance and employment decisions.

Furthermore, even to the extent that the ADA is an appropriate template, the Act does not support a regime of absolute genetic nondisclosure. An employer is not required to act in complete ignorance of an applicant's or employee's disability. Although the Act prohibits employers from inquiring about disabling conditions in

---

[103] *See supra* text accompanying notes 36-42 (summarizing provisions of the Americans with Disabilities Act).

[104] It is this feature of the ADA that we find to be most morally controversial. This may help to explain why employers have resisted ADA employment discrimination claims so fiercely, and why courts have ruled in their favor so frequently. *See* John W. Parry, *Trend: Employment Decisions Under ADA Title I—Survey Update*, 23 MENTAL & PHYSICAL DISABILITY L. REP. 294, 294 (1999) (finding that employers prevailed in ninety-four percent of ADA employment discrimination suits in federal court that yielded a judicial decision favoring either party, during the period 1992-1998).

preliminary employment screening, it explicitly authorizes employers to administer preplacement tests and examinations that would reveal the presence and nature of disabling conditions. In fact, the "reasonable accommodation" strategy necessitates that employers have such knowledge. One cannot determine whether and how to make cost-effective accommodations to a condition without having information, not only about the bare fact of its existence, but also the nature and severity of its impact on functional capacities.

Indeed, one can make the case that the brute luck principle *requires* disclosure of information about a person's inherited drawbacks. Without such disclosure, persons suffering from handicaps are in constant jeopardy of being held to unattainable expectations. Those with whom they deal will attribute deficiencies of performance to lack of effort or competence, rather than lack of capacity. Of course the genetically disadvantaged person has an incentive to disclose such limitations. But the disclosure must be full, honest, and verifiable. For, otherwise, the opposite injustice could occur. An individual could falsely attribute deficient performance to an inherited incapacity, when in fact it was caused by sheer laziness, inattentiveness, or lack of skill. Thus, the principle of just deserts, like the principle of allocative efficiency, requires full disclosure of information about congenital limitations.

There is a further objection to applying the antidiscrimination principle to genetic differences. The paradigmatic instances of invidious discrimination involve, in the language of *Carolene Products*' famous footnote four,[105] "discrete" categories such as race or gender. These categories are discrete in the sense that the variable defining the classification is discontinuous.[106] It is often said that race and even gender are social constructs, not biological realities.[107] But, even so, they are conventionally understood, and employed, as discontinuous social constructs. Genetic disadvantage, "brute (bad) luck," does not have this quality. It is a continuous, probabilistic variable. One can have more or less bad luck. One can have more or less severe genetic

---

[105] United States v. Carolene Prods. Co., 304 U.S. 144, 152 n.4 (1938).

[106] *See* Wolf, *supra* note 94, at 347-48 (detailing the common critiques of the practice of comparing race and gender antidiscrimination analysis to genetic discrimination).

[107] *See, e.g.*, Cheryl I. Harris, *Whiteness as Property*, 106 HARV. L. REV. 1707, 1737-41 (1993) (suggesting that "whiteness" is a social construct). So, too, genetic "abnormality" is socially constructed. *See* George J. Annas, *Mapping the Human Genome and the Meaning of Monster Mythology*, 39 EMORY L.J. 629, 650 (1990) (noting that many diseases and abnormalities are socially constructed).

predispositions. True, the possession of a particular allele or genetic mutation is a discontinuous variable. But, whether viewed as a biological reality or a social construct, the possession of an allele associated with the expression of a particular disease does not, by itself, define the person as belonging to a discrete category. Rather, it associates the person with a heightened probability, on a scale that varies continuously from zero to one, of contracting that particular disease. Risk of contracting a particular disease is, in turn, only one aspect of a multidimensional health profile.[108]

Who, then, is the object of protection in a regime that outlaws genetic discrimination? Anyone with a genetic predisposition for a disabling or life-threatening disease? That description encompasses the entire human race.[109] Only those with a probability of contracting disabling or life-threatening diseases that exceeds a particular cutoff, such as fifty percent? What about those with a probability of forty-nine percent? Only those with a heightened probability of contracting particularly severe diseases? Which diseases? "Heightened" as compared to what baseline? Where, along the continuously varying spectrum of genetic risk, do we separate the privileged from the oppressed? Without a history of invidious labeling, segregation, and oppression—the very social processes that create *Carolene Products*' "discrete and insular minorities"—the antidiscrimination principle itself furnishes no answers.

CONCLUSION

A meal consisting solely of criticism is rarely satisfying. All the more so, perhaps, is the meal served by this essay. Even if we are correct that the emerging genetic privacy regime is badly flawed, what then? Are we satisfied simply to leave people, naked before the law, to their genetic fates? The short answer to that question is an emphatic no. Unfortunately, the long answer will be too long, in both the formulating and the telling, for this particular occasion. We conclude this essay with only a foretaste of the argument.

We agree with the privacy advocates that the principle of brute

---

[108] *See* Wolf, *supra* note 94, at 348 (criticizing the tendency to bifurcate genetics into the realms of normal and abnormal).

[109] *See* Capron, *supra* note 102, at 690 ("[A]ll of us carry five to seven lethal recessive genes as well as a still undetermined number of genes that make us susceptible to developing diseases."); Monique K. Mansoura & Francis S. Collins, *Medical Implications of the Genetic Revolution*, 1 J. HEALTH CARE L. & POL'Y 329, 334 (1998) ("All of us carry an estimated five to fifty significant genetic alterations.").

luck places a moral duty on the collectivity to provide redress for the most egregious of genetic inequalities. Where we disagree is in the choice of the means to this end. A morally attractive social response to genetic inequality must have two parts: first, incentives to correct those conditions that can be corrected, and second, subsidies to redress the most severe conditions that cannot. Both strands of this strategy require genetic transparency. We must know not only how many people possess particular genotypes in order to conduct productive research about ameliorative strategies, but we must also know which individuals possess those genotypes in order to facilitate and encourage corrective or preventive interventions and provide support appropriate to their particular needs and means.

Where ignorance is an obstacle to this goal, society must adopt policies that encourage the production and dissemination of information, whether it be in the form of subsidies for scientific research, encouragement of genetic counseling, or education of insurers or employers. Where, on the other hand, lack of financial resources is the obstacle to genetic justice, subsidies must be provided. A subsidy can, of course, take many forms. It can be provided directly by the government to the individual, via either a direct cash payment, the provision of public health insurance, or a public job. Or, it can be provided by way of the private sector, in the form of cash subsidies or tax benefits provided to private insurers or employers who agree to furnish insurance coverage or employment to the genetically disadvantaged. There are good reasons for preferring some of these methods over others. But, from the perspectives of both efficiency and fairness, any one of these methods is preferable to conscripting unwilling private actors to provide subsidies that are concealed—but never fully or reliably—under a blanket of enforced ignorance.

In the final analysis, then, we are convinced that only a regime of genetic transparency can enable our society to confront openly its phobias about genetic diversity and begin, at last, fully to appreciate its blessings.