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### The Human Genome Project and the End of Insurance

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# THE HUMAN GENOME PROJECT AND THE END OF INSURANCE

#### Roberta M. Berry\*

I.	INTRODUCTION	
II.	VULNERABILITY, IGNORANCE, AND INSURANCE	210
	A. Vulnerability, Ignorance, and Risk	
	Management Motivation	210
	B. Risk Management Motivation and the Development	
	of Insurance	213
	C. Risk Management Motivation, Profit-Making,	
	and the Functioning of the Insurance Mechanism	216
	D. The Social Consequences of the Functioning of	
	the Insurance Mechanism	223
Ш.	THE INTERSECTION OF THE HGP AND INSURANCE	231
	A. The Collision at the Intersection	231
	B. Proposed Policy Responses	233
	1. Introduction	233

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	2.	Genetic Privacy Proposals	237
		Actuarially Justified Proposals	
	4.	Fair Limits Proposals	247
	5.	Community Rating Proposals	249
V	THE N	EXT INTERSECTION AND REVOND	254

#### I. INTRODUCTION

The Human Genome Project (HGP) is a federally funded biotechnology research program, which is projected to be completed in fifteen years at a cost of \$3 billion.<sup>1</sup> The purpose of the HGP is to decipher the human genome, which is the master control program of human biological life.<sup>2</sup> With knowledge gained from the HGP, diagnostic tests for genetic defects will soon be widely available,<sup>3</sup> and cures for diseases caused by these

<sup>1.</sup> The HGP was formally undertaken as a federal program in 1991 with an initial funding of approximately 135 million dollars. Daniel Kevles, Out of Eugenics: The Historical Politics of the Human Genome, in The Code of Codes, Scientific and Social Issues in the Human Genome Project 3, 36 (Daniel J. Kevles & Leroy Hood eds., 1992) [hereinafter The Code of Codes]. The target date for completion is 2005. Victor A. McKusick, The Human Genome Project: Plans, Status, and Applications in Biology and Medicine, in Gene Mapping: Using Law and Ethics as Guides 18, 18 (George J. Annas & Sherman Elias eds., 1992) [hereinafter Gene Mapping].

<sup>2.</sup> The human genome consists of 46 chromosomes located in the nucleus of every somatic human cell. Kevles, Out of Eugenics, in THE CODE OF CODES, supra note 1, at 16. If the HGP continues as planned, by the year 2005, HGP scientists will have mapped the human genome, assigning the approximately 50,000 to 100,000 human genes to their locations on the 46 chromosomes. McKusick, The Human Genome Project, in GENE MAPPING, supra note 1, at 26; see also Horace F. Judson, A History of the Science and Technology Behind Gene Mapping and Sequencing, in THE CODE OF CODES, supra note 1, at 37, 38 (discussing how the history of genetics casts light on present attempts to map and sequence genes). In addition, HGP scientists will have sequenced the three billion deoxyribonucleic acid (DNA) base pairs that constitute human genes, determining the sequence of DNA base pairs that functions as the code that directs human cellular activity. Walter Gilbert, A Vision of the Grail, in THE CODE OF CODES, supra note 1, at 83, 84. Base pairs are made up of four nucleotides arranged in only two kinds of pairs that connect at their bases: (1) adenine and thymine, and (2) guanine and cytosine. Judson, A History of the Science and Technology Behind Gene Mapping and Sequencing, in THE CODE OF CODES, supra note 1, at 37, 39. These base pairs form the steps of a spiral staircase; the twin railings of the staircase consist of two strands of DNA that twine around each other coaxially. Id. at 39. The base pairs are arranged such that there are exactly ten base pairs to each full turn of the double helix. Id.

<sup>3.</sup> See Gina Kolata, Tests to Assess Risks for Cancer Raising Questions, N.Y. TIMES, Mar. 27, 1995, at A1 (describing the controversy surrounding the imminent marketing of simple diagnostic tests for genetic defects that predispose individuals to breast and ovarian cancer); see also A Genetic Vulnerability to Carcinogens, 149 SCI. NEWS 188, 188 (1996) (stating that in the Feb. 3, 1996 LANCET, it was reported that "those who failed to inherit a functional copy of . . . [a gene that codes for a carcinogen-detoxifying enzyme] from either parent face four times the MDS [myelodysplastic syndrome] risk of those who inherited even one such gene. In the United States, one in six persons lacks a working copy of this gene.");

genetic defects will follow.4

The HGP has generated enthusiasm within the scientific and medical communities and among federal policymakers, who continue to fund the HGP while slashing the budgets of other federal research programs.<sup>5</sup> This enthusiasm is due to the HGP's promise of yielding knowledge that will support a medical revolution in the ability to diagnose and conquer disease.<sup>6</sup>

The HGP also has generated concerns.<sup>7</sup> New knowledge supports new power to do both good and evil. For example, knowledge from the HGP may revive interest in eugenic practices of a potentially very sophisticated and diabolical sort.<sup>8</sup> In addition, new knowledge generates unintended

Epilepsy Gene Identified, 149 SCI. NEWS 221, 221 (1996) ("A joint U.S.-Finnish team reports nabbing a gene that, when mutated, causes an inherited form of epilepsy."); Kathleen Fackelmann, Forecasting Alzheimer's Disease, 149 SCI. NEWS 312, 313 (1996) ("Eric M. Reiman of the Good Samaritan Regional Medical Center in Phoenix and his colleagues knew that people who inherit a gene called apolipoprotein E-IV run a 27 percent chance of developing Alzheimer's disease by age 85.").

- 4. As Leroy Hood concludes: "I believe that we will learn more about human development and pathology in the next twenty-five years than we have in the past two thousand." Leroy Hood, Biology and Medicine in the Twenty-First Century, in THE CODE OF CODES, supra note 1, at 136, 163; see also C. Thomas Caskey, Molecular Medicine; A Spin-Off from the Helix, 269 JAMA 1986, 1989-90 (1993) (assessing current pharmacological applications and future genetic correction therapies drawing upon knowledge gained from the HGP).
- 5. See Ron Cowen et al., Federal Budget 1996: R & D Would Fall, 147 SCI. NEWS 86, 86 (1995) (reporting that "funds for the multiagency Human Genome Project would rise to \$195 million, a 4.1 percent increase [in 1996]"). See generally Robert M. Cook-Deegan, Mapping the Human Genome, 65 S. CAL. L. REV. 579, 579 (1991) (discussing the history of the HGP).
- 6. See PHILIP KITCHER, THE LIVES TO COME 87-126 (1996) (noting both the potential and the limits of the HGP's promise for the near future).
- 7. Policymakers included in their funding for the HGP a provision for the study of the ethical, legal, and social implications of the HGP. A number of commentators have identified and analyzed areas of concern. See, e.g., THE CODE OF CODES, supra note 1; GENE MAPPING, supra note 1; JUSTICE AND THE HUMAN GENOME PROJECT (Timothy F. Murphy & Marc A. Lappé eds., 1994).
- 8. Daniel J. Kevles chronicles the eugenics movement in the United States, Great Britain, and Germany in the early twentieth century, including the proposal of British scientist Francis Galton to improve the human race through eugenics. Kevles, THE CODE OF CODES, supra note 1, at 3-12. Eugenists often advised the breeding of superior people, and the elimination of the biologically inferior by discouraging their reproduction or by precluding their immigration. *Id.* at 9. In the early twentieth century, eugenic sterilization laws were commonplace in the United States, and in Buck v. Bell, 274 U.S. 200 (1927), the constitutionality of applying such a law was upheld. Kevles, THE CODE OF CODES, supra note 1, at 10. Gradually, the study of human genetics disassociated itself from the crudest forms of genetic engineering. *Id.* at 11-18. The concern with eugenics merges with the ongoing debate regarding abortion. The HGP will advance the ability to engage in prenatal diagnosis which, in turn, will facilitate the abortion of fetuses that are genetically defective. As Evelyn F. Keller explains:

[D]espite the repeated emphasis on health care, on the diagnosis, treatment, and prevention of genetic disease, it is in fact primarily the possibility of diagnosis

consequences, some of which may be potentially harmful. For example, because the ability to diagnose will precede the ability to cure genetic diseases, individuals who fear that they have inherited incurable and fatal genetic diseases will face wrenching decisions as to whether or not to undergo genetic testing.<sup>9</sup> If they undergo genetic testing and receive bad news, not only must they live with this knowledge, but they also may be forced to cope with the consequences of dissemination of this information to

that is considered of practical relevance for the near future by even the most enthusiastic proponents of the human genome project; estimates of arrival times for therapeutic benefits run, optimistically, as long as fifty years hence. Thus, "treatment" is at best a long-term goal, and "prevention" means preventing the births of individuals diagnosed as genetically aberrant — in a word, it means abortion.

Evelyn F. Keller, Nature, Nurture, and the Human Genome Project, in THE CODE OF CODES, supra note 1, at 281, 295-96.

