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Genetic Discrimination in a Time of False Hopes

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FLORIDA STATE UNIVERSITY LAW REVIEW



THE IDEOLOGICAL CONTEXT OF THE DISABILITY RIGHTS CRITIQUE: WHERE MODERNITY AND TRADITION MEET

Janet Dolgin

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GENETIC DISCRIMINATION IN A TIME OF FALSE HOPES

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Law anticipated genetic discrimination in insurance. Legislators in the 1990s accepted genetic equity as a valuable, if abstract, concept largely removed from the realities of insurance underwriting or coverage decisions. Things may become complex quickly, however, when genetic discrimination laws face reality. Difficulties suggest themselves when one attempts to define “discrimination” in practice and then to match statutory language to the practical problem of limiting its effect. Enforcing genetic prohibitions raises perplexing regulatory problems, as forms of health finance morph more rapidly than regulators can anticipate.

The enterprise is vital notwithstanding the difficulties. Denial of coverage or care on the basis of genetics violates the principles of social solidarity that are, or should be, at the core of health insurance law. State and federal lawmakers enacted laws limiting or forbidding genetic discrimination in health coverage during the 1990s, a period of both broad economic growth and very stable health care costs. More recently, the economy has faltered and health care cost inflation has revived with a vengeance. Renewed health care cost inflation appears to be consistent with the nearly Malthusian tendency with which technological advances in health care and the increasing demands of an aging population drive the expense of health services

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ever higher.¹ A tight economy and increasing costs will create the perception of scarcity and further the pressure to ration care. In such times, the movement to genetic equity in insurance takes on a new character. In good times, the movement seemed a piece of incremental reform, marginally expanding insurance access. Under cost-containment scrutiny, however, it takes on a different cast. In these more restrained times, advocates of genetic equity in health insurance must firmly establish their position in anticipation of renewed attention to rationing.

This Article posits that overt rationing is inevitable. It argues that the genetic antidiscrimination movement, along with others pursuing health coverage equity, must consolidate its position in anticipation of retrenchment. Genetic equity should be regarded not as an exceptional goal, but as an aim consistent with a broader movement toward equitable access to health care in a time of scarcity.

Part I of this Article describes genetic discrimination as it pertains to health coverage. Part II examines the statutory response to genetic discrimination. It first considers but then rejects the possibility that genetic discrimination in health coverage can be remedied by the Americans with Disabilities Act (“ADA”).² It then examines specific genetic discrimination laws adopted in many states in recent years. Part III examines the difficulties that will arise in enforcing statutory prohibitions. It concludes that some of the enforcement difficulties may be avoided by clearer statutory drafting, while others are inherent in the modern forms of health finance. Part IV looks to the future—it recognizes that genetic discrimination laws cobbled onto existing insurance institutions may cause instability in insurance markets and that serving the goals of equitable access to health coverage requires broader systems change. It forecasts increasing cost pressures on health care delivery, and suggests that such pressures will lead inevitably to some form of rationing. It concludes that well-established antidiscrimination principles are essential for the integrity of any rationing response to scarcity.

It may be important at the outset to be clear on why an examination of genetic discrimination in health insurance is and is not important. There is very little evidence that insurers have used genetic makeup in any substantial way to assist in either underwriting or coverage decisions. Insurers may do so; however, should they be permitted? Are scientific advances likely to render prognostic testing feasible and economic? Such practices would be the appropriate sub-

1. See Drew E. Altman & Larry Levitt, *The Sad History of Health Care Cost Containment As Told In One Chart*, HEALTH AFF., Jan. 2002, at <http://www.healthaffairs.org/WebExclusives/2101Altman.pdf> (last visited January 29, 2003) (on file with author).

2. Americans with Disabilities Act of 1990, Pub. L. No. 101-336, 104 Stat. 327 (codified as amended at 42 U.S.C. §§ 12101-12213 (2000)).

ject of prohibitory legislation. More significantly, however, the wide adoption of genetic discrimination statutes in advance of need suggests a broad social rejection of the propriety of considering such information. The justification for genetic discrimination legislation and, generally, the relationship between these statutes and insurance are of great interest to those concerned with financing care for historically expensive populations, such as the chronically ill. These statutes suggest that support for the putative American tradition of matching the price of health insurance to anticipated risk by market methods is fading. The resurgence of health cost inflation, however, suggests that emerging principles of health insurance access equity will run squarely into a cost-conscious attempt to restrict funding for care.

I. THE PROBLEM OF GENETIC DISCRIMINATION IN HEALTH COVERAGE

“Genetic discrimination”³ is a topic that has attracted substantial scholarly interest in general⁴ and in the insurance context in particular.⁵ The use of genetic information for insurance purposes is controversial, notwithstanding several circumstances suggesting that genetic information is of little practical importance to insurers and un-

3. An early definition of “genetic discrimination” was “the denial of rights, privileges or opportunities on the basis of information obtained from genetically-based diagnostic and prognostic tests.” Lawrence Gostin, *Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests By Employers and Insurers*, 17 AM. J.L. & MED. 109, 110 (1991). That definition is underinclusive, as information providing the opportunity for disparate treatment can be obtained through means other than tests. Family history and manifestation of illness related to genetic conditions are other avenues for discovering genetic information that could be used to discriminate. See Lawrence O. Gostin & James G. Hodge, Jr., *Genetic Privacy and the Law: An End to Genetics Exceptionalism*, 40 JURIMETRICS J. 21, 51 (1999); see also Phillip B. Reilly, *Genetic Discrimination*, in GENETIC TESTING AND THE USE OF INFORMATION 106, 107 (Clarisa Long ed., 1999) (describing history of use of term); Jennifer S. Geetter, *Coding for Change: The Power of the Human Genome to Transform the American Health Insurance System*, 28 AM. J.L. & MED. 1, 2 (2002) (claiming “genetic discrimination” eludes definition).

4. See Colin S. Diver & Jane Maslow Cohen, *Genophobia: What Is Wrong With Genetic Discrimination?*, 149 U. PA. L. REV. 1439, 1441 (2001); Henry T. Greely, *Genotype Discrimination: The Complex Case For Some Legislative Protection*, 149 U. PA. L. REV. 1483, 1488 (2001); Zita Lazzarini, *What Lessons Can We Learn From The Exceptionalism Debate (Finally)?*, 29 J.L. MED. & ETHICS 149, 150 (2001); Lainie Friedman Ross, *Genetic Exceptionalism vs. Paradigm Shift: Lessons from HIV*, 29 J.L. MED. & ETHICS 141, 141 (2001); Sonia M. Suter, *The Allure And Peril of Genetics Exceptionalism: Do We Need Special Genetics Legislation?*, 79 WASH. U. L.Q. 669, 670 (2001).

5. See Kenneth S. Abraham, *Understanding Prohibitions Against Genetic Discrimination in Insurance*, 40 JURIMETRICS J. 123, 123-24 (1999); Mark A. Hall, *Legal Rules And Industry Norms: The Impact Of Laws Restricting Health Insurers' Use of Genetic Information*, 40 JURIMETRICS J. 93, 94 (1999); Mark A. Hall & Stephen S. Rich, *Genetic Privacy Laws And Patients' Fear Of Discrimination by Health Insurers: The View from Genetic Counselors*, 28 J.L. MED. & ETHICS 245, 247 (2000); Mark A. Rothstein & Sharona Hoffman, *Genetic Testing, Genetic Medicine, and Managed Care*, 34 WAKE FOREST L. REV. 849, 851 (1999).

derwriters. First, the genetic code as our “book of life,”⁶ through which actuaries may thumb to ascertain our future health history, is a seriously strained metaphor.⁷ The relationship between our genetic makeup and our health is complex. Very few diseases have clear relationships with a single genetic characteristic. Most diseases have complex causes, some genetic and some environmental.⁸ Genetic testing is, therefore, in most cases a very imperfect means of projecting future illness. Second, genetic treatments have not materialized at a rate that creates a major impact on health care costs, suggesting that insurers will be unlikely to undertake aggressive steps to limit access to this category of care. Third, most Americans with health insurance coverage are not in plans that medically underwrite. Instead, they are covered by Medicare, Medicaid, or large employment-based groups that determine coverage on the basis of group membership or categorical status and not on the basis of medical condition.⁹

Nevertheless, genetic discrimination is both controversial and important. It is controversial because the suggestion that people will be denied coverage or care on the basis of their genetic makeup is viewed as quintessentially unjust. To the extent that advantage should follow desert, genetic discrimination is disfavored for disadvantaging people on the basis of characteristics irrevocably set at the moment of conception. In addition, use or abuse of genetic information threatens to reveal intimate physical information.¹⁰ As is true with any intimate information, its disclosure may be embarrassing. Perhaps more significantly, this intimate genetic information is often unwelcome even to the subject—many of us do not want to know the future.¹¹ The major emphasis of the genetic discrimination discussion, however, is on the *use* to which genetic information is put. It may be used to treat people disparately in employment, social relationships, and access to services.¹²

Some instances of alleged disparate treatment have been the sub-

6. See Elizabeth Pennisi, *Finally, the Book of Life and Instructions for Navigating It*, 288 SCIENCE 2304, 2305 (2000); see also NICHOLAS WADE, LIFE SCRIPT 19 (2001).

7. See LORI B. ANDREWS, FUTURE PERFECT: CONFRONTING DECISIONS ABOUT GENETICS, 148-49 (2001); Greely, *supra* note 4, at 1486-87; Suter, *supra* note 4, at 688-89.

8. Greely, *supra* note 4, at 1486-87.

9. *Id.* at 1488.

10. See Diver & Cohen, *supra* note 4, at 1440-41.

11. See Rothstein & Hoffman, *supra* note 5, at 852-53.

12. 143 CONG. REC. S7863-01 (July 22, 1997) (statement of Sen. Daschle) (“Many employers may not hire individuals whom they believe will require time off . . . [because of a genetic] disease[,]” even though genetic testing only indicates a predisposition to the disease and not the actual development of the disease itself); President William J. Clinton, Remarks on Genetic Discrimination at the White House Office of the Press Secretary (Feb. 8, 2000) (transcript available at <http://www.ofcn.org/cyber.serv/teledem/pb/2000/feb.html>) (on file with author); Extension of remarks by Hon. Louise McIntosh Slaughter, Preventing Genetic Discrimination in Health Insurance (Jan. 7, 1997) (transcript available at <http://thomas.loc.gov/cgi-bin/query>) (on file with author).

ject of enforcement activity.¹³ Generally applicable genetic discrimination statutes address disparate treatment on the basis of genetic makeup.¹⁴ These statutes employ two strategies for combating such discrimination.¹⁵ The first is to maintain confidentiality with respect to genetic information through privacy rules.¹⁶ This forestalls the opportunity for disparate treatment by holding close the data on the basis of which type of discrimination might occur. The second is to prohibit or regulate the use of genetic information when testing is permitted or information is otherwise disclosed.¹⁷ This strategy enforces the legislature's judgment of the acceptable and unacceptable circumstances in which genetic condition may be taken into account, for example, in employment or public accommodations decisions.

In the health insurance context, "genetic discrimination" can thus be a remarkably plastic term and requires separate analysis. "Discrimination" in insurance law is often not a term of approbation, but rather refers to a common task of actuaries: the assortment of risks according to their likely realization and cost. Such assortment has been grist for the mill for insurers and actuaries, as they attempt to match the price of coverage against its likely cost and to charge applicants for coverage according to their (hopefully relevant) individual characteristics. Under some circumstances, insurance law requires such discrimination, forcing firms to charge premiums for coverage of risks in relation to the expected cost of such coverage.¹⁸

In recent years, discrimination in insurance (genetic discrimination in particular) has come to be used to describe circumstances in

13. EEOC v. Burlington N. & Santa Fe Ry. Co., No. 02-C-0456 (E.D. Wis. May 8, 2002). A 2.2 million dollar settlement was awarded to thirty-six individuals who were subjected to genetic testing by their employer after developing Carpal Tunnel Syndrome.

14. In Ohio:

No health insurance corporation, in processing an application for coverage for health care services under an individual or group health insuring corporation policy, contract, or agreement or in determining insurability under such a policy, contract, or agreement, shall do any of the following:

- (1) Require an individual seeking coverage to submit to genetic testing or screening
- (2) Take into consideration the results of genetic screening or testing
- (3) Make any inquiry to determine the results of genetic screening or testing
- (4) Make a decision adverse to the applicant based on entries in medical records or other reports of genetic screening or testing

OHIO REV. CODE ANN. § 1751.64(B) (West 2001).

In New Mexico: "Discrimination by an insurer against a person or member of the person's family on the basis of genetic analysis, genetic information or genetic propensity is prohibited." N.M. STAT. ANN. § 24-21-4(A) (Michie 2001).

15. Diver & Cohen, *supra* note 4, at 1444-45.

16. COLO. REV. STAT. ANN. Ch. 10-3-1104.7(1)(c) (2002); N.J. STAT. ANN. Ch. 10:5-5 (2001).

17. OHIO REV. CODE ANN. Ch. 1751.64 (2002); MD. CODE ANN., INS. § 27-909(c)(1) (2001).

18. See *infra* text accompanying notes 59-60.

which insurers use applicants' or insureds' characteristics to treat them differentially, in a manner disapproved of by legislatures. Genetic discrimination in health coverage usually refers to one of two different genetic sorting techniques. The first, which might be called discrimination in underwriting, occurs when a health insurer¹⁹ uses genetic characteristics to determine whether to provide coverage to a person. The second, which might be called discrimination in coverage, occurs when a health insurer makes decisions on the basis of genetic characteristics to pay for particular treatment.

Genetic discrimination statutes regulate both the disclosure and use of genetic information in the insurance relationship.²⁰ They seek to assure that an individual's genetic information will not leak out of the insurance process to taint his or her other public and private relationships. In addition, these statutes directly shape the insurance relationship by setting out whether and when genetic information may be employed by insurers. These latter statutory ends, governing the use of genetic information by insurers, reach both the irrational and the rational use of genetic information. While the roots of genetic discrimination laws are in the history of irrational genetic information, such as the use of carrier status for sickle cell anemia as a predictor of primary disease expression, current laws clearly prohibit the use of genetic information under circumstances when its use would undoubtedly be entirely rational.²¹ The next Section examines the varied laws governing genetic discrimination in health insurance.

II. THE LAW'S RESPONSE TO GENETIC DISCRIMINATION IN HEALTH INSURANCE

A. Federal Law

1. The Murky Role of the ADA

The ADA recites a congressional finding that America should assure people with disabilities "equality of opportunity, full participation, independent living, and economic self-sufficiency"²² and a statutory purpose of "the elimination of discrimination against individuals with disabilities."²³ President George H. Bush spoke expansively at the Act's signing, predicting that the ADA would advance the day

19. "Health insurer" here broadly includes private insurance companies, employment-based health and welfare plans, or other entities administering plans responsible for paying health-related costs incurred by members, whether or not they are "insurers" for purposes of state insurance law.

20. Diver & Cohen, *supra* note 4, at 1443-44; Suter, *supra* note 4, at 691-92.

21. See Abraham, *supra* note 5, at 127; Greely, *supra* note 4, at 1500; John V. Jacobi, *The Ends of Health Insurance*, 30 U.C. DAVIS L. REV. 311, 332-33 (1997).

22. 42 U.S.C. § 12101(a)(8) (2000).

23. *Id.* § 12101(b)(1).

“when no Americans will ever again be deprived of their basic guarantee of life, liberty, and the pursuit of happiness.”²⁴ The United States Equal Employment Opportunity Commission²⁵ and others²⁶ opined that the ADA is sufficiently broad to reach and prohibit genetic discrimination in health insurance. For two reasons,²⁷ however, it is now increasingly clear that the ADA will not be so interpreted.

First, the ADA protects against disability discrimination only those with an “impairment that substantially limits . . . major life activities,”²⁸ those with a “record of such an impairment,”²⁹ and those “regarded as having such an impairment.”³⁰ The Supreme Court has found that the ADA’s definitions set a “demanding standard” for disability.³¹ The individual’s condition must be such that it “prevents or severely restricts the individual from doing activities that are of central importance to most people’s lives.”³² In addition, the condition must *presently* cause a substantial limitation; it is not sufficient that the condition did in the past, or may in the future, limit an individual’s actions.³³

An individual with an unexpressed genetic trait has a greater or lesser probability of developing an illness, depending on the relationship between the genetic trait and the disease.³⁴ It is unlikely, however, that he or she *presently* experiences any limitations on daily activities.³⁵ In addition, it is unlikely that he or she would be able to es-

24. President George Bush, Remarks by the President During the Ceremony for the Signing of the Americans with Disabilities Act of 1990 (July 26, 1990), in *THE LEGISLATIVE HISTORY OF THE AMERICANS WITH DISABILITIES ACT 844* (G. John Tysse ed., 1991).

25. Paul Steven Miller, *Genetic Discrimination in the Workplace*, 26 *J.L. MED. & ETHICS* 189, 191 (1998) (citing EEOC Compliance Manual, §§ 902-946 (1995)).

26. See Frances H. Miller & Philip A. Huvos, *Genetic Blueprints, Employer Cost-Cutting, and the Americans with Disabilities Act*, 46 *ADMIN. L. REV.* 369, 374-75 (1994).

27. There is an additional reason beyond the two described in the text for doubting that the ADA could effectively limit genetic discrimination in health insurance. Where the defendant is an insurer or insurance broker, a growing but not unanimous body of law holds that the protections against discrimination in public accommodations under Title III of the ADA, 42 U.S.C. §§ 12181-12189 (2000), do not reach the *contents* of insurance products but only equal access to the opportunity to purchase such coverage, however limited that coverage may be on the basis of disability. See *Weyer v. Twentieth Century Fox Film Corp.*, 198 F.3d 1104, 1115 (9th Cir. 2000); *Doe v. Mut. of Omaha Ins. Co.*, 179 F.3d 557, 563 (7th Cir. 1999); *Ford v. Schering-Plough Corp.*, 145 F.3d 601, 608 (3d Cir. 1998). *But see* *Carparts Distrib. Ctr. v. Auto Wholesalers Ass’n of New Eng., Inc.*, 37 F.3d 12, 19-20 (1st Cir. 1994); *Boots v. N.W. Mut. Life Ins. Co.*, 77 F. Supp. 2d 211, 213-16 (D.N.H. 1999).

28. 42 U.S.C. § 12102(2)(A) (2000).

29. *Id.* § 12102(2)(B).

30. *Id.* § 12102(2)(C).

31. *Toyota Motor Mfg. v. Williams*, 534 U.S. 184, 194 (2002).

32. *Id.*

33. *Sutton v. United Airlines, Inc.*, 527 U.S. 471, 482-83 (1999).

34. Greely, *supra* note 4, at 1485.

35. It may be that an inheritable genetic condition impairs the ability of a person to engage in the activity of reproduction, for fear of transmitting the condition to offspring. See *Bragdon v. Abbott*, 524 U.S. 624, 641-42 (1998) (finding that an HIV infection con-

establish that the insurer “regarded [him or her] as” disabled.³⁶ This “regarded as” prong of the ADA is met only if “a covered entity mistakenly believes that a person has a physical impairment that substantially limits one or more major life activities, or . . . mistakenly believes that an actual, nonlimiting impairment substantially limits one or more major life activities.”³⁷ In the absence of the covered entity’s erroneous belief in a *current* impairment substantially limiting major life activities, a person may not state a claim of disability under the “regarded as” prong. Because a person with an unexpressed genetic condition is unlikely to be regarded as “disabled,” then he or she may not state a claim under the ADA.

The second barrier to an ADA action to remedy genetic discrimination in insurance is the statute’s insurance “safe harbor” provision. Congress did not leave the relationship between insurance practices and disability to be interpreted according to the ADA’s general provisions, but spoke to coverage issues directly in § 501(c).³⁸ This section permits insurers and employers providing either insured or self-insured plans to engage in traditional risk classification practices so long as such practices are not a “subterfuge” for unlawful discrimination.³⁹ Depending on the definition of “subterfuge,” § 501(c) can be a permissive safe harbor for covered entities or a substantial protection for people with disabilities. As with the application of the term “disability” to individuals with unexpressed genetic traits, the EEOC weighed in early on with an interpretation that has met with little respect in the courts.

The EEOC issued compliance guidance in 1993 in which it interpreted § 501(c) as requiring that risk classification for health benefits purposes be “justified by the risks or costs” associated with cover-

trolled an individual’s decision to have a child). But the Court in *Toyota Motor* held that a finding of disability based on severe impairment of the activity of reproduction must be made on a “case by case basis.” 534 U.S. at 195 (quoting 29 C.F.R. pt. 1630, App. § 1630.2(j) (2001)).

36. 42 U.S.C. § 12102(2)(C) (2000).

37. *Sutton*, 527 U.S. at 489.

38. 42 U.S.C. § 12201(c) (2000).

39. Section 501(c) permits an insurance company or seller of “bona fide” coverage subject to state law and sponsors of “bona fide” health coverage subject to state law to underwrite, classify, and administer risks in conformity with state law. 42 U.S.C. § 12201(c)(1)(2). It also permits any person to sponsor or administer a plan of health coverage not subject to state law so long as the plan is “bona fide.” 42 U.S.C. § 12201(c)(3). In this context, “bona fide” merely means that the plan “exists and pays benefits.” *Fitts v. Fed. Nat’l Mortgage Ass’n*, 236 F.3d 1, 4 (D.C. Cir. 2001) (quoting *Pub. Employee Ret. Sys. of Ohio v. Betts*, 492 U.S. 158, 166 (1989)). “No covered entity, notwithstanding the permissive language of § 201(c) generally, may use a benefits plan as a ‘subterfuge’ to evade the employment and public accommodations provisions of the ADA.” 42 U.S.C. § 12201(c). As is discussed in the text, the meaning of “subterfuge” in this context has been controversial.

age.⁴⁰ A principal means by which the EEOC suggested a covered entity could justify differential treatment of risks, such as the capping of coverage for one condition but not another, is by producing “legitimate actuarial data” to prove that all actuarially similar conditions are treated in the same manner.⁴¹ This principle of actuarial equivalence was accepted early on by some courts,⁴² although it has been rejected more recently by the circuit courts that have considered the issue.⁴³

The contrary (and now prevailing) interpretation of § 501(c) rejects the requirement of actuarial equivalence. Instead, it reads “subterfuge” as consistent with the use of the term in the Age Discrimination in Employment Act (“ADEA”).⁴⁴ The clear modern trend is to interpret “subterfuge” as “a scheme, plan, stratagem, or artifice of evasion.”⁴⁵ Interpreting the ADEA, the Supreme Court has rejected both the legislative history and EEOC guidance suggesting a different meaning of subterfuge and has instead adhered to a “dictionary” interpretation of a specific intent to evade the non-discrimination requirements of the statute.⁴⁶ Courts have rejected similar reliance on legislative history and EEOC guidance for an interpretation of the ADA and have required plaintiffs asserting subterfuge to demonstrate more than mere absence of actuarial equity and instead to demonstrate a conscious plan to discriminate.⁴⁷

Under the now-prevailing view of the law, therefore, an individual seeking to employ the ADA to remedy an instance of alleged genetic discrimination in health coverage would face two barriers. If she has suffered discrimination on the basis of unexpressed genetic traits, an ADA claim would likely fail for lack of standing—an unexpressed genetic trait is unlikely to be considered disabling. Should an individual cross that barrier by, for example, establishing that the unexpressed genetic trait substantially interferes with her reproductive

40. EEOC, Interim Enforcement Guidance on Application of ADA to Disability Based Distinctions in Employer Provided Health Insurance, N-915.002, § III(C)(2) (June 8, 1993). The EEOC Compliance manual has been amended and this section now appears in EEOC Compliance Manual, No. 915.003, § (IV)(B) (2000), available at <http://www.eeoc.gov/docs/benefits.html> (on file with author).