#### 9. As Charles Cantor explains:

In fifteen years, we will probably be able to apply a single multiplex test to fetuses in utero, babies at birth, or, in many cases, parental carriers, a test that will detect somewhere between 100 and 1,000 of the most common genetic diseases, disease predispositions, and genetic risk factors for environmental insults, drug dose responsiveness, and the like. We will be able to do this extensive fingerprint for any individual, but we will, at least initially, be unable to offer any help based on this information. Such impotence in the face of information exposes one of the serious social issues raised by the genome project. . . . To be told that you will come down with a disease for which there is no therapy is virtually to be robbed of hope.

Charles Cantor, The Challenges to Technology and Informatics, in THE CODE OF CODES, supra note 1, at 98, 105.

See Hood, Biology and Medicine in the Twenty-First Century, in THE CODE OF CODES, supra note 1, at 136, 159 ("The gap between the ability to diagnose and the ability to treat genetic diseases could well be five to twenty or more years."); see also Barbara B. Biesecker et al., Genetic Counseling for Families with Inherited Susceptibility to Breast and Ovarian Cancer, 269 JAMA 1970, 1973 (1993) (discussing psychological implications of diagnosis); Ellen W. Clayton, Screening and Treatment of Newborns, 29 HOUS. L. REV. 85 (1992) (discussing psychological, social, economic and legal implications of newborn screening); Richard A. Epstein, Lecture, The Legal Regulation of Genetic Discrimination: Old Responses to New Technology, 74 B.U. L. REV. 1, 10-11 (1994) (discussing benefits of gaining knowledge from testing even though cures are not available); Marjorie Shaffer, Science Academy Panel Urges Federal Oversight of Genetic Tests, BIOTECHNOLOGY NEWSWATCH, Nov. 15, 1993, at 1 (discussing a variety of problems posed by screening tests).

As Nancy Wexler concludes:

So here we confront our worst fears: our scientific success puts us on the threshold of an era of unknown but imaginable dangers. We can predict the flood but cannot leave or stop the tide. We can tell people that they possess the gene and will eventually come down with the disease, but we have no cure or even therapy to offer to soften the blow.

Nancy Wexler, Clairvoyance and Caution: Repercussions from the Human Genome Project, in THE CODE OF CODES, supra note 1, at 211, 224.

others, such as employers and educational institutions.<sup>10</sup>

This article examines the unintended consequences of the knowledge gleaned from the HGP for individuals who want to buy life, disability, or health insurance coverage, and for insurance companies that are in the business of selling such coverage. As genetic test information becomes widely available, insurance companies will increasingly seek access to this information. If insurance companies are permitted access to this information, individuals whose tests reveal that they are predisposed to disease, vulnerable to risk factors for disease, or destined to suffer disease may face increased costs for coverage, reduced offers of coverage, or refusals of coverage altogether. If insurance companies are not permitted access to this information, the consequence may be the end of insurance.

But, paradoxically, even if insurance companies are permitted access to this information, the consequence still may be the end of insurance. The reason for this paradox is the peculiarly destructive effect of too much knowledge on the functioning of insurance. The insurance mechanism evolved in a physical and social environment characterized by vulnerability to disease and ignorance as to whether, how, and when disease might strike. Genetic testing will introduce new knowledge that will contribute to the eventual reduction in vulnerability to disease, and that will immediately reduce ignorance about disease. The consequence of this new knowledge may be the destruction of the environment necessary for the continued functioning of the insurance mechanism.

How should policymakers respond to the perplexing problems that the availability of new genetic knowledge will pose for individuals and insurance companies? This article argues that public policymakers should base their policy prescriptions on an appreciation of the purpose or "end" of insurance from the perspective of both individuals and insurance companies. They also should consider the private and public benefits that are byproducts of the attainment of these ends. Finally, policymakers should assess competing

<sup>10.</sup> Biesecker et al., supra note 9, at 1973 ("[O]nce a family member chooses to share this information [regarding diagnosis] with health care professionals outside the genetics clinic, it is essentially impossible to protect the privacy of the test results."). These institutions may be tempted to apply diagnostic information for their own institutional ends. See Dorothy Nelkin, The Social Power of Genetic Information, in THE CODE OF CODES, supra note 1, at 177, 177-90 (discussing the social implications of diagnostic information); see also Daniel J. Kevles, Vital Essences and Human Wholeness: The Social Readings of Biological Information, 65 S. CAL. L. REV. 255 (1991); Evelyn F. Keller, Genetics, Reductionism, and the Normative Uses of Biological Information: Response to Kevles, 65 S. CAL. L. REV. 285 (1991). Employers may attempt to deny employment to those genetically predisposed to occupational disease or likely to increase employers' health care costs because of genetic disease. See generally Lori B. Andrews & Ami S. Jaeger, Confidentiality of Genetic Information in the Workplace, 17 Am. J.L. & MED. 75 (1991) (discussing existing legal protection for confidentiality in the workplace).

policy proposals by comparing their relative effects upon current and potential private and public benefits. Part II identifies the purposes of insurance and canvasses these private and public benefits. Part III assesses the effects of four current policy proposals and concludes that these proposals too readily sacrifice various private and public benefits of insurance for little or no gain. Part IV suggests alternative policy measures. Part IV concludes that the end of insurance in its present form will come, and the HGP will hasten the day, but the end of insurance should come about as a consequence of the next medical revolution, not as a result of enactment of ill-considered policy measures.

#### II. VULNERABILITY, IGNORANCE, AND INSURANCE

#### A. Vulnerability, Ignorance, and Risk Management Motivation

Individuals have always been vulnerable to disease, disability, and premature death, and ignorant as to the whether, how, and when these misfortunes might befall them. With increased medical knowledge, this vulnerability and ignorance have been reduced. But medical knowledge still falls far short. Scientists working on the HGP often cite the combination of vulnerability to and ignorance about disease as motivating their work.<sup>11</sup>

In addition, because individuals are vulnerable to disease but ignorant as to whether, how, and when they will suffer disease, they are unable to plan their affairs to minimize the hardships that it can bring. Individuals often cite this combination of vulnerability and ignorance as motivating their desire to obtain genetic tests even before cures are available.<sup>12</sup>

Among the hardships that disease can bring are financial losses, such as health care expenses, lost income due to disability, and curtailment of income due to premature death. Individuals display a motivation to reduce financial losses and to reduce their ignorance regarding the probability, magnitude, and timing of these financial losses. This motivation may be called "risk management motivation."

Commentators variously ascribe risk management motivation to underlying human desires, such as, loss aversion, 13 risk aversion, 14 and

<sup>11.</sup> See, e.g., James D. Watson, A Personal View of the Project, in THE CODE OF CODES, supra note 1, at 164, 164-73.

<sup>12.</sup> See Epstein, supra note 9, at 7-13; A.J. Hostetler, Her Positive Tests Won't Dictate Life, S. BEND. TRIB., Nov. 30, 1994, at A2; Wexler, supra note 9, at 212.

<sup>13.</sup> Loss aversion refers to the desire to safeguard status or wealth against loss. Individuals who seek to avoid disease, disability, or premature death may be motivated not only by a desire to preserve their health status but also by a desire to preserve their wealth against associated financial losses.

Some researchers assert that individuals have context-specific desires for loss avoidance that may be satisfied by risk management strategies, including the purchase of insurance. See

desire for security and peace of mind.15 It is difficult to arrive at a

Amos Tversky & Daniel Kahneman, Rational Choice and the Framing of Decisions, J. Bus., Oct. 1986, at S251, S257-75 (discussing various explanatory models, including "regret" theory and "prospect" theory) [hereinafter Tversky & Kahneman, Rational Choice]. Tversky and Kahneman observed that individuals make choices under conditions of uncertainty that are highly dependent upon the language used to express the choices. Id. They also observed that choices tend to be affected by life experiences, leading to bias in predicting the probability of events. Amos Tversky & Daniel Kahneman, Judgment Under Uncertainty: Heuristics and Biases, 185 Sci. 1124, 1127 (1974). Regardless of the explanations for these choices, the observed effects indicate that the purchase of personal insurance may yield psychological benefits to individuals by assuaging their fears of loss.

14. Risk aversion refers to the preference for a high probability of a small financial loss as opposed to a low probability of a large financial loss. A risk averse party may well prefer a certain small loss to a less than certain large loss even though the expected value (magnitude multiplied by probability) of the certain loss is greater. Kenneth Abraham describes risk aversion as follows:

A risk-neutral party is indifferent as between a small risk of suffering a large loss and greater risk of suffering a small loss, when each risk has the same *expected value* — the probability of a loss multiplied by its magnitude if it occurs. In contrast, a risk-averse party would prefer the large risk of suffering a small loss to a smaller risk of suffering the large loss.

KENNETH S. ABRAHAM, INSURANCE LAW & REGULATION: CASES AND MATERIALS 2 (2nd ed. 1995) [hereinafter ABRAHAM, INSURANCE LAW & REGULATION].