41. EEOC Compliance Manual, No. 915.003, § III(C)(2)(a),(b) (2000), available at <http://www.eeoc.gov/docs/benefits.html> (on file with author).

42. See, e.g., *Doukas v. Metro. Life Ins. Co.*, 950 F. Supp. 422, 432 (D.N.H. 1996).

43. See, e.g., *Palozzi v. Allstate Life Ins. Co.*, 204 F.3d 392 (2d Cir. 2000); *Leonard F. v. Isr. Disc. Bank of N.Y.*, 199 F.3d 99, 104-05 (2d Cir. 1999); *Ford v. Schering-Plough Corp.*, 145 F.3d 601, 611-12 (3d Cir. 1998); *EEOC v. Deloitte & Touche, LLP*, 2000 WL 1024700 (S.D.N.Y. July 25, 2000).

44. 29 U.S.C. §§ 621-634 (2000).

45. *Leonard F.*, 199 F.3d at 105 (quoting *United Air Lines, Inc., v. McMann*, 434 U.S. 192, 203 (1977)).

46. *Pub. Employee Ret. Sys. of Ohio v. Betts*, 492 U.S. 158, 170-72 (1989); see *McMann*, 434 U.S. at 203.

47. *Leonard F.*, 199 F.3d at 104-06.

activities,⁴⁸ she would be faced with the burden of establishing that the coverage decision is not protected by the insurance safe harbor. Most critically, she would have to demonstrate that the coverage was guided not “merely” by business judgment, but rather was motivated by discriminatory animus and a desire to harm the individual because of her genetic condition.⁴⁹

2. HIPAA's Specific but Limited Protections

The general disability discrimination provisions of the ADA do not, then, reach genetic discrimination. Bills establishing general genetic discrimination prohibitions have been proposed,⁵⁰ but none has been adopted to date. Congress did address an aspect of genetic discrimination in health coverage as part of the Health Insurance Portability and Accountability Act (“HIPAA”).⁵¹ HIPAA protects the “portability” of health coverage by requiring, *inter alia*, that group health plans limit periods of exclusion from coverage for preexisting conditions, thereby permitting workers to change jobs without risking loss of coverage for ongoing conditions.⁵² HIPAA bars group plans from considering unexpressed genetic conditions as “preexisting conditions” for purposes of coverage limitation,⁵³ and bars plans from considering genetic information in making membership eligibility de-

48. See *Bragdon v. Abbott*, 524 U.S. 624, 641-42 (1998). *But see* *Toyota Motor Mfg. v. Williams*, 534 U.S. 184, 195 (2002).

49. See *Betts*, 492 U.S. at 168-75 (describing the difference between the (rejected) business justification rule under the ADEA and the subjective animus rule affirmed by the Court).

50. Genetic Information Nondiscrimination Act of 2002, S. 1995, 107th Cong. (2002) (prohibiting health insurers from using genetic information to impose enrollment restrictions or adjust group premiums, making it unlawful for an employer to discriminate based on genetic information, and requiring genetic information to be treated as part of a confidential medical record); Genetic Nondiscrimination in Health Insurance and Employment Act of 2001, H.R. 602, 107th Cong. (2001) (making it unlawful to discriminate because of genetic information in employment and prohibiting health plans from discriminating in enrollment, eligibility contribution rates, or premiums based on genetic information); Genetic Nondiscrimination in Health Insurance and Employment Act of 2001, S. 318, 107th Cong. (2001) (making it unlawful for an employer to discriminate because of protected genetic information; an employer can request, require, collect, or purchase information if used for monitoring of biologic effects of workplace toxic substances; also, a group health plan or a health insurance issuer cannot discriminate in enrollment in health insurance based on genetic information).

51. Pub. L. No. 104-191, 110 Stat. 1955 (1996) (codified at 29 U.S.C. §§ 1181-1182 and 42 U.S.C. §§ 300gg to 300gg-41); *see generally* Coleen E. Medill, *HIPAA and its Related Legislation: A New Role for ERISA in the Regulation of Private Health Care Plans*, 65 TENN. L. REV. 485 (1998).

52. Pub. L. No. 104-191, 110 Stat. 1955 (1996) (codified at 42 U.S.C. § 300gg(a) (2000)); *see* Diver & Cohen, *supra* note 4, at 1449-50; Rothstein & Hoffman, *supra* note 5, at 869.

53. Pub. L. No. 104-191, 110 Stat. 1955 (1996) (codified at 42 U.S.C. § 300gg(b)(1)(B) (2000)).

terminations.⁵⁴

This protection, unlike that of the ADA, clearly applies to genetic conditions and has some concrete, if limited, value in preventing genetic discrimination. For group coverage, it limits the use of genetic information by imposing periods of exclusion from coverage and determining group eligibility. It provides for “continuation coverage” and guaranteed renewal from sellers of individual coverage for individuals with a sufficiently long history of continuous coverage, and prohibits insurers from citing genetic conditions to avoid those requirements.⁵⁵ Plans are free, however, to decline to cover particular treatments or to impose “limitations or restrictions on the amount, level, extent, or nature of the benefits or coverage” as they see fit.⁵⁶ In addition, the term “genetic information” is not a defined term, and the extent of the protection offered from genetic discrimination is therefore uncertain.

B. State Laws: Evolution and Limits

Federal law provides only very limited protection from genetic discrimination in health coverage. The ADA is likely to be totally ineffective in this area, and HIPAA provides only limited benefits. State genetic discrimination legislation has expanded into this near-vacuum. Insurance has long been regulated in the first instance by the states, a tradition formalized with the 1948 passage of the McCarran-Ferguson Act.⁵⁷ State law regulating health insurance has shifted over time, moving from limited regulation to protect free markets for health insurance to more intrusive regulation imposing restrictions on insurance practices for the purpose of advancing social goals.

Selecting among and accurately quantifying risk is a core task for insurance companies. Firms seek to assess risk more precisely than their competitors and (where prices may easily be varied) match the premium closely to the expected cost of coverage or (where prices are less easily varied) choose to offer coverage to better risks and to de-

54. Pub. L. No. 104-191, 110 Stat. 1955 (1996) (codified at 42 U.S.C. § 300gg-1(a)(1)(F) (2000)).

55. Pub. L. No. 104-191, 110 Stat. 1955 (1996) (codified at 42 U.S.C. §§ 300gg-41, 300gg-42 (2000)).

56. Pub. L. No. 104-191, 110 Stat. 1955 (1996) (codified at 42 U.S.C. § 300g-1(a)(2)(B) (2000)).

57. 15 U.S.C. §§ 1011-1015 (2000). Under the McCarran-Ferguson Act, “The business of insurance, and every person engaged therein, shall be subject to the laws of the several States which relate to the regulation or taxation of such business.” *Id.* § 1012(a). Further, “[n]o Act of Congress shall be construed to . . . supersede any law enacted by any State for the purpose of regulating the business of insurance . . . unless such Act specifically relates to the business of insurance.” *Id.* § 1012(b).

cline coverage to poorer risks.⁵⁸ State regulation of insurance historically concerned itself with monitoring the solvency of insurance companies and protecting insureds from outright fraud and misrepresentation. To the extent state regulators concerned themselves with the mechanics of underwriting, they were concerned primarily with an abuse quite different from genetic discrimination. Regulators were concerned with favoritism shown to sophisticated purchasers, by which favored customers paid less than the expected cost of coverage while unsophisticated customers made up for the difference by paying above their actuarially “true” premium.

To combat this perceived flaw in the insurance market, states adopted unfair trade practices acts; these acts came to be interpreted as *requiring* insurers to segment insured populations by their level of actuarial risk in order to prevent the forced (or at least unknowing) subsidization of one group of insureds by another and instead to mandate “fair discrimination.”⁵⁹ The principle that rating differentials must be actuarially justified spawned the first state prohibitions of genetic discrimination. These laws barred insurers from considering recessive genetic traits such as that for sickle cell anemia or Tay-Sachs when making rating or underwriting decisions.⁶⁰ These statutes merely enforced the general rule requiring actuarial justification, as the presence of the trait in and of itself bears no relationship with an individual’s health risk.⁶¹

The next phase of state genetic discrimination legislation swept more broadly and varied from the actuarial validity principle. In the 1990s, states began to adopt genetic discrimination statutes that barred insurers from considering genetic information that bore some relationship to the subject’s future health. These newer statutes barred insurers from taking into account genetic evidence that an individual might be more likely to experience an illness than a person without the genetic trait. These statutes barred the use of specifically identified genetic tests or the information gained from others’ use of

58. See KENNETH ABRAHAM, *DISTRIBUTING RISK* 67-68 (1986); SYLVIA A. LAW, *BLUE CROSS: WHAT WENT WRONG?* 75-77 (2d ed. 1976).

59. Jacobi, *supra* note 21, at 321-22; Leah Wortham, *Insurance Classification: Too Important to be Left to the Actuaries*, 19 U. MICH. J.L. REFORM 349, 381-86 (1986). States occasionally created exceptions to this “fair discrimination” requirement. For example, race is an actuarially valid factor in predicting life expectancy, but its use in pricing life insurance is nevertheless widely prohibited by state law. ABRAHAM, *supra* note 58, at 76.

60. See Jacobi, *supra* note 21, at 331.

61. See, e.g., MD. CODE ANN., INS. § 27-208 (West 2001) (barring insurance decisions based on “sickle-cell trait, thalassemia-minor trait, hemoglobin C trait, Tay-Sachs trait, or genetic trait *that is harmless in itself*”) (emphasis added). It is conceivable that there would be an actuarial justification for the use of such information in connection with health insurance that included dependent coverage, as the health of offspring could be affected. See Greely, *supra* note 4, at 1489.

these tests by insurers.⁶² These statutes part ways with the earlier model based on unfair trade practices acts: they bar the use of genetic information even if it is clearly relevant to assessing risk.

These new statutes demonstrate a legislative determination to shift the meaning of non-discrimination from a principle requiring equal treatment *absent* an actuarial showing of difference to one requiring equal treatment *notwithstanding* actuarial difference.⁶³ More recent statutes adhere to the principle that it is inappropriate to charge individuals with the actuarial cost of their inherited traits and extend the protection even further. The protection is extended by barring the use of genetic information whatever its source. The prohibition, then, extends beyond the use of laboratory test results, and encompasses information on “genetic characteristics” from any source and of any type.⁶⁴ The evolution of these state statutes demonstrates an uneven and incomplete but discernable progression from state policy protecting individuals from irrational discrimination in insurance practices to one protecting individuals from the rational but disfavored practice of actuaries’ taking into account genetic information in setting the availability, terms and conditions of coverage.

III. EQUALIZING COVERAGE: SHORT TERM CONCERNS

Genetic discrimination laws effect a social judgment that an individual’s access to health coverage should not depend on the results of a genetic lottery. Legislators employ “addition by subtraction” to accomplish this goal. They subtract the factor of genetic condition from those permissibly considered in insurance decisions in order to add coverage to people who may otherwise be excluded. Long-term concerns with this equalitarian strategy are examined in Part IV. However, in this Part, more immediate concerns are examined: Assuming the wisdom of and continuing political viability of the genetic anti-discrimination movement, what implementation concerns must be addressed?