Risk aversion is often expressed in terms of the economic theory of diminishing marginal utility. If it is true that the last dollar earned by an individual is less valuable to the individual than the first dollar earned because individuals satisfy pressing desires first, then individuals will prefer to pay more of their last and less valuable dollars earned to protect against the risk of loss of their more valuable first-earned dollars. To the extent that individuals display this preference, they are risk averse. An insurance company, in contrast, is largely risk neutral, in that all dollars taken in and paid out are of equal value to it; the insurance company only desires a difference between dollars in and dollars out because this allows it to make a profit. Kenneth Arrow asserts diminishing marginal utility as one of his series of assumptions in developing a theory of ideal insurance against the cost of health care. Kenneth J. Arrow, *Uncertainty and the Welfare Economics of Medical Care*, 53 Am. ECON. REV. 941, 959-60 (1963).

Kenneth Abraham relates risk aversion to the purchase of insurance:

People apparently are willing to pay more than their expected loss for insurance against the loss. Otherwise insurance companies could not finance administrative expenses or earn profits. This risk aversion may in part reflect the diminishing marginal utility of income. People pay a few of their last-earned dollars in order to avoid the risk of losing their first-earned dollars. Certain loss of the amount of an insurance premium reduces utility less than does the possibility of a larger loss, even when the risk of the larger loss has an expected value equal to the amount of the insurance premium.

KENNETH S. ABRAHAM, DISTRIBUTING RISK 24 (1986) [hereinafter ABRAHAM, DISTRIBUTING RISK] (footnote omitted).

15. See, e.g., MARK A. HALL, REFORMING PRIVATE HEALTH INSURANCE 5 (1994).

A number of commentators have noted that government-sponsored social insurance programs and private insurance policies reflect a common desire to cope with the uncertainties of life by shifting resources from the richer to poorer years of an individual's life. See Robert E. Goodin & Julian Le Grand, Introduction, in NOT ONLY THE POOR: THE MIDDLE CLASSES

definitive account of these underlying desires because different individuals often display different attitudes toward risk, and particular individuals often display conflicting attitudes toward risk. Some individuals gamble, some conserve their cash, some ride motorcycles, and some refuse to buy cars lacking the latest safety equipment. Particular individuals may skydive in the morning, but decline apples with pesticide residues at lunch; they may purchase insurance against the risk of premature death but not against the far more likely risk of disability. But regardless of the desires that may underlie risk management motivation, individuals engage in a variety of behaviors calculated to manage risk by reducing their financial losses and their ignorance regarding these financial losses. 17

Efforts to reduce financial losses may address the probability or severity of disease or accident or the probability or magnitude of financial losses associated with them. To reduce the probability or severity of disease or accident, individuals may eat well, exercise, wear seat belts, work in safe industries, or refrain from risky recreational activities, such as skiing. To reduce the probability or magnitude of financial losses, individuals may purchase life, health, or disability insurance or transfer their financial losses to family, church, community members, governmental support programs, or even to their creditors through bankruptcy.

Efforts to reduce ignorance regarding financial losses may consist of "self-insuring" or purchasing personal insurance. Both approaches reduce ignorance regarding the probability, magnitude, and timing of financial losses. Individuals may "self-insure" by setting aside a portion of monthly income sufficient to offset any financial losses that may occur in association with disease or accident. These individuals thereby substitute a 100% probability of the financial loss of a certain amount every month for the uncertain probability, magnitude, and timing of financial losses that might occur in association with disease or accident. Individuals also may reduce ignorance by purchasing personal insurance. As with self-insurance, personal insurance substitutes a 100% probability of financial loss of a certain amount, in the form of a premium payment made on a regular monthly or other periodic basis for the uncertain probability, magnitude, and timing of

AND THE WELFARE STATE 3, 5-6 (Robert E. Goodin & Julian Le Grand eds., 1987) [hereinafter NOT ONLY THE POOR]; Robert E. Goodin & Julian Le Grand, Not Only the Poor, in NOT ONLY THE POOR, supra at 203, 213-14. For further discussion, see infra part III.B.5 & IV.

<sup>16.</sup> See, e.g., Tversky & Kahneman, Rational Choice, supra note 13, at S255 (discussing risk aversion with respect to gains and risk seeking with respect to losses); see also Kenneth J. Arrow, Risk Perception in Psychology and Economics, 20 ECON. INQUIRY 1, 1-8 (1982) (discussing irrational risk judgments).

<sup>17.</sup> See ABRAHAM, DISTRIBUTING RISK, supra note 14, at 1-2; HALL, supra note 15, at 5-6; ROBERT H. JERRY II, UNDERSTANDING INSURANCE LAW 9-11 (1987).

financial losses that might occur in association with disease or accident.<sup>18</sup>

Thus, individuals are motivated to manage risk by reducing their financial losses and their ignorance regarding financial losses. The history of life, disability, and health insurance reveals increasing reliance on personal insurance as a means to manage risk.

#### B. Risk Management Motivation and the Development of Insurance

Life, disability, and health insurance are relatively recent inventions. Their enormous growth is largely a phenomenon of the twentieth century. Their growth reflects, in part, their increasing capacity to serve as a desirable means of managing risk and, in part, the diminishing desirability of other means of managing risk. Their growth also reflects the tremendous economic expansion of the twentieth century; individuals increasingly have come to hold financial assets they wish to protect against loss and financial assets with which to purchase such protection. Finally, their growth has been influenced in a variety of ways by governmental regulation and by competing governmental programs.

Modern life insurance emerged in the eighteenth century<sup>20</sup> and grew in the nineteenth century in tandem with the development of a modern, urban, wage-earning, individualistic society.<sup>21</sup> The life insurance industry expanded rapidly beginning in the late nineteenth century and throughout the twentieth century due to rapid urbanization, economic growth, and the disintegration of extended families and neighborhoods, which had been the primary sources of support for families in the event of the deaths of breadwinners.<sup>22</sup> These social and economic developments in the twentieth

<sup>18.</sup> Unlike self-insurance, personal insurance also reduces vulnerability to financial losses that may exceed expected losses. See infra part II.C. (discussing unpredicted financial losses).

<sup>19.</sup> See ABRAHAM, INSURANCE LAW & REGULATION, supra note 14, at 1 n.1. (stating that religious and social groups in a number of ancient societies acted as intermediaries, taking in funds from their members and disbursing them to those members who suffered sickness or disability); JERRY, supra note 17, at 16; see also J. OWEN STALSON, MARKETING LIFE INSURANCE: ITS HISTORY IN AMERICA 3-28 (1942) (discussing the management of various forms of risk).

<sup>20.</sup> Cruder forms of life insurance, such as the tontine, began in the late seventeenth century in England, but modern life insurance did not evolve until more than a century later. SHEPARD B. CLOUGH, A CENTURY OF AMERICAN LIFE INSURANCE 18-19 (1946); see STALSON, supra note 19, at 17.

<sup>21.</sup> Historians of the development of life insurance commonly note that it evolved at a time when the development of capitalism increasingly alienated individuals and their families from communities of support. See CLOUGH, supra note 20, at 3-17; B. MICHAEL PRITCHETT, FINANCING GROWTH: A FINANCIAL HISTORY OF AMERICAN LIFE INSURANCE THROUGH 1900, 4-19 (1985); STALSON, supra note 19, at 7-18.

<sup>22.</sup> See MORTON KELLER, THE LIFE INSURANCE ENTERPRISE 1885-1910 (1963). Keller writes:

century also contributed to the establishment of governmental programs to support families in financial need.<sup>23</sup>

Disability insurance emerged in the late nineteenth century.<sup>24</sup> The disability insurance industry grew in the post—World War I years only to suffer serious financial difficulties during the period between 1929 and 1940. During this turbulent economic period, claims increased in volume and average length. In addition, liberal definitions of disability contributed to increased claims.<sup>25</sup> However, the disability insurance business rebounded thereafter; from the late 1960s, the disability insurance business has grown steadily and has been especially successful in extending coverage to higher income groups of insureds.<sup>26</sup> Beginning in the 1950s, a number of governmental programs were established to provide income protection, especially for families of lower income workers in the event of disability.<sup>27</sup>

Early efforts to provide health insurance in the nineteenth century met with little success.<sup>28</sup> The first health care insurance plan offered in the United States was developed by Baylor University Hospital in 1929. The Baylor Plan provided coverage of hospital expenses, initially for a group of

of commercial and professional people. Both developments strengthened the appeal of life insurance in the late nineteenth century. The rise of the cities created an ever growing mass of people detached from the relationships and environment that once had provided security. Previously, on the farm or in the small town, the clan-family or one's neighbors provided social stability and economic safety; property was landed, permanent, protected. In the shifting, expansive, uncertain life of the city, where assets were more fluid and more in jeopardy, the immediate family unit had to seek out its own security. In a world of changing residences, jobs, and friends, life insurance could be a tangible expression of family continuity, responsibility, and security.