The first such concern is for drafting clarity. In many instances, genetic discrimination legislation fails to serve its apparently-intended goals due to correctable incompleteness of the protections offered. The second concern is less readily remedied. The enforcement of genetic discrimination prohibitions is premised on a trans-

62. See, e.g., COLO. REV. STAT. ANN. § 10-3-1104.7 (2002) (prohibiting the use of genetic test results for health insurance underwriting or rating purposes); MINN. STAT. § 72A.139 (2001).

63. See *Health Ins. Ass’n of Am. v. Corcoran*, 551 N.Y.S.2d 615, 618 (N.Y. App. Div. 1990), *aff’d mem.*, 565 N.E.2d 1264 (N.Y. 1990); see also *Jacobi*, *supra* note 21, at 331-32.

64. See CAL. INS. CODE § 10123.3 (West 2002); HAW. REV. STAT. § 431:10A-118 (2001); NEB. REV. STAT. § 44-7, 100 (2001); N.J. STAT. ANN. § 17B:30-12(e) (West 2002).

parency of methods that no longer characterizes the relevant aspects of the insurance business. The prohibition of *overt* discrimination is no longer sufficient (if it ever was). The managed care transformation of insurance practices forces attention to less visible practices controlled not by simple directives and commands, but by subtle nudges and incentives. Strategies for addressing both concerns are described in this Part.

A. Ambiguities in the Law: Speaking Clearly

Laws prohibiting genetic discrimination in health care are both largely untested and widely varied. They are largely untested for several reasons. First, few diseases have been identified definitively with particular genetic conditions. Diseases believed to be associated with genetic traits have not, as of yet, been connected by researchers to specific traits.⁶⁵ Many diseases that have been linked to genetic components are related to more than one genetic anomaly, as well as environmental factors.⁶⁶ The complex relationship between genetic information and disease confounds attempts to predict future illness solely, or primarily, on the basis of genetic information.⁶⁷ The uncertainty of the value of genetic information under such circumstances renders it insufficiently valuable in the risk assessment process to justify an insurer's brooking the possible political and public disapproval associated with genetic underwriting.⁶⁸ It is likely, however, that advances in genetics will produce information sufficiently predictive of future illness to render genetic underwriting economically plausible.⁶⁹

When insurers find genetic information economically interesting, the differences among the state statutes will begin to matter. As is described more fully above, statutes prohibiting or regulating the use of genetic information by insurers fall into three general categories: those barring the use of genetic information irrelevant to the assessment of risk; those barring the use of information derived from specifically identified laboratory tests; and those barring the use of broadly defined "genetic information."⁷⁰ The first species of discrimination is irrational, and the enforcement of insurance practices should be grist for the mill for state insurance departments. The second and third, however, forbid rational insurer activity by imposing

65. See Greely, *supra* note 4, at 1493.

66. *Id.* at 1484-86; Rothstein & Hoffman, *supra* note 5, at 855-56.

67. Diver & Cohen, *supra* note 4, at 1454-55.

68. See ABRAHAM, *supra* note 58, at 67-68.

69. See Gostin & Hodge, *supra* note 3, at 26-27; Rothstein & Hoffman, *supra* note 5, at 855-57; John R.W. Yates, *Medical Genetics*, 312 BRIT. MED. J. 1021, 1021-24 (1996) (recognizing advances in the use of genetic information in predicting illness).

70. See *supra* Part II.B.

rules forbidding the use of information relevant to the assessment of risk.

Assuming advancements in science are sufficient to make the game worth the candle, insurers will have an interest in probing the statutes' ambiguities.⁷¹ The lesson of the ADA suggests that ambiguous language will be interpreted to narrow, not broaden, the statutory protections. As the ADA has been interpreted under the shadow of resistance to the cost of accommodation, so would genetic discrimination statutes be interpreted under the shadow of the rising cost of health coverage. Ambiguous language in the ADA regarding the disability status of people suffering disparate treatment for disabling conditions subject to correction has been interpreted to sharply narrow the ADA's reach, notwithstanding substantial legislative history and EEOC interpretative guidance to the contrary.⁷² Similarly, ambiguous language in the ADA regarding insurance underwriting practices affecting people with disabilities has been read to support pre-ADA risk segmentation practices, notwithstanding substantial legislative history and EEOC interpretative guidance to the contrary.⁷³ In both cases, the language of the statute contained genuine ambiguity. In both cases the interpretation favoring a narrow construction, less costly to those required to comply with the statute, was favored.

The second wave of genetic discrimination statutes tends to contain few serious ambiguities, but the statutes' very specificity sharply limits their reach. They tend to prohibit only the use of specifically described laboratory tests for genetic traits.⁷⁴ Laboratory tests not specifically prohibited by the statutes may therefore be permissible, as would any method of determining genetic traits not reliant on laboratory tests—for example, inquiring into family history of illness.⁷⁵ The third wave of statutes corrects this flaw (if it is a flaw) by more broadly prohibiting the use of "genetic characteristics" (however discovered) in underwriting or pricing health insurance.⁷⁶

71. Self-interested insurers will begin to use genetic information when the tests are cost effective, scientifically accurate, predictively powerful, and lawful. See T.H. Cushing, *Should There Be Genetic Testing in Insurance Risk Classification?*, 60 DEF. COUNS. J. 249, 252 (1993); Jacobi, *supra* note 21, at 327-31.

72. See *supra* text accompanying notes 35-38 (discussing *Sutton v. United Air Lines*, 527 U.S. 471 (1999)).

73. See *supra* text accompanying notes 45-48 (discussing the trend toward reading the ADA's "safe harbor" provision as permitting traditional actuarial methods).

74. Geetter, *supra* note 3, at 52; William F. Mulholland II & Ami S. Jaeger, *Comment: Genetic Privacy and Discrimination: A Survey of State Legislation*, 39 JURIMETRICS J. 317, 320 (1999).

75. See Geetter, *supra* note 3, at 52; Greely, *supra* note 4, at 1495-96; Suter, *supra* note 4, at 702.

76. See CAL. INS. CODE § 10140(b) (West 2002); HAW. REV. STAT. ANN. § 431:10A-118(b) (Michie 2002); NEB. REV. STAT. ANN. § 44:749 (2002); N.J. STAT. ANN. § 10:5-5

These broader statutes avoid the over-specificity concerns of those of the second wave, but they will raise new interpretation concerns as courts attempt to determine what information is “genetic” and therefore excluded from insurers’ use.⁷⁷

As genetic testing becomes an issue more practical than academic, the questions asked about genetic testing legislation will become more pointed. The lessons to be drawn from the ADA’s fate suggest that statutory ambiguity is the enemy of consumer protection. Legislatures, therefore, would be wise to consider how well their current law matches the goals they set for it. The reasons for passage of legislation barring or regulating the use of genetic information for health coverage purposes can be reduced to two. First, limitations on the use of genetic information may encourage people who would benefit from genetic testing to avail themselves of that technology. Absent such protection, they may be concerned that the results of genetic testing could impair their ability to obtain or retain health coverage. At sufficient levels, such concern could interfere with the scientific and therapeutic benefits of genetic testing.⁷⁸

The second reason for passage of genetic discrimination legislation is the belief that such legislation makes health coverage more readily available. Having health coverage is a very good predictor of access to health care;⁷⁹ access to health care is a primary good, one that all rational people find desirable;⁸⁰ and the natural lottery of genetic endowment is an inappropriate basis on which to allocate such an important good.⁸¹ Genetic discrimination legislation serves this goal by taking genetic information out of the allocative formula.

(West 2001); N.M. STAT. ANN. § 24-21-4 (Michie 2002); VA. CODE ANN. §§ 38.2-508.4 (Michie 2001); see also Mulholland & Jaeger, *supra* note 74, at 320; Suter, *supra* note 4, at 702-03.

Pending federal legislation appears to fit into the broader version of genetic discrimination statutes, although none has yet passed. See S. 318, 107th Cong. (2001); H.R. 602, 107th Cong. (2001).

77. See Suter, *supra* note 4, at 702-04.

78. *Id.* at 707-08.

79. The Institute of Medicine’s Committee on the Consequences of Uninsurance recently released its findings. It concluded: “In summary, uninsured adults receive health care services that are less adequate and appropriate than those received by patients who have either public or private health insurance, and they have poorer clinical outcomes and poorer overall health than do adults with private health insurance.” INST. OF MED., COMM. ON THE CONSEQUENCES OF UNINSURANCE, CARE WITHOUT COVERAGE: TOO LITTLE, TOO LATE 87 (2002); see also Diane Rowland et al., *Uninsured in America: The Causes and Consequences*, in THE FUTURE OF THE U.S. HEALTHCARE SYSTEM: WHO WILL CARE FOR THE POOR AND UNINSURED? 25, 38 (Stuart H. Altman et al. eds., 1998) (“The research on differences in care patterns for uninsured versus insured individuals increasingly reveals that the uninsured are more likely to incur adverse health outcomes.”).

80. See Geetter, *supra* note 3, at 65-66; Suter, *supra* note 4, at 706-07.

81. See Geetter, *supra* note 3, at 65-66; Suter, *supra* note 4, at 706-07.

Legislation serving the first goal is directed at the use of genetic information derived from genetic “tests,” for the evil to be avoided is not the differential treatment of people based on their genetic heritage, but use of information derived from laboratory tests—tests otherwise useful for scientific or therapeutic purposes. Some genetic discrimination laws directed to this goal suffer from excessive specificity, limiting coverage to specifically enumerated tests.⁸² Technology is advancing, and a wide variety of tests are used to ascertain different genetic conditions.⁸³ Statutes intended to provide comfort that testing undertaken for research or therapeutic purposes cannot be used for insurance purposes must more broadly catalogue currently available technology and anticipate future developments. One means of doing so is to define the tests functionally, so as to capture laboratory tests analyzing human genetic material and proteins for the purpose of identifying inherited or genetic characteristics.⁸⁴

As is described above, however, many recent genetic discrimination statutes are focused on the broader goal of preventing insurers from differentially treating individuals in underwriting and coverage decisions.⁸⁵ States seek through these laws to interfere in the insurance marketplace to limit the use of relevant risk-predicting information related to genetic makeup. Unlike laws focused on laboratory tests, these more recent laws are premised on the notion that it is fundamentally unfair to differentially treat individuals for coverage purposes on the basis of immutable characteristics.⁸⁶ It is natural, then, that these laws would bar insurers from considering genetic information beyond that revealed by laboratory tests, and extending to family history and health history.⁸⁷

These statutes raise a set of interpretive concerns which are different from those raised by statutes limited to the results of laboratory tests. Fundamentally, laws banning consideration of information on genetic factors derived from any source are in substantial tension with general principles of risk assessment that continue to animate

82. See, e.g., CAL. INS. CODE § 10147(e) (West 2002); MD. CODE ANN. INS. § 27-909(a)(5) (2002); MINN. STAT. ANN. § 72A.139.2(b) (West 2002); see also Greely, *supra* note 4, at 1494-96.

83. See THE N.Y. TASK FORCE ON LIFE AND THE LAW, GENETIC TESTING AND SCREENING IN THE AGE OF GENOMIC MEDICINE 31-40 (2000); Greely, *supra* note 4, at 1494-96.

84. See Greely, *supra* note 4, at 1495 (describing MICH. COMP. LAWS ANN. § 550.1401 (West 2000), as an example of a law broadly defining genetic testing).

85. See Gostin & Hodge, *supra* note 3, at 51-52; Greely, *supra* note 4, at 1494-95.

86. See Geetter, *supra* note 3, at 65; Suter, *supra* note 4, at 706-07.

87. S.C. CODE ANN. § 38-93-10(2) (Law. Co-op. 2001). (defining genetic information as “information about genes, gene products, or genetic characteristics derived from an individual or a family member of the individual”); see also N.J. STAT. ANN. § 10:5-5(oo) (West 2002) (defining genetic information as “information about genes, gene products or inherited characteristics that may derive from an individual or family member”).

the business of health insurance.⁸⁸ But short of that substantial concern, these statutes raise definitional issues that can be resolved with careful drafting.⁸⁹ Here, too, prudence suggests that legislatures consider precisely what circumstances beyond the results of laboratory tests are beyond the scope of consideration by insurers. One can infer at least probabilistic information about an individual's genetic makeup from many sources, including the results of genetic tests of the individual's relatives, the health history of the individual's relatives, results of the individual's own genetic tests, and the individual's own health history. Legislators can control the interpretation of genetic discrimination statutes if they clearly define what conditions may and may not be considered in the underwriting and coverage process.