Id. at 9 (footnote omitted).

- 23. See, e.g., JERRY, supra note 17, at 36-37 (describing governmental programs of life insurance for members of the Armed Forces).
- 24. CHARLES E. SOULE, DISABILITY INCOME INSURANCE: THE UNIQUE RISK 1 (1984). Earlier forms of disability insurance were more limited in the scope of their coverage. *Id.*; see also JERRY, supra note 17, at 15-18.
- 25. SOULE, *supra* note 24, at 4. The most significant problem faced by the emerging disability income insurance business was defining the risk insured against. MONROE BERKOWITZ ET AL., PUBLIC POLICY TOWARD DISABILITY 45 (1976).
- 26. SOULE, *supra* note 24, at 14. From the 1970s to the present, the disability insurance market has increasingly focused on the professional, white-collar market, essentially abandoning the lower income blue-collar market to governmental programs for disability insurance. *Id.*
- 27. See EDWARD H. YELIN, DISABILITY AND THE DISPLACED WORKER 1, 43-44 (1992). Federal and state programs, developed in 1956, increasingly offered income protection to lower income individuals with the effect of squeezing out much of the lower-income, private disability insurance market. Id.; see, e.g., BERKOWITZ ET AL., supra note 25, at 48; SOULE, supra note 24, at 11-12.
- 28. PAUL STARR, THE SOCIAL TRANSFORMATION OF AMERICAN MEDICINE 241 (1982); see also HALL, supra note 15, at 13-16.

Dallas school teachers, and then for others.<sup>29</sup> Blue Cross plans emerged in the 1930s and began by providing coverage of hospital expenses in exchange for payment of annual fees that were based upon the average health care costs of the community rather than upon risk characteristics of individual insureds or the past experience of groups of insureds.<sup>30</sup> Blue Shield was the first insurance company to offer similar coverage for physicians' fees.<sup>31</sup> Soon, commercial insurance companies developed health insurance policies based upon the successful examples of Blue Cross and Blue Shield.<sup>32</sup>

The extension of health insurance coverage to the vast majority of the U.S. public was due to the rapid expansion of group health care coverage offered through employers in the post–World War II period. The expansion was fueled by government regulatory decisions that excluded certain fringe benefits from wartime ceilings on wage increases, and at the same time excluded health insurance benefits from employees' taxable incomes.<sup>33</sup> As a result, employers were able to offer compensation to their employees at no tax costs to the employees. In the 1960s, substantial governmental programs began providing health care benefits to the aged, the poor, and the medically needy.<sup>34</sup>

Insurance companies selling life, disability, and health insurance have generally succeeded to this point in persuading increasing numbers of

<sup>29.</sup> RASHI FEIN, MEDICAL CARE, MEDICAL COSTS 10 (1986). The Baylor Plan was a means of assuring payment to Baylor University Hospital, which had suffered increasingly from delinquent accounts, in part because of increasing health care costs. *Id.*; see also STARR, supra note 28, at 295-98 (describing the financial insecurity of hospitals and the value of insurance plans in ensuring their stability).

<sup>30.</sup> RITA RICARDO-CAMPBELL, THE ECONOMICS AND POLITICS OF HEALTH 210 (1982); Bryan Ford, The Uncertain Case for Market Pricing of Health Insurance, 74 B.U. L. REV. 109, 113 (1994). Blue Cross was the invention of hospital representatives and health care providers who wished to ensure the financial security of hospitals as well as to make hospital care more widely available to patients. FEIN, supra note 29, at 11-14, 17. For a discussion of community rating, that is, setting premiums according to average health care costs of members of a community, see infra parts II.C & III.B.5.

<sup>31.</sup> STARR, supra note 28, at 307; Ford, supra note 30, at 112.

<sup>32.</sup> FEIN, supra note 29, at 19-20.

<sup>33.</sup> FEIN, supra note 29, at 22 (noting that employers deduct health insurance contributions as a cost of doing business just as with wages); STARR, supra note 28, at 310-11 (noting that "[a] more or less fortuitous development during the war stimulated the interest of employers in using group health plans to improve loyalty and recruitment. In 1942 the War Labor Board decided that fringe benefits up to five percent of wages would not be considered inflationary, and so employers, finding labor scarce during the war, increased employee benefits to attract and keep their workers."); Anne P. Birge, The Pending Crisis in Employer-Provided Health Benefits for Retirees: Are Tax Breaks for Employers the Answer?, 19 N.Y.U. REV. L. & SOC. CHANGE 797, 798 (1992); Ford, supra note 30, at 114.

<sup>34.</sup> Governmental programs include Medicaid Title XIX (providing coverage for some poor persons) and Medicare Title XVIII (providing coverage for most elderly persons). See Social Security Amendments of 1965, Pub. L. No. 89-97, 79 Stat. 286 (1965) (codified as amended at 42 U.S.C. §§ 1395-1396u (1988 & Supp. IV 1992)).

insureds to use insurance as a risk management device. The desirability of insurance is due to its relative effectiveness in managing risk and to the additional private benefits that the functioning of the insurance mechanism yields.

## C. Risk Management Motivation, Profit-Making, and the Functioning of the Insurance Mechanism

The purpose of insurance from the perspective of individuals is risk management. The purpose of insurance from the perspective of insurance companies is to make a profit.<sup>35</sup> Insurance companies collect premium dollars from insureds and then invest a portion of these premium dollars. An insurance company makes a profit if the amount of premiums plus investment earnings exceeds the amount of its administrative expenses plus the costs of claims of insureds. But an insurance company can make a profit only if it succeeds in two tasks: first, the insurance company must be able to predict the premium amounts it must charge if it is to make money in excess of administrative expenses and claims costs; and second, the insurance company must persuade insureds that it is worth their while to pay these premiums.

To accurately predict the premium amounts it must charge, an insurance company must predict its administrative expenses and the expected costs of claims. Predicting claims is the more challenging and significant undertaking. To predict claims, the insurance company must obtain particular information regarding the characteristics of its insureds and statistical data correlating these characteristics with claims. The insurance company also must combat behavior by insureds that otherwise would undermine the accuracy of its predictions.

Insurance companies use this particular information regarding insureds and statistical data in a process called underwriting.<sup>36</sup> In the case of individually underwritten insurance policies, the insurance company obtains information about individuals to predict claims. In the case of life insurance,

<sup>35. &</sup>quot;To make a profit" in this context refers to making money in excess of the claims of insureds and administrative expenses of the insurance company, regardless of the form of organization of the insurance company, that is, mutual, fraternal or stock. See ABRAHAM, INSURANCE LAW & REGULATION, supra note 14, at 1; JERRY, supra note 17, at 34-36; ROBERT E. KEETON & ALAN I. WIDISS, INSURANCE LAW: A GUIDE TO FUNDAMENTAL PRINCIPLES, LEGAL DOCTRINES, AND COMMERCIAL PRACTICES 33-35 (student ed. 1988).

<sup>36.</sup> As used in this article, "underwriting" refers to the process by which insurance companies classify individuals according to their predicted risk for the purpose of deciding whether to offer or refuse them coverage, what restrictions to impose on any coverage offered them, and what rates to charge them for any coverage offered. See generally ABRAHAM, DISTRIBUTING RISK, supra note 14, at 64-100; HALL, supra note 15, at 11; JERRY, supra note 17, at 14.

risk factors correlated with claims for loss of life might include age, sex, and history of disease.<sup>37</sup>

Insurance policies issued to groups, such as employment groups, typically are experience-rated. This means that, in underwriting the group, the insurance company obtains information about the claims experience of the group and uses this information to make statistical predictions of claims.<sup>38</sup> Community-rated health insurance policies, whether issued to individuals or groups, are underwritten on the basis of community-wide information.<sup>39</sup> The insurance company obtains information about the claims experience of a community and uses this information to predict claims.<sup>40</sup>

In addition to predicting claims, insurance companies must combat behavior by insureds that might undermine the accuracy of their predictions. These behaviors generate phenomena known as adverse selection and moral hazard.

Adverse selection refers to any process that results in an undesirably high proportion of high-risk insureds purchasing insurance coverage from a particular insurance company. Adverse selection often results when an insured misrepresents or conceals information about the insured's risk factors. For example, if an insured knows about a family history of heart disease but fails to tell the life insurance company, the insurance company most likely will offer the insured a bargain premium for life insurance, that is, a premium that is too low in light of the insured's risk of financial losses associated with heart disease. If the insured knows further that the insured does in fact suffer from heart disease and that death is imminent, the insured may succeed in essentially transferring all financial losses associated with

<sup>37.</sup> Life insurance policies typically are individually underwritten, as are some health and disability polices. See Harry Ostrer et al., Insurance and Genetic Testing: Where Are We Now?, 52 Am. J. Hum. Genet. 565, 566-69 (1993); Robert J. Pokorski, Use of Genetic Information by Private Insurers, in JUSTICE AND THE HUMAN GENOME PROJECT, supra note 7, at 91, 98-100.

<sup>38.</sup> Health insurance policies and disability insurance policies typically are experiencerated in this way. Even when using experience rating, insurance companies may seek some particular information about individuals for the sake of excluding individuals from coverage or excluding coverage of pre-existing conditions. See Ostrer et al., supra note 37, at 566-67; Pokorski, Use of Genetic Information by Private Insurers, in JUSTICE AND THE HUMAN GENOME PROJECT, supra note 7, at 91, 99.

<sup>39.</sup> Modified community rating schemes also seek particular information about individuals, such as their ages, for the sake of establishing two or more tiers of premiums for community members. See HALL, supra note 15, at 63.

<sup>40.</sup> Blue Cross and Blue Shield initially offered community-rated health insurance policies. See discussion of the history of health insurance at *supra* part II.B.

<sup>41.</sup> ABRAHAM, DISTRIBUTING RISK, supra note 14, at 15, 68, 123-24; HALL, supra note 15, at 10-12; JERRY, supra note 17, at 14; see also Epstein, supra note 9, at 9-13 (discussing the strategic use of information gained through genetic diagnostic tests).

premature death to the insurance company and its other insureds.<sup>42</sup>

The insured's motivation to reduce the magnitude of financial losses associated with the insured's premature death is understandable. But the consequences for the insurance company may be devastating. If enough individuals succeed in obtaining bargains, an adverse selection price spiral will result.<sup>43</sup> In an effort to cover the costs of unpredicted claims, the insurance company will raise its premiums. Lower risk individuals will decline insurance coverage offered at these higher premiums, opting instead to purchase insurance at lower premiums from other insurance companies or to engage in other risk management strategies, such as self-insuring. The insurance company will suffer adverse selection of insureds, that is, it will retain ever more high-risk insureds as it continues to increase premiums in an effort to cover increasing costs of claims. This adverse selection price spiral may well conclude with the insurance company's insolvency.<sup>44</sup>

However, insurance companies do have means of combatting adverse selection. In the underwriting process, the insurance company can ask individuals questions about their health status, order medical tests, and obtain medical records. In this way, insurance companies can discover otherwise private information about individuals' risk factors. However, this self-defense against adverse selection will succeed only if the information obtained by the insurance companies is indeed reliable. If individuals could lie with impunity when asked questions about their health status, some most likely would lie; insurance companies, then, could not obtain reliable information. Regulatory law, in this case the law of misrepresentation and concealment, works fairly well to police lying by imposing penalties upon insureds who do lie, usually loss of coverage.

An insurance company can also combat adverse selection simply by

<sup>42.</sup> See generally Epstein, supra note 9, at 12-13.

<sup>43.</sup> See HALL, supra note 15, at 11-12 (describing the adverse selection price spiral).

<sup>4.</sup> *Id*.

<sup>45.</sup> See Hall, supra note 15, at 11; Pokorski, Use of Genetic Information by Private Insurers, in JUSTICE AND THE HUMAN GENOME PROJECT, supra note 7, at 91, 99.

<sup>46.</sup> Individuals do lie even though they risk the loss of coverage. See ABRAHAM, INSURANCE LAW & REGULATION, supra note 14, at 14-16. Presumably, in the absence of any external disincentives, people would lie more often.

<sup>47.</sup> Some lying, and consequently adverse selection, is inevitable. See HALL, supra note 15, at 11. Jurisdictions vary in determining two questions: (1) what kinds of misrepresentations subject insureds to penalty and (2) what is the passage of time after which coverage of insureds is incontestable despite insureds' misrepresentations. Id. Some amount of adverse selection will persist because some insureds will have relevant information that insurance companies do not know is relevant. Id. Also, obtaining statistical information regarding risk factors and reliable information regarding particular individuals is expensive. Id. Thus, insurance companies constantly calculate the expense of pursuing additional information compared to the expense of suffering adverse selection. Id.; see also KEETON & WIDISS, supra note 35, at 567-76.

insuring groups of individuals. If the group is organized for some purpose other than the purchase of insurance, such as employment, an insurance company will be well protected against the strategic use of information by individuals in the group.<sup>48</sup> For example, individuals are far more likely to join an employment group to earn a living rather than to obtain a bargain premium. Furthermore, employment groups consist of individuals who are at least healthy enough to perform their employment duties.

The second threat to the ability of insurance companies to predict claims is moral hazard.<sup>49</sup> Moral hazard refers to the consequences of bargain-seeking behavior by insureds after they purchase insurance rather than at the time of purchase, as with adverse selection. A bargain-seeking insured may choose to engage in behavior that increases the costs of claims because the insured knows that the insurance company will pay for these increased costs. For example, the insured may engage in risky conduct secure in the knowledge that, should death occur, financial compensation to the insured's family is assured. Similarly, an insured may be quicker to engage the services of health care providers or to seek inefficient or unnecessary health care services.<sup>50</sup> Moral hazard, if unchecked, also may drive an insurance company to insolvency.

However, insurance companies have means of combatting moral hazard as well. First, insurance companies can protect themselves with contractual provisions that preclude claims incurred as a result of an insured's risky conduct. For example, life insurance policies may exclude coverage if an insured commits suicide<sup>51</sup> or dies as a result of engaging in specified risky activities, such as skydiving.<sup>52</sup> Health insurance policies typically require insureds to obtain pre-approvals of hospital admissions to guard against overuse of health care services or impose co-payments or deductibles as counter-incentives to overuse.<sup>53</sup> Disability insurers typically limit the percentage of salary they pay to insureds in the event of disability to discourage insureds from remaining idle when they are fit enough to return

<sup>48.</sup> See HALL, supra note 15, at 12.

<sup>49.</sup> See ABRAHAM, DISTRIBUTING RISK, supra note 14, at 14-15, 35-36, 60, 66 (discussing moral hazard); see also HALL, supra note 15, at 12-13 (stating that moral hazard is responsible for much of the structure and content of an insurance policy); JERRY, supra note 17, at 13-14.

<sup>50.</sup> In addition, in the case of health insurance, providers of health care services may encourage moral hazard. Because providers are subject to a number of incentives to provide services, including personal gain, patient benefit, and fear of liability, they tend to provide extra services if they know that their patients have insurance coverage and, thereby, increase the claims of their patients. See Arrow, supra note 14, at 961-62.

<sup>51.</sup> ABRAHAM, INSURANCE LAW & REGULATION, supra note 14, at 342 (describing exclusion under accidental life insurance policies).

<sup>52.</sup> See id. at 339-40 nn.2-3.

<sup>53.</sup> See HALL, supra note 15, at 13.

to work.<sup>54</sup> Also, to the extent insurance companies base future premiums upon an insured's past claims, they create financial disincentives to moral hazard.<sup>55</sup>

To make a profit, an insurance company must not only determine the premium amounts it needs to charge, but also must persuade insureds to pay these premiums in exchange for insurance coverage rather than to pursue other risk management strategies. There are five private benefits that make insurance particularly attractive as a risk management device.

Two distinctive features of insurance yield private benefits to individuals who purchase insurance rather than use alternative risk management strategies. First, insurance reduces insureds' risk of unpredicted financial losses. Second, insurance conveys information through the underwriting process that enables individuals to reduce their vulnerability to disease, disability, and premature death.

Insurance uniquely reduces an insured's risk of unpredicted financial losses. These financial losses are not predicted because the causes are not understood, or the causes are understood but undiscoverable or too expensive to be worth discovering. For example, the causes of many types of cancer are not understood; the causes of some genetic diseases are understood but are undiscoverable or undiscoverable at a reasonable cost, given current technology. Other risk management strategies do not reduce the risk of unpredicted financial losses. Reducing risky conduct reduces only those financial losses known to be correlated with that conduct; by definition, it cannot be directed at reducing the risk of unpredicted financial losses. Self-insurance does not reduce the risk of unpredicted financial losses. Rather, self-insurance requires the self-insured individual to save against the possibility of unpredicted financial losses or suffer the consequences of

<sup>54.</sup> See ABRAHAM, INSURANCE LAW & REGULATION, supra note 14, at 399.

<sup>55.</sup> See Henry T. Greely, Health Insurance, Employment Discrimination, and the Genetics Revolution, in THE CODE OF CODES, supra note 1, at 264, 272-73 (discussing the accuracy of health status, diagnostic health groups, and prior or current use of medical services in predicting future costs of Medicare patients).

<sup>56.</sup> See HALL, supra note 15, at 7. As Abraham explains:

Expected loss is a prediction of an insured's actual losses. For two reasons, however, actual losses vary from expected loss. First, calculations of expected loss normally do not and cannot be based on all relevant variables. A classification based on one or a few variables is likely to be at best a rough estimate of any individual insured's actual loss. . . . Second, expected loss is only the predictable component of any individual's actual loss. For practical purposes a large component of most individuals' and enterprises' actual losses must be considered to occur by chance. Such random losses are either impossible to predict at all given current knowledge or too costly to predict.

failing to do so.57

The insurance mechanism reduces the risk of unpredicted financial losses by distributing this unpredicted risk among the pool of insureds. Due to the law of large numbers, the actual financial losses for the pool will be close to the aggregate financial losses predicted for the pool by an insurance company.<sup>58</sup> Thus, an insurance company can successfully predict its costs of claims in order to make a profit, and its insureds enjoy the benefit of reduced risk of unpredicted financial losses.