B. Avoiding the Effect of Clear Laws: Covert Discrimination

The preceding Section cautions that the fate of the ADA suggests that vague consumer protection statutes will be eviscerated by courts. It further points out aspects of current genetic discrimination law that contain ambiguity, and suggests clarification. This Section assumes, first, that a jurisdiction has adopted genetic discrimination legislation⁹⁰ of the third, or broadest, type as described in Part III.A. This type bars insurers from considering genetic information from any source in underwriting or coverage decisions.⁹¹ Second, it assumes that the legislation has been drafted to avoid the textual ambiguities discussed above.⁹² Clarity in legislative drafting, while important, is insufficient to implement public policy; the laws must be enforced.

Some enforcement is easy. Overt violations of core provisions of genetic discrimination laws can be detected and corrected by regulators. For example, regulators can combat the solicitation of prohibited information in insurance applications and contracts by requiring firms to file those forms for review prior to use.⁹³ Similarly, regulators can respond when informed that an insurer, using prohibited genetic criteria, is refusing to approve a treatment otherwise within the range of covered services. Much more troubling and difficult to regulate is covert cheating in either underwriting or coverage decisions. History suggests that such covert cheating will occur in con-

88. See *infra* Part IV.A.

89. See Greely, *supra* note 4, at 1496-97.

90. For purposes of the discussion in this section, the legislation could be state or federal. The importance of the distinction between state and federal enactment of genetic discrimination legislation is addressed below in Part IV.A.

91. See *supra* text accompanying notes 64-65.

92. See *infra* Part III.A.

93. See CAL. INS. CODE § 882 (West 2001); N.J. STAT. ANN. § 26:2J-4 (West 2001).

nection with genetic discrimination laws, and that it will be difficult to control.

Insurers, interested in maintaining a competitive edge in risk assessment,⁹⁴ will have an interest in cheating at the enrollment stage to the extent they believe that the prohibited genetic information is relevant to the underwriting process. History suggests that some insurers subject to laws limiting their ability to use relevant risk data will seek to avoid the effects of the laws to avoid enrolling high-risk members. Both Medicare and Medicaid permit program beneficiaries to enroll in private managed care plans under some circumstances.⁹⁵ Both programs bar participating managed care plans from considering the health, experience, or other risk factors when enrolling program beneficiaries in their plans.⁹⁶ There is some evidence that Medicare HMOs, and better evidence that Medicaid HMOs, have screened applicants surreptitiously to favor low-risk beneficiaries.⁹⁷

Enforcement of laws prohibiting insurers from considering risk information faces difficulties as it attempts to cabin activity which is quite fundamental to the history and economics of the business of insurance. Two paths may be taken. In the first, civil and criminal sanctions are levied against insurers who are discovered to have violated the laws, with the aim of specifically and generally deterring similar conduct in the future.⁹⁸ The second path seeks methods to serve the goal of access for high-risk individuals while accommodating the income maximization impulses of the insurers. One such method would bar differential treatment of applicants on the basis of risk factors, but would recognize insurers' higher costs. This recognition may come through adjusting premiums on the basis of risk. This is an appropriate strategy in a program such as Medicare, with a single payer.⁹⁹ In the alternative, in a program in which community rating or other risk-leveling methods have been applied to markets with multiple purchasers, a reinsurance method may be adopted to compensate insurers with aggregate risk experience over a set

94. See *supra* text accompanying notes 59-60.

95. See 42 U.S.C. § 1395w-21 (2000) (specifying enrollment requirements for Medicare); *id.* § 1396u-2 (specifying enrollment requirements for Medicaid).

96. See *id.* § 1395w-21(g) (specifying Medicare requirements); *id.* § 1396b(m)(2)(A)(v) (specifying Medicaid requirements).

97. See RICHARD KRONICK & JOY DE BEYER, *MEDICARE HMOs: MAKING THEM WORK FOR THE CHRONICALLY ILL* 10-11 (1999) (describing mixed evidence on whether Medicare HMOs engaged in improper risk-selection activity); Sharon L. Davies & Timothy Stoltzfus Jost, *Managed Care: Placebo or Wonder Drug for Health Care Fraud and Abuse?*, 31 GA. L. REV. 373, 387-88 (1997) (discussing Medicaid HMOs engaged in improper risk-selection activity).

98. See Davies & Jost, *supra* note 97, at 387-88, 394-404.

99. See Joseph P. Newhouse et al., *Risk Adjustment And Medicare: Taking A Closer Look*, HEALTH AFF., Sept.-Oct. 1997, at 26.

threshold.¹⁰⁰ This latter method “suppresses the incentive to engage in risk selection in various indirect and surreptitious ways” by assuring some substantial recognition of the income loss otherwise resulting from the loss of risk assessment methods.¹⁰¹

Disparate treatment in plan enrollment is only half of the problem addressed in genetic discrimination legislation. The other major problem is discrimination in coverage—disparate treatment in deciding which treatments will receive funding. Coverage discrimination occurs when insurers fail to approve funding for treatments that rely on genetic technology to treat genetic conditions¹⁰² or fail to approve conventional treatments for genetic conditions in circumstances in which treatment would otherwise be covered.¹⁰³ Coverage discrimination occurs, and can be expected to occur in genetic circumstances for two reasons. First and most obviously, cost pressures and the resulting cost containment methods pioneered by managed care organizations increase the chances that care formally included in the contractual terms of the insurance plan will be improperly denied.¹⁰⁴

Insurers may also engage in coverage discrimination as an alternative method of engaging in underwriting discrimination. Suppose a firm wishes to exclude individuals with presumably expensive genetic conditions from its plan. Suppose further that the discrimination law clearly stated that genetic conditions could not be considered in the application or underwriting process and that the clear provisions of the law were efficiently enforced. The firm may be unable—without being caught—to prevent the individual from enrolling in the insurance plan. Under such circumstances, an insurer may choose to achieve indirectly what is denied directly by providing services to the reluctantly-enrolled member in a way that discourages the member from remaining a plan member.

100. See Mark A. Hall, *The Competitive Impact of Small Group Health Insurance Reform Laws*, 32 U. MICH. J.L. REFORM 685, 694 (1999).

101. *Id.*

102. See W. French Anderson, *Gene Therapy: The Best of Times, the Worst of Times*, 288 SCIENCE 627 (2000); James M. Wilson, *Human Gene Therapy: Present and Future*, 10 HUM. GENOME NEWS 1, 1-2 (1999).

103. OHIO REV. CODE ANN. § 1751.64(B) (West 2001):

No health insuring corporation . . . shall do any of the following:

(2) Take into consideration the results of genetic testing . . .

(4) Make a decision adverse to the applicant based on entries in medical record, or other reports of genetic screening or testing . . .

(D) No health insuring corporation shall cancel or refuse to issue or renew coverage for health care services based on the results of genetic screening or testing.

New Mexico law states that “discrimination by an insurer against a person or member of the person’s family on the basis of genetic analysis, genetic information or genetic propensity is prohibited.” N.M. STAT. ANN. § 24-21-4(A) (Michie 2001).

104. See *infra* Part IV.B.

There are several subtle ways for plans to discourage a member of a disfavored class of individuals with potentially expensive genetic conditions. They can strive for excellence in services of little interest to the disfavored class, while settling for mediocrity in areas of particular interest to that class. They can add extra services of interest to the unaffected population and hew to the basics in areas of interest to the more expensive group. They can move more slowly and less efficiently with approvals and pre-certifications for disfavored services, and target medical necessity utilization review to services of particular interest to people with genetic conditions.¹⁰⁵

Clearly these actions would violate genetic discrimination laws if intentionally undertaken to drive away people with genetic conditions—and perhaps even if such disparate treatment were not crafted for such a purpose. Further, they may be unwise from even a coldly-calculating business proposition in light of the spillover effects bad services to one class of insureds may have on the firm's reputation with preferred classes of customers.¹⁰⁶ But this harmful behavior may be economic in some circumstances and used as a method to drive away people who are perceived as bad risks.¹⁰⁷ The potential for such behavior is taken sufficiently seriously to generate proposals to counter its effect.

Covert forms of discrimination are, of course, more difficult than overt forms to detect and remedy. In health insurance, there are at least two senses in which discrimination could be said to be covert. Covert discrimination could arise when an insurer decides to discriminate and, in order to avoid detection, hides the decision and disguises the result. The more common sense form of covert discrimination could arise in the health insurance arena through the natural action of a structure designed to limit utilization and subject that structure to a patchwork of only partially successful controls. The structure of modern health insurance is based on managed care. It is well understood that managed care plans control costs in part by cre-

105. See KRONICK & DE BEYER, *supra* note 97, at 14-17 (discussing subtle methods by which managed care organizations might disfavor people with chronic illnesses in delivering services); Jacobi, *supra* note 21, at 395-96; Newhouse et al., *supra* note 99, at 27-28.

106. See KRONICK & DE BEYER, *supra* note 97, at 211.

107. The stakes for risk selection are high. The most expensive ten percent of the population accounts for about seventy percent of health care expenditures in any year. A plan that avoids these high-risk individuals—or at least one that avoids more of them than its competitors—experiences a substantial economic advantage. See Lynn Etheredge et al., *What is Driving Health Systems Change?*, HEALTH AFF., Dec. 1996, at 93, 96; see also Richard Kronick et al., *Diagnostic Risk Adjustment for Medicaid: The Disability Payment System*, HEALTH CARE FINANCING REV., Spring 1996, at 7-9 (explaining that a Medicaid HMO enrolling members from the least expensive fifth of program participants would earn substantial profits, while an HMO enrolling members from the most expensive fifth of the program would suffer substantial losses).

ating incentives for health care providers to reduce utilization.¹⁰⁸

There is extensive literature on patient protection in managed care, and it will not be canvassed here.¹⁰⁹ Suffice it to say that protecting individuals from genetic discrimination in the form of covert, improper coverage denials can be seen as within the broader enterprise of protecting individuals from covert denials of coverage by managed care organizations in general. Formal governmental enforcement has an important role in this enterprise, as regulators review insurance plans for compliance with structural regulations calculated to minimize the opportunity and incentive to stint on care.¹¹⁰ One important form of such regulatory oversight is the close review of the contracts governing the relationship between insurers and consumers. This traditional form of regulation takes on added significance as cost-containment pressures drive insurers to aggressively control utilization.¹¹¹ It is inescapable, however, that, in a health insurance system driven by market and not regulatory theory, consumer-driven checks against inappropriate denials of coverage are a more significant check.¹¹²

One consumer-driven corrective to stinting is formal or informal litigation. Consumers suffering improper denial of coverage can sue in the traditional sense, either under state contract law¹¹³ or section 502 of the Employee Retirement Income Security Act ("ERISA").¹¹⁴ Much less formally, plan members can invoke internal grievance procedures to resolve coverage disagreements.¹¹⁵ An intermediate form of dispute resolution permits a plan member to appeal a denial of coverage to independent, outside reviewers. This independent review usually submits disputes to professionals unconnected to the plan

108. See John V. Jacobi, *Patients at a Loss: Protecting Health Care Consumers Through Data Driven Quality Assurance*, 45 KANS. L. REV. 705, 710-17 (1997); Louise G. Trubek, *Informing, Claiming, Contracting: Enforcement in the Managed Care Era*, 8 ANNALS HEALTH L. 133, 133-34 (1999).

109. See generally John Blum, *Overcoming Managed Care Regulatory Chaos Through a Restructured Federalism*, 11 HEALTH MATRIX 327 (2001); Barry R. Furrow, *Regulating the Managed Care Revolution: Private Accreditation and a New System Ethos*, 43 VILL. L. REV. 361 (1998); David A. Hyman, *Regulating Managed Care: What's Wrong With a Patient Bill of Rights*, 73 S. CAL. L. REV. 221 (2000); Russell Korobkin, *Determining Health Care Rights From Behind a Veil of Ignorance*, 1998 U. ILL. L. REV. 801.

110. John V. Jacobi, *Canaries in the Coal Mine: The Chronically Ill in Managed Care*, 9 HEALTH MATRIX 79, 115-16 (1999).

111. See Trubek, *supra* note 108, at 141-43.

112. See *id.* at 138-41.

113. State law remedies are unavailable to the vast majority of those with private insurance as a result of ERISA preemption. See *infra* Part IV.A.

114. ERISA provides a private cause of action for members of employment-based plans to challenge a denial of promised coverage. 29 U.S.C. § 1132 (2000). See Kathryn J. Kennedy, *Judicial Standard of Review in ERISA Benefit Claim Cases*, 50 AM. U. L. REV. 1083, 1091-94 (2001).

115. See Trubek, *supra* note 108, at 138-39.

and certified by state insurance officials.¹¹⁶ This mechanism is sure to gain additional significance as a result of the Supreme Court's recent finding that state laws mandating plans to cooperate in independent utilization review are not preempted by ERISA.¹¹⁷ One shortcoming of these adversarial mechanisms is that they require a "trigger event." That is, patients are likely to invoke them when they have been denied coverage of a discrete treatment but are unlikely to invoke them when they have suffered the more diffuse harm of coverage for a lesser quality of care.¹¹⁸ Another shortcoming is that patients are unable to invoke them if they are unaware that they have been denied coverage. They are more likely to be unaware of such denials as insurers shift utilization decisions to physicians and as physicians therefore become less likely to notify patients of costly alternatives.¹¹⁹

Other consumer protection devices must be available to consumers to counter insurers' stinting tendencies. A cluster of such devices accept market discipline as an alternative to direct government oversight and seek to supplement the tools available to consumers in their efforts to navigate health insurance markets. In market systems, quality is controlled by the cumulative conduct of individual purchasers, who reward producers willing to provide desired services at a reasonable price. Such market-driven quality assurance mechanisms are effective only to the extent that consumers have sufficient information to judge the quality of services offered by market participants.¹²⁰ Some regulatory tools seek to take advantage of the natural tendency of markets to reward quality by empowering consumers. This form of regulation is directed at improving the balance of information access between plans and consumers in order to enhance the ability of consumers to evaluate the quality of plans. The goal of such regulations is to reduce information deficits so that consumers can reward with patronage the plans that deliver what all plans promise: high-quality care.¹²¹

The publication of evaluative data on health plans serves the goal of leveling the playing field between consumers and plans. Public entities and private organizations such as the National Committee for Quality Assurance gather, analyze, organize, and publish data describing the structure and performance of plans.¹²²

116. *See id.*

117. *Rush Prudential HMO, Inc., v. Moran*, 536 U.S. 355, 340 (2002).

118. *Jacobi*, *supra* note 108, at 757-59.

119. *Id.* at 759-62.

120. *Id.* at 766.

121. *See Jacobi*, *supra* note 108, at 762-64; *Trubek*, *supra* note 108, at 136-38.

122. *Jacobi*, *supra* note 108, at 770-73; *Trubek*, *supra* note 108, at 136-38.

In the context of genetic discrimination, such evaluative systems can serve two goals. First, they can facilitate determination of which plans are engaged in stinting activity by evaluating consumer surveys, structural measures, and health outcomes for particular forms of treatment.¹²³ Consumers concerned about the manifestations of genetic discrimination can thereby obtain a window into the behavior of various plans and choose accordingly. Second, they permit regulators to monitor plan activity for early warning signs of stinting. Even if the population of consumers concerned about a form of genetic discrimination is too small to have a powerful market impact, regulators could discern improper behavior by evaluating the data and audit the plan's practices to determine if there has been a violation of the law.

In the event, then, that genetic science develops sufficiently in its diagnostic and therapeutic capabilities to render genetic discrimination a more significant problem than it now is, current genetic discrimination statutes form a basis for the regulation of insurance to limit the effects of such discrimination in underwriting and coverage decisions. The statutes must be clarified, however, to make crystal clear the conduct that is prohibited; absent such clarity, genetic discrimination statutes are likely to face the fate of the ADA: gradual diminution in effect due to courts' constantly erring on the side of regulated entities and against the interests of consumers. In addition, regulators must apply to this form of improper insurance practice the array of consumer protection devices, now in their infancy, developed to protect consumers from the dark shunning and stinting tendencies of managed care organizations. These two steps are necessary to assure the immediate ability of genetic discrimination statutes to have an effect in the insurance market. The next Section explores the broader issues in insurance law and policy raised by genetic discrimination statutes.

IV. THE FUTURE OF GENETIC DISCRIMINATION

The previous Part described implementation concerns that will arise if and when genetic science advances sufficiently to render genetic discrimination in health insurance a substantial public policy concern. That Part assumed, in addition to advances in science, that a general agreement in genetic discrimination laws is intended to serve at least two goals: first, assuring individuals that the advantages of genetic testing for diagnostic and research purposes would not be outweighed by the disadvantages attendant on the revelation of genetic information to insurers and others; and second, ensuring that the "genetic lottery" is not used as a basis for differential treat-

123. See Jacobi, *supra* note 108, at 767-68.

ment in health insurance underwriting or coverage decisions. This Part also adopts those assumptions and, in addition, assumes that the technical drafting and enforcement concerns raised in the previous Part have been resolved. It addresses the public policy concerns that would arise were genetic discrimination laws to have important application (because genetic discrimination had become economically advantageous to insurers) and effective structure (because drafting and enforcement concerns had been resolved).¹²⁴ This Part addresses two such concerns, one related to the stability of the insurance market and the other related to allocative equities arising during times of growing scarcity in health care resources.

A. Adverse Selection and Exceptionalism

1. Regulating Around Adverse Selection

Genetic discrimination statutes create—are intended to create—information asymmetries between individuals and insurers, as individuals learn more about their future risk and insurers are prohibited from sharing in that knowledge. It is unclear at this point how valuable such information will be for insurance purposes, as it is uncertain how close the connection is between simple genetic variation and most illnesses.¹²⁵ To the extent genetic tests develop strong predictive capability, their results may be valuable to individuals as they decide whether or not to invest in health insurance. If applicants for coverage have access to prognostic information and insurers do not, adverse selection may come into play, with high-risk individuals opting for coverage and low-risk individuals opting out. An extreme version of this scenario has been described as follows:

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

124. One other practical concern for genetic discrimination laws should be mentioned for the sake of completeness. ERISA has the well-understood effect of fracturing health insurance regulation. States have the primary responsibility of regulating insurance, but they are inhibited from regulating some aspects of employment-based health insurance, and ERISA itself does not fill in the regulatory gaps in any satisfactory way. See Karen A. Jordan, *Coverage Denials in ERISA Plans: Assessing the Federal Legislative Solution*, 65 MO. L. REV. 405 (2000); Larry J. Pittman, *ERISA's Preemption Clause: Progress Towards a More Equitable Preemption of State Laws*, 34 IND. L. REV. 207 (2001); Edward A. Zelinsky, *Travelers, Reasoned Textualism, and the New Jurisprudence of ERISA Preemption*, 21 CARDOZO L. REV. 807 (1999). The Supreme Court has shifted from a practice of strictly construing ERISA preemption while imploring Congress to correct a clearly unintended effect of the legislation to one of more narrowly construing ERISA preemption to permit states greater regulatory authority over employment-based insurance plans. See *Rush Prudential HMO, Inc., v. Moran*, 536 U.S. 355 (2002); *N.Y. State Conference of Blue Cross & Blue Shield Plans v. Travelers Ins. Co.*, 514 U.S. 645 (1995).

125. See Greely, *supra* note 4, at 1498.

classifications. 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.¹²⁶

The problems posed by adverse selection may be of more technical than practical interest for several reasons. First, most people with private health coverage obtain it as an incident of employment, a context in which there historically has been limited individual experience rating, and where lower-risk members and potential members have had incentives to purchase coverage (where they explicitly share in the cost of coverage) that may overcome cost-based disincentives derived from their knowledge of their low-risk status.¹²⁷ Second, the distribution of genetic risk may be quite complex, frustrating attempts to assort most individuals into valid categories based on genetic risk. Insurers faced with expanding knowledge of genetic traits that have an effect on health only in complex combination with other genetic traits or with environmental conditions may not gain information appropriate to the risk categorization of applicants. If, for example, many applicants have a mixture of genetic indications of a low probability of many different illnesses, actuaries may be faced with a situation in which “the cost of refining classifications is not worth the competitive benefit derived,”¹²⁸ and the genetic information may become background noise in the underwriting process. Third, low-risk individuals often decide to purchase health coverage even if the premium exceeds that reflecting their actuarial risk. That is, they may be sufficiently risk-averse to purchase “overpriced” coverage rather than risking the prospect of being uninsured in the event of a significant illness not related to genetics—for example, traumatic injury or illness caused by infectious disease.¹²⁹

It may be, on the other hand, that genetic information will come to provide sufficiently significant information about risk to cause considerable dislocations attributable to adverse selection in insurance markets. Regulation is not helpless to combat such effects. Genetic equity principles can be sustained notwithstanding the emergence of significant adverse selection problems, through the adoption of several available corrective modifications to the insurance market. Some of these steps would be modest in nature, and some would require more radical change.

126. Diver & Cohen, *supra* note 4, at 1456 (citations omitted).

127. *Id.*

128. ABRAHAM, *supra* note 58, at 68.

129. See Jacobi, *supra* note 21, at 389; Korobkin, *supra* note 109, at 823-24.

Many states adopted reforms in the 1990s limiting the ability of health insurers to engage in risk selection. These statutes, aimed at individual and small group markets (the last bastions of the market permitting insurer risk selection), imposed explicit limits on the extent to which insurers could vary premiums on the basis of predicted risk and required insurers to offer coverage and to renew coverage once accepted.¹³⁰ Legislators anticipated that these limits to risk selection would produce some adverse selection, and they therefore included in the reforms corrective measures. To encourage people to obtain coverage before the need for treatment arises, they permitted insurers to impose preexisting illness exclusions.¹³¹ The reforms barred insurers from using price differentials as a risk selection mechanism, and states anticipated that insurers may use plan design as a proxy, discouraging the enrollment of high-risk individuals by offering coverage deficient in services vital to people with chronic illnesses.¹³² To counter this effect, states mandated uniform standard coverage packages¹³³ and instituted a variety of reinsurance mechanisms which equalize the burden of covering high-risk subscribers.¹³⁴

Although the record is ambiguous, these steps seem to have been, in some measure, successful in permitting states to shift individual and small group insurance markets to a more egalitarian footing, while avoiding extreme adverse selection;¹³⁵ and similar mechanisms could likewise correct existing adverse selection problems caused by genetic discrimination laws. The stakes could be quite high. Absent regulatory correction, the adverse selection caused by substantial asymmetries of information between applicants and insurers could greatly impair the operation of insurance markets.¹³⁶ Even if successful, the corrective measures will require substantial regulatory oversight of insurance markets. The dislocations caused by implementing meaningful genetic discrimination laws evokes an important question: why exclude genetic information and not other information predictive of future health status?¹³⁷ The next Section briefly examines

130. See Hall, *supra* note 100, at 691-94; Jacobi, *supra* note 21, at 370-73.

131. See DEL. CODE ANN. tit. 18, § 7201 (2001); N.J. STAT. ANN. § 17B:18-64 (West 2002). Federal law limits the ability of insurers to impose periods of preexisting illness exclusions, but only when an insured has been continually covered by insurance for twelve months. 29 U.S.C. § 1182 (2000). This provision of federal law is entirely consistent with the goal of encouraging individuals to obtain coverage before needing treatment but limits excessive or repeated periods of exclusion beyond those considered necessary by Congress. See Jacobi, *supra* note 21, at 376-77.