The insurance mechanism provides a second unique benefit in that it potentially reduces vulnerability to disease, disability, and premature death by conveying information and incentives regarding risk factors to insureds. For example, if an insurance company offers non-smoker discounts when it sets rates, this communicates to insureds that smoking is associated with a higher risk of financial losses and provides financial incentives to stop smoking. Assuming that an insured is willing and able to control a risk factor identified, the information and incentives conveyed can reduce the insured's vulnerability to disease, disability, and premature death. This benefit is unique to insurance as a risk management device because it is

The concept of risk can be made more precise by distinguishing between the calculated odds that a bad event will occur, which is the primary risk, and the chance that the calculation might prove wrong as real events occur, which is the secondary risk.

The core social benefit of insurance is that it reduces secondary risk by reducing variance. This reduction occurs through what is known as the law of large numbers, which states that, for a given risk (say, of a coin turning up tails), variance is reduced the more times the risk is incurred.

Insurance reduces secondary risk, which is the risk that the calculated odds will not bear themselves out, by pooling a large number of similar risks.

HALL, supra note 15, at 7.

<sup>57.</sup> Typically, individuals and entities self-insure only to a point. They then purchase "stop loss" insurance to cover financial losses beyond that point. ALAN A. SORKIN, HEALTH ECONOMICS 177 (1992).

<sup>58.</sup> Mark Hall describes unpredicted financial losses or "secondary risk" in health insurance and the law of large numbers as follows:

<sup>59.</sup> Reductions in risk due to information and incentives are most significant in the context of property and casualty insurance. See ABRAHAM, DISTRIBUTING RISK, supra note 14. Potentially, the information and incentives also may yield both public benefit and harm. For further discussion of these possibilities, see infra text accompanying notes 68-69, 82-83.

<sup>60.</sup> The effectiveness of this communicative process is controversial. See HALL, supra note 15, at 30. However, some dramatic effects have been found in employers' wellness programs, instituted, in part, to reduce experience-rated health insurance premiums. Id. Also, reductions in worker injuries have been found under experience-rated workers' compensation coverage, in which employers' premium costs are increased according to the claims experience of the employment groups. Id.; Christopher J. Bruce & Frank J. Atkins, Efficiency Effects of Premium-Setting Regimes Under Workers' Compensation: Canada and the United States, 11 J. LAB. ECON. S38, S60-S67 (1993). See the related discussion regarding the public benefit of improved efficiency infra part II.D.

accomplished through the insurance underwriting process.

Insurance companies also have developed three other private benefits to help persuade individuals to purchase insurance. First, the sale of life, disability, and health insurance through group insurance policies offers administrative savings and convenience.<sup>61</sup> Second, health insurance has evolved into a means of conveniently financing routine health care services.<sup>62</sup> Third, life insurance often includes convenient options for personal savings.<sup>63</sup>

First, with respect to administrative savings, group policies administered through employers or other group policyholders significantly reduce administrative costs. These cost savings result from an insurance company selling and providing service to one policyholder rather than numerous insureds and experience-rating the group rather than engaging in far more costly individual underwriting of numerous insureds.<sup>64</sup>

Second, individuals may benefit from insurance as a convenient long-term financing mechanism for losses of high probability and low magnitude. In particular, employer-sponsored comprehensive health insurance has evolved into a means of financing fairly predictable health care expenses through group periodic premium payments.<sup>65</sup>

Third, some life insurance policies have long offered the benefit of a savings feature.<sup>66</sup> Through regular contributions to insurance policies with an investment component, insureds of even fairly modest means have found a simple and convenient means of saving money.<sup>67</sup>

Thus, the insurance mechanism has enabled insurance companies to make profits and insureds to manage their risk while realizing other private benefits. This is, in itself, as socially desirable as any other mutually-

<sup>61.</sup> See KEETON & WIDISS, supra note 35, at 982-84. This private benefit potentially yields both public benefit and harm. While at its inception employer-sponsored insurance was considered socially beneficial, in that it encouraged a strong bond between employers and employees, it is now often deplored for generating "job-lock". Job-lock refers to the phenomenon of employees remaining in undesirable employment situations only because they do not want to lose their insurance benefits. See Roberta Berry, National Health Care Reform: Welfarism Out of Context, 46 WASH. U.J. URB. & CONTEMP. L. 95, 106-07 (1994).

<sup>62.</sup> See HALL, supra note 15, at 31. This private benefit potentially yields both public benefit and harm, as discussed at infra text accompanying notes 90-94.

<sup>63.</sup> See PRITCHETT, supra note 21, at 13-19. This private benefit potentially yields both public benefit and harm, as discussed at *infra* text accompanying notes 87-89.

<sup>64.</sup> See KEETON & WIDISS, supra note 35, at 982-84.

<sup>65.</sup> See HALL, supra note 15, at 10.

<sup>66.</sup> KELLER, supra note 22, at 9-10.

<sup>67.</sup> PRITCHETT, supra note 21, at 13 (noting that whole-life insurance has long been a means by which a broad spectrum of individuals could save and stating: "The common impression that the life insurance industry mobilized the funds of many small or reluctant savers seems to be a valid one. The general economic history of the period is consistent with this conclusion, though it is difficult to test directly in a careful way.").

beneficial marketplace transaction. However, the functioning of the insurance mechanism also yields other consequences that are matters of societal concern. Organized society, through its policymakers, often examines the social consequences of otherwise unobjectionable marketplace transactions to determine whether these transactions are, on balance, desirable and whether private and public benefits could be maximized and harms minimized through governmental intervention in the marketplace.

## D. The Social Consequences of the Functioning of the Insurance Mechanism

The history of life, disability, and health insurance reveals the success of insurance as a device to satisfy the private ends of insureds and insurance companies. This history also reveals a variety of social consequences of the functioning of the insurance mechanism. These consequences include: (1) increased efficiency through the communication to insureds and group policyholders of information and incentives pertaining to risk, but with potentially unacceptable ethical consequences in some cases; (2) economic growth and health care innovation resulting from the injection of large amounts of health insurance dollars into the health care sector, but with bioethical questions raised by innovation and social policy questions raised by increases in health care costs; (3) protection of the public purse by providing a private mechanism for safeguarding against financial losses, but only to the extent that this mechanism remains affordable; and (4) advances in social solidarity through the sharing of misfortune, but at the expense of excluding the most vulnerable from the community of shared risk.

Increasing efficiency, in the context of insurance, means reducing the total cost of insurance.<sup>68</sup> If the underwriting process yields the private benefit of reduced vulnerability to disease, disability, and premature death, and reduces associated financial losses, society will benefit from increased efficiency.<sup>69</sup> Everyone in society benefits if the financial losses of any member of society are reduced because the resources otherwise required to pay for the financial losses are freed for other beneficial uses.

The fact that increased efficiency is socially beneficial is not controversial. However, efficiency can be increased only if the information communicated to insureds is accurate and if insureds are willing and able to act on this information.<sup>70</sup> Whether these conditions are satisfied by the

<sup>68.</sup> See ABRAHAM, DISTRIBUTING RISK, supra note 14, at 64-100 (discussing efficiency in the insurance context). As Abraham notes, increased efficiency most clearly flows from the functioning of the insurance mechanism in the context of property and casualty insurance. Id.

<sup>69.</sup> See discussion supra part II.C.

<sup>70.</sup> See discussion supra part II.C.

functioning of the insurance mechanism is debatable. Furthermore, some gains in efficiency may come only at the unacceptable price of the violation of important ethical principles or public policies.<sup>71</sup>

The history of life insurance suggests it has promoted some gains in efficiency. The increased efficiency has derived from the ability and motivation of life insurance companies to gather statistical information correlating certain risk factors with mortality and to convey information and incentives regarding these risk factors to insureds through the underwriting process. However, any gains in efficiency will be limited because numerous risk factors are beyond the control of insureds, such as sex and age, or are very difficult to control, such as occupation. The such as a sex and age, or are very difficult to control, such as occupation.

Whether disability insurance or health insurance has contributed to increased efficiency is questionable. The difficulty lies in the willingness and ability of individuals to avoid or reduce the health risks that are communicated to them through the underwriting process<sup>74</sup> and to choose more efficient providers of health care services. 75 There is evidence that the immediacy of financial incentives, such as reduced premiums, may affect insureds' behavior even though more generalized fears of suffering and death do not.<sup>76</sup> However, most health insurance and disability insurance is purchased through group plans, which, generally, are experience-rated rather than individually underwritten.<sup>77</sup> This means that all members of the group are charged the same premiums regardless of the risk each individual insured poses. 78 Given the attenuated relationship between an individual's conduct and the portion of experience-rated group premiums that the individual pays, experience-rated group insurance premiums are unlikely to directly influence individual conduct.

Experience-rated group disability and health insurance may increase efficiency, however, if employers receive incentives to improve the safety of

<sup>71.</sup> See discussion supra part II.C.

<sup>72.</sup> See CLOUGH, supra note 20, at 11 (noting the influence of life insurance companies in promoting public health measures as well as healthly behavior among insureds).

<sup>73.</sup> See ABRAHAM, DISTRIBUTING RISK, supra note 14, at 76-83.

<sup>74.</sup> See id. at 24; HALL, supra note 15, at 29.

<sup>75.</sup> See HALL, supra note 15, at 30-31; see also Arrow, supra note 14, at 961-62 (regarding moral hazard caused by selection of inefficient providers and over-stimulation of demand by providers).

<sup>76.</sup> See HALL, supra note 15, at 29 n.17. Hall notes that financial incentives of this sort actually do appear to affect behavior. Id.

<sup>77.</sup> See the discussion at supra part II.C.

<sup>78.</sup> This is qualified by the fact that insurance companies commonly refuse to cover preexisting conditions. See Pokorski, Use of Genetic Information by Private Insurers, in JUSTICE AND THE HUMAN GENOME PROJECT, supra note 7, at 99-100. To the extent that the causes of these exclusions from coverage are within the control of insureds, the exclusions create incentives to reduce health risks. However, there is no such beneficial effect when these health conditions are not within the control of insureds.

the workplace. The incentives may be communicated by changes in the portion of the premiums for group insurance that employers pay on behalf of their employees.<sup>79</sup> Employers also increasingly offer incentives, such as wellness programs, to their employees to improve their health and, thereby, reduce premium payments of both employers and employees.<sup>80</sup>

Individually underwritten and experience-rated health insurance also may promote efficiency through incentives to obtain efficient health care services. If premiums are adjusted to reflect the financial losses incurred by insureds, this will generate incentives among insureds and employers paying premiums on their behalf to see to it that insureds obtain services from efficient providers of health care services.<sup>81</sup>

However, the pursuit of efficiency may exact an unacceptable price. To the extent disease is minimized through changes in behavior or in workplace conditions, no impingement upon other values occurs. But if, for example, insurance companies communicate incentives, through premium cost or coverage, to individuals to abort genetically defective fetuses<sup>82</sup> or to employers to not hire or retain employees with genetic defects,<sup>83</sup> other important ethical and public policy concerns arise.

With respect to investment in economic growth and in health care innovation, the historical contributions of insurance companies are substantial. However, given that these investments are the consequence of tax-favored policies, the net public benefit is a matter of controversy. Furthermore, health care sector growth and innovation have raised bioethical questions and contributed to escalating health care costs that potentially reduce access to health care.

The first individual life insurance policies in the United States were issued by the Corporation for the Relief of Poor and Distressed Presbyterian Ministers and of the Poor and Distressed Widows and Children of Presbyterian Ministers.<sup>84</sup> The corporation pursued an aggressive investment

<sup>79.</sup> Dramatic evidence of increased efficiency achieved through experience rating of insurance was revealed in a study of workers' compensation. See Bruce & Atkins, supra note 60, at passim. Employers have a very direct interest in decreasing their workers' compensation insurance premiums by reducing injuries because workers' compensation statutes require them to provide the coverage. Id.

<sup>80.</sup> There is evidence that employers increasingly offer health promotion programs. See HALL, supra note 15, at 29-30 nn.17-19; Nancy A. Jeffrey, "Wellness" Plans Try to Target the Not-So-Well, WALL St. J., June 20, 1996, at B1. See the related discussion of moral hazard supra part II.C.

<sup>81.</sup> See HALL, supra note 15, at 30-31.

<sup>82.</sup> See Paul R. Billings et al., Discrimination as a Consequence of Genetic Testing, 50 Am. J. Hum. Genet. 476, 480-81 (1992).

<sup>83.</sup> See Mark A. Rothstein, Genetic Discrimination in Employment and the Americans with Disabilities Act, 29 Hous. L. Rev. 23, 28 (1992).

<sup>84.</sup> PRITCHETT, supra note 21, at 4-5.

program with the capital it received from individuals affiliated by religious conviction.<sup>85</sup> With the development of mutual insurance companies in the mid-nineteenth century, the life insurance business grew significantly.<sup>86</sup> As the accumulation of investment capital in life insurance companies grew, investment in the U.S. economy by these companies contributed significantly to an increase in commerce and wealth.<sup>87</sup> This investment also helped increase the availability of credit, reduce interest rates, and provide a stronger secondary market for securities.<sup>88</sup>

However, life insurance company investment in the economy is, in large part, a consequence of the favorable tax treatment for the investment feature offered with many life insurance policies. To the extent insureds' dollars have been diverted from other investments or uses, and investment through life insurance companies has enjoyed a tax "subsidy," the net public benefit is questionable.

Health insurance has generated economic growth through the enormous expenditure of premium dollars in the health care sector. In particular, the stimulus has accelerated the development of new health care technologies and pharmaceuticals. However, these innovations have raised difficult bioethical questions and have contributed to rapid escalation in the costs of health care. 90

The level of investment in the health care sector may be judged inappropriate despite the advances stimulated by this investment. Governmental tax policy that excludes health benefits from taxable income has generated more health insurance, and hence, more health care spending

Pritchett undertakes an empirical examination of investment by life insurance companies and finds that these companies made substantial investments, although generally not in formative or high-risk American companies:

The examination reveals that life insurance companies did gather the resources of millions of policy holders and make them available for both public and private investment. However the nature of the insurance business, together with restrictive regulation, systematically made this general infusion of funds unavailable to firms in their formative and high-risk years. Thus, life insurance investments were a less critical financing feature of particular industries during formative and innovative periods than they might otherwise have been.

<sup>85.</sup> Id. at 5.

<sup>86.</sup> Id. at 7.

<sup>87.</sup> See PRITCHETT, supra note 21, at 2-3.

Id.; see also CLOUGH, supra note 20, at 9-10.

<sup>88.</sup> PRITCHETT, supra note 21, at 73.

<sup>89.</sup> See Alan Gunn & Larry D. Ward, Cases, Text and Problems on Federal Income Taxation 198-200 (3d ed. 1992).

<sup>90.</sup> See Warren Greenburg, Competition, Regulation and Rationing in Health Care 139-57 (1991).

than individuals would have chosen in the absence of this tax "subsidy". In addition, health insurance is susceptible to moral hazard, which may be thought of as excess investment in the health care sector. Advances in health care technology also have raised numerous bioethical issues, especially with respect to treatment of the terminally ill. Bioethical concerns may qualify somewhat enthusiasm for the advances that innovation has brought in curing disease and relieving suffering. Finally, the level of investment may be judged inappropriate because increased health care expenditures contribute to cost escalation. The rising cost of health care has seriously reduced the availability and affordability of health insurance for millions of U.S. citizens, which, in turn, may reduce their access to health care and may negatively affect their health status.

Life, disability, and health insurance undoubtedly have contributed to a third public benefit, protection of the public purse. Life insurance expanded greatly with the rapid industrialization of the nineteenth century and the disintegration of social organizations that previously had provided protection for family members. Governmental entities increasingly assumed responsibility for providing for those left destitute. The emergence of life insurance offered individuals a private means of providing for the well-being of their survivors. 96

<sup>91.</sup> See HALL, supra note 15, at 15 n.5 (regarding multi-billion dollar tax subsidy for health insurance); see also Paul J. Donahue, Federal Tax Treatment of Health Care Expenditures: Is It Part of the Health Care Problem?, 46 WASH. U.J. URB. & CONTEMP. L. 141 (1994).

<sup>92.</sup> See Arrow, supra note 14, at 961-62; see also HALL, supra note 15, at 22-24. For a further discussion of moral hazard, see supra part II.C.

<sup>93.</sup> See generally SORKIN, supra note 57, at 157; CLARK C. HAVIGHURST, HEALTH CARE LAW AND POLICY 1232-86 (1988).

<sup>94.</sup> See Hall, supra note 15, at 1-4 (surveying declining private health insurance coverage during the 1980s). Assessing the net social harm in consequence of this reduction is very difficult, however. Although the reduced availability and affordability of health insurance is undeniable, the extent to which this reduction also has reduced access to health care services is difficult to assess. See Berry, supra note 61, at 100-11, 106 n.39. Also difficult to assess is the extent to which reduced access to health care services affects the health status of those deprived of access. Id. at 117-20. Furthermore, assessing the overall social benefit or social harm in consequence of increased investment but reduced availability and affordability of health insurance is complicated by the differential impact of these phenomena upon different groups within society. For example, the net result may be that the sickest members of society have enjoyed an improvement in their health status thanks to increased investment in health care technology, while the working poor may have suffered a reduction in their health status due to the reduced availability and affordability of health insurance.