132. See Korobkin, *supra* note 109, at 824-25.

133. See *id.* at 827.

134. See CONN. GEN. STAT. ANN. § 38a-569 (West 2001); N.J. STAT. ANN. § 17B:18-66 (West 2002). See also Jacobi, *supra* note 21, at 375; Korobkin, *supra* note 109, at 827.

135. See Hall, *supra* note 100, at 725-26.

136. See Diver & Cohen, *supra* note 4, at 1457-58.

137. See Abraham, *supra* note 5, at 127.

the genetic exceptionalism debate.

2. *Exceptionalism, Incrementalism, and Social Pooling*

American insurance law has permitted or even encouraged insurers to consider the risk profile of an individual or group applying for health coverage, although recent incremental changes in insurance law suggest a trend toward social pooling.¹³⁸ Genetic discrimination laws forbid consideration of one form of relevant risk data.¹³⁹ As was true with the (at times) exceptional treatment of HIV information,¹⁴⁰ the justification for the exceptional treatment of genetic information for purposes including underwriting and coverage decisions has been questioned.¹⁴¹ Should genetic information be treated differently than other health status information?

Genetic discrimination legislation's two goals—encouragement of genetic testing for diagnostic and research purposes and protection of individuals from unfair coverage and treatment¹⁴²—suggest different answers to this question. To the extent that the goal of genetic discrimination laws is “only” to remove inhibitions to participation in genetic testing, exceptionalism arguments have some force. Unlike other health information, it is argued, genetic characteristics are immutable and invariably forecast future health conditions.¹⁴³ Genetic information, then, may loom uniquely large in the minds of people contemplating participation in genetic testing, and the social value of genetic testing is sufficiently high to support unique protections from others' use of resulting genetic information. There is some force to these arguments. However, as understanding emerges of both the complexity of the genetic causes of disease and the complexity of the relationship between genetics and environment for most diseases,¹⁴⁴ this justification weakens.¹⁴⁵

More comprehensive genetic discrimination laws are clearly motivated by the second goal: genetic equity in coverage.¹⁴⁶ The trend toward these broader laws suggests a rejection of insurance underwrit-

138. See generally Jacobi, *supra* note 21, at 314-18.

139. See Abraham, *supra* note 5, at 127.

140. See Ronald Bayer, *Public Health Policy and the AIDS Epidemic: An End to HIV Exceptionalism?*, 324 NEW ENG. J. MED. 1500 (1991).

141. For a more complete discussion of the genetic exceptionalism debate, one that encompasses primarily the issue of informational privacy but also the use of genetic information, see, for example, Gostin & Hodge, *supra* note 3, at 21; Lazzarini, *supra* note 4, at 149; Ross, *supra* note 4, at 141; Suter, *supra* note 4, at 669.

142. See *supra* text accompanying notes 79-82.

143. See Gostin & Hodge, *supra* note 3, at 34-35; Ross, *supra* note 4, at 142-43; Suter, *supra* note 4, at 710-15.

144. See Greely, *supra* note 4, at 1485-87.

145. See Gostin & Hodge, *supra* note 3, at 31-32; Ross, *supra* note 4, at 142-43; Suter, *supra* note 4, at 710-15.

146. See *supra* text accompanying notes 81-82.

ing and coverage decisions that differentiate on the basis of inherited traits, conditions clearly beyond the control of the individual. By passing broader genetic discrimination laws, legislators suggest that it is unfair to subject individuals to disadvantage in insurance purchase or use on the basis of inherited characteristics.¹⁴⁷

Taken in isolation, this view has considerable appeal. Viewed in the context of an insurance system traditionally governed by differential risk assessment, however, two observations should be made. First, as is discussed above, genetic discrimination laws may necessitate substantial regulatory intervention to limit adverse selection.¹⁴⁸ In addition, however, there is the broader equity concern. While individuals with unfavorable genetic characteristics do not “deserve” resulting disadvantage in insurance access, it is not clear that they have any greater claim to remedial action than do individuals disadvantaged by reason of previous traumatic injury or infectious disease.¹⁴⁹ No person who has or acquires characteristics, without her own fault, marking her as a high risk for future health utilization “deserves” lesser access to health coverage.

If, as it appears, genetic information is not sufficiently exceptional to separate it from other information useful in the process of risk selection, genetic discrimination laws can be justified only as part of a larger incremental reform movement in health insurance. If the future of the American health insurance system is a model in which insurers rely on risk selection where such business methods are economically valuable, then selecting genetic conditions as an exception to the rule is difficult to justify. There is thin but suggestive evidence, however, that the American health insurance system is moving incrementally toward a system in which access to coverage is not tied to risk and in which the guiding principle is not individual assessment but social pooling to improve access to coverage and care.

Federal and state law has shifted in recent years to limit risk segmentation in insurance markets. As is described above, many states have adopted reforms limiting the ability of health insurers to engage in risk selection in individual and small group markets.¹⁵⁰ In addition, HIPAA,¹⁵¹ passed in 1996, imposed federal restrictions on insurers’ ability to impose risk-related restrictions on coverage in some circumstances.¹⁵² The swift acceptance of genetic discrimination

147. See Geetter, *supra* note 3, at 65-66.

148. See *supra* Part IV.A.1.

149. See Abraham, *supra* note 5, at 127 (“[T]he puzzle is why the law should prohibit health insurers from using genetic information that is the product of the natural lottery—while permitting them to use information that reflects other features of this lottery.”).

150. See *supra* Part IV.A.1.

151. See *supra* text accompanying notes 51-53.

152. See Jacobi, *supra* note 21, at 376-79.

laws, seen against this background, suggests that the law's protections represent not merely a case of special pleading, but rather, they are part of a larger trend of incremental insurance reform.

Splashy, systemic reform of the American health insurance market has famously failed.¹⁵³ The failure of large-scale reform, however, was more a product of American skepticism of large government than a lack of public interest in making health coverage available on a more egalitarian footing.¹⁵⁴ An argument can be made that incremental reform is currently proceeding (slowly and unevenly) on two fronts in the direction of assuring access to health coverage, regardless of health status and ability to pay.

The first front is discussed above; it comprises laws moving away from risk segmentation and toward community rating and social pooling. This evolutionary movement increases the social cost of coverage, in part, due to the cost of increased regulation and, in part, due to the increased risk profile of those covered.¹⁵⁵

The second front for incremental reform concerns payment for coverage. Independent of the cost of insurance reform, the cost of health care coverage is rising rapidly.¹⁵⁶ At the same time, long-term trends suggest that employment-based coverage is weakening, with less coverage and higher cost-sharing, particularly for low-income workers.¹⁵⁷ Over time, the public sector has come to play a larger role, with nearly one-half of care now financed by public programs.¹⁵⁸ As low-income workers and their families found limited access to decent employment-based health coverage,¹⁵⁹ the government has

153. See generally THEDA SKOCPOL, *BOOMERANG: CLINTON'S HEALTH SECURITY EFFORT AND THE TURN AGAINST GOVERNMENT IN U.S. POLITICS* (1996).

154. See Suter, *supra* note 4, at 724-25.

155. See Geetter, *supra* note 3, at 70-74; Hall, *supra* note 100, at 695-97.

156. See Altman & Levitt, *supra* note 1, at 84; Milt Freudenheim, *Health Insurers Are Seeking 20% Rate Rise*, N.Y. TIMES, June 5, 2002, at C2.

157. See Henry S. Faber & Helen Levy, *Recent Trends in Employer-Sponsored Health Insurance Coverage: Are Bad Jobs Getting Worse?*, 19 J. HEALTH ECON. 93, 102 (2000); John Holahan & Johnny Kim, *Why Does the Number of Uninsured Americans Continue to Grow?*, HEALTH AFF., July-Aug. 2000, at 188, 194-95.

158. See Sherry Glied, *Health Insurance and Market Failure Since Arrow*, 26 J. HEALTH POL. POL'Y & LAW 957, 964 (2001); Ctrs. for Medicare and Medicaid Servs., Office of the Actuary, *National Health Expenditures by Type of Service and Source of Funds: Calendar Years 1960-99* (Nov. 12, 2001), available at <http://www.hcfa.gov/stats/nhe-oact/tables/nhe99.csv>; Steffie Woolhandler & David U. Himmelstein, *Paying for National Health Insurance—And Not Getting It*, HEALTH AFF., July-Aug. 2002, at 88, 88 n.1 (citing <http://www.hcfa.gov/stats/nhe-oact/tables/nhe99.csv>). Woolhandler and Himmelstein calculate the public share at 59.8 %, the higher figure arrived at by adding to direct public expenditures the tax subsidies supporting "private" insurance. *Id.* at 91-92.

159. See ELLEN O'BRIEN & JUDITH FEDER, *THE KAISER COMM'N ON MEDICAID AND THE UNINSURED, EMPLOYMENT-BASED HEALTH INSURANCE COVERAGE AND ITS DECLINE: THE GROWING PLIGHT OF LOW-WAGE WORKERS* 7 (May 1999), available at <http://www.kff.org/content/1999/2134/2801plightoflowwageworkers.pdf> (last visited January 29, 2003) (on file with author).

picked up the slack. Medicaid programs expanded, and programs covering low-income children and adults who are not eligible for Medicaid have been created.¹⁶⁰ This trend slowed or even reversed briefly in the late 1990s, at the height of economic expansion.¹⁶¹ This pause is clearly temporary, as the end of extraordinarily good economic times and increased health care cost inflation once again threaten the employment-based insurance system. As a recent analysis concluded,

[u]ltimately, the combination of higher growth in health care costs, through its effect on premiums, and a slowing economy threaten a major increase in the number of people who are uninsured. Evidence is already appearing that small employers are dropping coverage in response to sharp premium increases. When employers shield workers less from premium increases, rates of employee take-up will continue to fall.¹⁶²

Putting these trends together, it can be predicted that private insurance coverage will continue to erode and that government will be called upon to finance coverage for an increasingly large percentage of the population. Further, the public program expansions in recent years have often been structured so as to permit government to simply purchase coverage from private insurers.¹⁶³ Government gains comfort as a purchaser of coverage if the market from which it selects coverage is structured according to policies consistent with broad coverage of individuals of all risk categories; government (as a purchaser of coverage) is not served by insurance markets designed to limit coverage to those most in need of access to health care.

The pieces of this incrementalist reform agenda, then, include both a shift in regulatory structure toward social pooling and away from individual risk selection and an increasing commitment of public funds to finance the purchase of coverage for those priced out of the market. As has been stated, the evidence that insurance markets are moving in the right direction is thin but suggestive. The evidence that government will continue the trend of financing a greater portion of health care is no more certain.¹⁶⁴ The next Section assumes,

160. See generally Sara Rosenbaum & David Rousseau, *Medicaid at Thirty-Five*, 45 ST. LOUIS U. L.J. 7 (2001).

161. See John Holahan & Mary Beth Pohl, *Changes In Insurance Coverage: 1994-2000 And Beyond*, HEALTH AFF., Apr. 2002, available at http://www.healthaffairs.org/WebExclusives/Holahan_Web_Excl_040302.htm.

162. Bradley C. Strunk et al., *Tracking Health Care Costs*, HEALTH AFF., Sept. 2001, available at http://www.healthaffairs.org/WebExclusives/Strunk_Web_Excl_09502.htm (citations omitted).

163. See *id.*

164. Full discussion of the reluctance of Americans to accept public responsibility for health coverage is beyond the scope of this Article. American opinion on the broad public finance of health care continues to span the spectrum from that regarding health care as a

somewhat hopefully, that some version of incremental reform is adopted and that broad coverage is available to all, independent of their ability to pay or the market's evaluation of their risk status. It raises questions regarding the effects of scarcity in health services on access to services for people with genetic conditions.

B. Scarcity and Equity

Genetic discrimination laws were enacted before substantial need arose and reflected, in part, a social consensus that people with genetic conditions suggestive of future health risk should not be disparately treated in health insurance underwriting and coverage decisions. The discussion above describes appropriate steps for crafting and enforcing genetic discrimination laws in order to achieve that goal and suggests effects that these laws may have on health insurance markets in the future. The previous Section argues that genetic discrimination legislation's effect on health insurance markets is consistent with a trend of incremental reform of America's health insurance market toward an ethos of social pooling, in which marketplace tendencies to exclude those most in need of health coverage would be subverted in the service of broader access to care.

The previous discussion somewhat artificially excluded consideration of health care cost inflation in gauging the strength of the social commitment to genetic equity. This Section briefly sketches out the cost containment and rationing pressures that are likely to arise in the near future and concludes that explicit genetic discrimination should be firmly in place before those pressures become strong. It is not unlikely that strong pressures to ration care will coincide with the time when genetic science has advanced sufficiently to test social resolve in favor of genetic equity. When the pressure to ration medically useful care becomes strong, abstract concepts of equity may face critical reevaluation.

The pressure to ration, of course, derives from health care cost in-

primary good suitable for public finance to that regarding it as a consumer preference good, like any other, best left to the private market. See Uwe E. Reinhardt, *Turning Our Gaze From Bread and Circus Games*, HEALTH AFF., Spring 1995, at 33, 33. Elsewhere, Reinhardt related an anecdote reflecting the view held by some that broadening health coverage to encompass all Americans is fundamentally contrary to America's economic interests:

At a congressional retreat during the health reform debates of 1993-1994, James Monagan, M.D. . . . asked a prominent economist . . . why one of the richest nations on earth finds it so difficult to give all of its citizens access to the kind of health care taken for granted by the middle class. To which the economist replied: "Has it occurred to you that that is why we are among the richest nations on earth?"

Uwe E. Reinhardt, *Can Efficiency in Health Care Be Left to the Market?*, 26 J. HEALTH. POL'Y & L. 967, 975 n.2 (2001).

flation. After a brief hiatus, health care cost inflation has returned with a vengeance.¹⁶⁵ Two prominent health finance analysts have demonstrated that health care inflation well above the rate of background inflation has been the norm for the past four decades, with brief periods of low inflation, and notwithstanding a wide variety of strategies to corral health care costs:

[N]either regulation, voluntary action by the health care industry, nor managed care and market competition have had a lasting effect on our nation's health care costs. Some might argue that we were not serious or comprehensive enough about any one of these approaches for them to have had a lasting impact. On the other hand, it could be argued that the point is academic; we were as serious as public and political support for any one approach would allow.¹⁶⁶

The authors suggest that the cost-containment efforts are doomed to fail until the need for rationing is faced; in the alternative, they suggest that the cost history is traceable to "the American people's uncontrollable desire for the latest and best health care," which will not lessen and which dooms us to an ever-rising spiral of cost.¹⁶⁷

Henry Aaron argues that the resurgence of health care cost inflation is to be expected and is consistent with decades-old trends. He suggests, in fact, that the factors leading to inflation are intensifying.¹⁶⁸ The factors that will only increase in salience over time are technological innovation in health care (particularly pharmaceuticals) and an aging population; the one-time factor is the bounce-back from spent managed care cost-containment efforts.¹⁶⁹ As Americans' appetite for innovative treatments is only exceeded by the interest of entrepreneurial health care firms and professionals, the technological inflation driver is sure to continue in force. Similarly, the population is aging—a good thing, given the alternative—and therefore requires more and more intense services.

In the short run, Americans are likely to react to health inflation as we always have: "try small things that work at the margin, complain a lot, but ultimately pay the bill."¹⁷⁰ The time is imminent, however, when decisions will have to be made to deny insured people coverage for services that are "genuinely beneficial or that patients

165. See Freudenheim, *supra* note 156; Christopher Oster, *At a Premium: Insurance Costs Loom as a Cloud Over the Economy*, WALL ST. J., Apr. 11, 2002, at A1.

166. Altman & Levitt, *supra* note 1, at W83.

167. *Id.*

168. Henry J. Aaron, *The Unsurprising Surprise of Renewed Health Care Cost Inflation*, HEALTH AFF., Jan. 2002, at W85, available at <http://healthaffairs.org/WebExclusives/2101Aaron.pdf> (last visited January 29, 2003) (on file with author).

169. *Id.* at 86.

170. Altman & Levitt, *supra* note 1, at W84.

and their physicians [think] are beneficial.”¹⁷¹ That is, care will have to be rationed. Unlike other industrialized nations, America has no political process through which hard decisions on the funding of health treatments can be openly discussed,¹⁷² although we have experimented with such a process in a clumsy and experimental way.¹⁷³ We have relied in surprisingly large part on the talismanic significance of statutory and contractual limits of coverage to that which is medically necessary, a term that lacks a cost-effectiveness component and, in any event, is sufficiently vague as to provide little practical guidance.¹⁷⁴ Even very desirable goods must compete in some sense with others. As health care costs increase, so will conflicts. For some goods and services, this eventuality would merely lead to individual choices to refuse one good or service for another. In the case of health care, however, with its high and uncertain costs, the history of insurance, and the “non-elective” nature of many consumption choices, some form of rationing is inevitable.

It is beyond the scope of this Article to predict what processes and with what resulting procedures Americans will construct their rationing system. Instead, I simply point out that *any* such system is likely to threaten care for people with genetic conditions. They face the threat likely to be faced by all with new or unusual health needs—the disfavored position in a game of musical chairs. In the game of musical chairs, players circle a ring of chairs and sit down when the music stops. One person cannot do so; others have already taken all available chairs, and the player left standing is “out,” due to her inability to gain a seat. If expensive and effective genetic treatments emerge, they will be new and unfamiliar. If we come to accept limits on spending for medically necessary care, the risk is high that those who would benefit from unfamiliar, new and expensive treatments will be left standing, as others, beneficiaries of older, more familiar treatments, occupy all of the chairs. In other words, the failure to thoughtfully plan for scarcity places at risk the more vulnerable members of society—the poor, the disabled, and, in these circumstances, those who claim the benefit of expensive new treatments. Forethought is therefore essential.

But how? Some taxonomy of “medically necessary” treatments must be derived in order to assort care between those types that will draw resources and those that will not. If history is any guide, there

171. Aaron, *supra* note 168, at W86.

172. *See id.* at 85-86.

173. *See* Michael J. Astrue, *Pseudoscience and the Law: The Case of the Oregon Medical Rationing Experiment*, 9 ISSUES LAW & MED. 375 (1994); Note, *The Oregon Health Care Proposal and the Americans With Disabilities Act*, 106 HARV. L. REV. 1296 (1993).

174. *See generally* William M. Sage, *Physicians As Advocates*, 35 HOUS. L. REV. 1529 (1999).

will be a tendency to favor established treatments over the new and treatments valued by the majority rather than those favored by the minority. Here, the egalitarian underpinnings of both disability law and genetic discrimination law must be called upon to make the case that it is illegitimate to make choices against coverage on the basis of the disability status of the expected recipient or on the basis of the genetic condition of the expected recipient. Disability-neutral and genetic-neutral methods of utilization management are called for.

One much-discussed approach to dealing with scarcity was recently developed by Daniel Callahan.¹⁷⁵ Callahan suggests a means to approach scarcity:

[I]t is a fundamental mistake to generalize from the success of the past to assume like gains in the future. As George Washington once noted, "It would be . . . unreasonable to suppose that because a man has rolled a snowball till it acquired the size of a horse that he might do so till it was as large as a house." Success there will surely be, and medical progress as well. But (a) the future is unlikely to hold great gains such as there were in the past, that is, medial gains that have a decisive *population* health benefit; (b) future advances will be proportionately far more expensive to find and to implement than those of the past; and (c) future advances will be considerably more likely to be ambiguous, perhaps even contradictory, in their human benefit.¹⁷⁶

Callahan's solution is to substitute a vision of "sustainable medicine" for our current bias in favor of all beneficial medicine. It is a vision of medicine with limits, and it requires that we accept fundamental limits on our ability to rely on medicine to extend our lives indefinitely. In some aspects, Callahan's vision comports easily with the egalitarian vision of genetic discrimination.¹⁷⁷ In others, it raises the specter of majoritarian bias that has historically threatened people with disabilities and now threatens people with genetic conditions. Callahan states as a goal of sustainable medicine "a decent level of physical and mental competence" and endorses "finite and steady-state health goals and . . . limited aspirations for progress and technological innovation."¹⁷⁸

Callahan's vision stands, in one sense, for what is inevitable: the creation of a methodology for reducing our thirst for ever more expensive and only marginally beneficial (if that) technological developments. It also presents a vision that can be construed as dangerous to those who are "different," including people with disabilities and

175. DANIEL CALLAHAN, FALSE HOPES (1998).

176. *Id.* at 48.

177. *Id.* at 35 (defining a component of sustainable medicine as involving equitable distribution and equal opportunity for benefit).

178. *Id.*

people with genetic conditions. If “we” embrace a vision with limited aspirations, are we anticipating a game of musical chairs, in which either established treatments or treatments for the majority (or both) are appropriate, but new treatments or treatments for people with disabilities or genetic conditions are not? The push to rationing is coming, and the danger is clear. The struggle for disability rights shows that egalitarian notions are more easily embraced in the abstract than when practical costs are apparent. At each step of the way, as disability and genetic discrimination in health insurance is encountered, egalitarian positions, rooted in the disability rights history, must be advanced. A norm of social pooling without regard for disability or genetic condition must be reinforced. The stakes are high now, but the future brings greater dangers as false hopes for endless medical progress are confronted.

CONCLUSION

Genetic discrimination laws, adopting a notion of genetic equity in underwriting and coverage decisions, have broad support. That support is suspect, however, for two reasons. First, the laws were enacted at a time when genetic discrimination was a largely abstract notion, with genetic diagnostic and treatment methods in their infancy. Second, they were adopted, in large part, during times of plenty, with relatively low health care cost inflation and high employment supported by a robust economy. The laws are varied and sometimes vague. The hard lessons learned from the dismemberment of the ADA by courts seizing on statutory ambiguities to limit individual rights suggest that genetic statutes be clarified in advance of the time when genetics makes their protected vitally important, and that enforcement mechanisms be clearly set out.

Genetic discrimination laws are important both in their own right and as bellwethers for a movement of incremental reform of insurance law. These reforms, of which genetic discrimination laws are a part, move a system, perversely making access to health coverage more readily available the less a person needs it, to one operating on a more egalitarian footing. These reforms will confront a tradition of health insurance law surprisingly hostile to social pooling mechanisms, and care must be taken to avoid adverse selection and other transitional market faults.

The laws will face their sternest tests and will be most vital to protect access to health coverage as health care cost inflation surges. The inevitable real increases in health care costs will increasingly strain reasonable limits on society’s ability to pay. Rationing in some form will be inevitable. People with expensive genetic conditions or who will benefit from as-yet undiscovered genetic treatments will

face the same problem in a rationing regime as will others with new, unfamiliar, or disfavored health needs. They will face a game of musical chairs in which individuals with “traditional” illness and health care needs will believe they are entitled to sit when the music stops. The equitable principles underlying genetic discrimination laws must be well-entrenched before this game is played, in order to ensure that difficult choices will be made in an equitable manner.