<sup>95.</sup> See supra part II.B.

<sup>96.</sup> See KELLER, supra note 22, at 6 (noting that in the 19th century, "[i]ncome tax remittances were granted to life insurance policyholders on the ground that they reduced pauperism and crime.") (footnote omitted). Accomplishing a public purpose through the private exercise of personal responsibility is a topic of intense debate in current U.S. politics.

Disability and health insurance evolved later and also provided a means for individuals to affordably assume personal responsibility for their own well-being and that of their families. <sup>97</sup> In the case of health insurance, however, this public benefit has been substantially muted by the rapid cost escalation caused, in part, by the favored tax treatment of health insurance. This cost escalation will force some of those no longer able to afford health insurance to resort to public support in the event of disease or accident.

Social solidarity, meaning a sharing of misfortune, is a fourth public benefit of insurance. However, the community of those who share misfortune via the insurance mechanism is largely a community of those who are ignorant about the particulars of their future misfortune. Those who are most vulnerable and who are knowledgeable about the particulars of their vulnerability are often excluded from the community as a result of insurance company efforts to combat adverse selection.

Critics of insurance note that insurance companies increasingly seek exclusivity rather than inclusivity. Insurance companies rigorously seek to exclude the riskiest from the insurance pool, asserting their need to combat adverse selection, the public benefit of efficiency, and the principle of noncoercive actuarial fairness. 99 Critics assert that a sharing of misfortune

While most perceive an important role for the state in providing for the destitute, the debate centers upon questions of appropriate incentives to assure that individuals capable of avoiding destitution for themselves and their families undertake personal responsibility to do so. Current conservative and communitarian scholarship emphasizes the need to nurture both personal responsibility and community ties that reinforce personal responsibility and provide some protection in the event of hardship. See, e.g., AMITAI ETZIONI, THE SPIRIT OF COMMUNITY: RIGHTS, RESPONSIBILITIES, AND THE COMMUNITARIAN AGENDA (1993); GERTRUDE HIMMELFARB, THE DE-MORALIZATION OF SOCIETY: FROM VICTORIAN VIRTUES TO MODERN VALUES (1995); MICKEY KAUS, THE END OF EQUALITY (1992); MARVIN OLASKY, THE TRAGEDY OF AMERICAN COMPASSION (1992).

- 97. See discussion supra part II.B.
- 98. See Deborah Stone, The Struggle for the Soul of Health Insurance, 18 J. HEALTH POL. POL'Y & L. 287, 313 (1993); Norman Daniels, The Genome Project, Individual Differences, and Just Health Care, in JUSTICE AND THE HUMAN GENOME PROJECT, supra note 7, at 110, 112-20; Donald W. Light, The Practice and Ethics of Risk-Related Health Insurance, 267 JAMA 2503, 2505 (1992).
- 99. See Daniels, The Genome Project, Individual Differences, and Just Health Care, in JUSTICE AND THE HUMAN GENOME PROJECT, supra note 7, at 112-20; Norman Daniels, Insurability and the HIV Epidemic: Ethical Issues in Underwriting, 68 MILBANK Q. 497, 501-03 (1990); Deborah A. Stone, Ad Missions: How Insurance Companies Sell Ideology, AM. PROSPECT, Winter 1994, at 19, 20; Stone, supra note 98, at 290-92. Compare Daniels, supra; Norman Daniels, supra; Stone, supra; with Pokorski, Use of Genetic Information by Private Insurers, in JUSTICE AND THE HUMAN GENOME PROJECT, supra note 7, at 103-09 (asserting that the use of genetic test information will be relatively rare and that it is justified as actuarially fair); and Epstein, supra note 9, at 13, 18-23 (arguing that insurers and other third parties should not be restricted in their access to genetic information); see also the discussion of efficiency at supra text accompanying notes 68-83 and the discussion of actuarial fairness at infra part III.B.3.

that includes most individuals but excludes those individuals most unfortunate, violates the very idea of social solidarity as a sharing of misfortune. This view of social solidarity is founded on a broader vision of social justice that seeks the redistribution of social goods and the sharing of misfortune according to egalitarian or modified egalitarian principles. In this view, the insurance mechanism should be a vehicle for achieving a just distribution of the burdens of misfortune. This just distribution must be achieved if organized society is to permit insurance companies to continue to do business in the marketplace. Public policy should be devised and implemented accordingly. In the social society is to permit insurance companies to continue to do business in the marketplace.

However, insureds do not purchase insurance for the purpose of sharing misfortune, although undoubtedly they may be motivated to share misfortune within families and among others bound by ties of affection, loyalty, or community.<sup>103</sup> Individual insureds strike deals with insurance companies

[Certain insurance industry advertisements] draw distinctions between "us" and "others," between people who deserve our sympathy and people who don't.

Some people argue that pricing health insurance according to individual risk factors encourages people to act responsibly about their health, but there are other ways to provide such incentives without destroying insurance. Insurance should be about community solidarity and mutual obligation. Instead, insurers promote an ethic of self-sufficiency and deafness to the plight of others . . . . This politics of selfishness . . . undermines the possibility of health insurance reform.

Stone, supra note 99, at 19-20. Stone concludes that "the very purpose of insurance is to create economic security by pooling large numbers of people, spreading the risk of major losses to few people among the many." *Id.* 

103. Stone and others who hold the all-inclusive view of social solidarity primarily assert that insurance should be directed toward this end, not that it now is or historically has been. To the extent that critics may want to claim that insurance was developed to achieve this end, or historically has been employed to achieve this end, the empirical case remains to be made. The early historical development of life insurance suggests that a motivation to share misfortune as well as to manage risk may have animated the enterprise. The first U.S. life insurance company served the survivors of Presbyterian Ministers and relied upon the contributions of individuals who felt a common religious affiliation. See PRITCHETT, supra note 21, at 5; see also KELLER, supra note 22, at 6. While it is most likely that the predominant motivation of these insureds was the self-interested desire to manage their own risk, perhaps they viewed the assistance to fellow survivors either as a purpose as well or, at least, as an additional private benefit that made the use of this device for managing risk

<sup>100.</sup> See Henry J. Aaron, Issues Every Plan to Reform Health Care Financing Must Confront, 8 J. Econ. Persp. 31, 36 (1994); Daniels, supra note 99, at 506-07, 511-24; Light, supra note 98, at 2506-08; Stone, supra note 98, at 290-92; see also NORMAN DANIELS, JUST HEALTH CARE 36-58 (1985) [hereinafter DANIELS, JUST HEALTH CARE] (expressing a similar concept within the context of a larger account of a just distribution of health care).

<sup>101.</sup> See DANIELS, JUST HEALTH CARE, supra note 100, at 36-58. Daniel's view draws upon John Rawls' influential vision of a system that is egalitarian with respect to the distribution of certain social goods, but only to the extent the least well off are benefitted. See JOHN RAWLS, A THEORY OF JUSTICE 157-61 (1971).

<sup>102.</sup> Stone asserts:

to manage risk, and insurance companies strike deals to make profits. The insurance mechanism has proven remarkably adept at satisfying these purposes, but if they could be satisfied without the involvement of any other individuals, without any transfer or distribution of risk, they would be.

The social solidarity achieved when these deals are struck, even though not all-inclusive, is still a valuable public benefit. Insurance allows self-interested individuals, pursuing their own risk management ends, to achieve these ends only if they help others manage risk through the cooperative undertaking of insurance. Insurance companies and regulators generally perceive social solidarity as an important public benefit and seek to maximize inclusivity to the fullest extent consistent with the functioning of the insurance mechanism.<sup>104</sup>

preferable to other alternatives. The subsequent flourishing of life insurance, however, reflects the emergence of a social system in which the ties of community solidarity steadily weakened, and private devices that satisfied the human desire for risk management were substituted. See generally CLOUGH, supra note 20; KELLER, supra note 22; PRITCHETT, supra note 21; STALSON, supra note 19. See supra part II.C. for a discussion of the historical development of life insurance.

Perhaps the governmental programs that evolved in tandem with the development of private life, disability, and health insurance might better be viewed as having as their end the achievement of social solidarity in the all-inclusive sense. However, the reality as opposed to the rhetoric of these governmental programs suggests that their enactment and evolution better reflect the use of governmental mechanisms primarily to serve the risk management motivation as well. See JAMES M. BUCHANAN & GORDON TULLOCK, THE CALCULUS OF CONSENT 189-99 (1962) (arguing that governmental social programs reflect the private desire for insurance not available in the marketplace). For further discussion of this issue, see part III.B.5.

Much of the commentary favoring a national health insurance plan is premised upon the assertion that social solidarity in the all-inclusive sense is or should be the purpose of insurance; underwriting is criticized as antithetical to achievement of this purpose because it imposes more burdens in the form of higher premiums or exclusions from coverage upon those who suffer or are relatively more likely to suffer, health misfortune. See, e.g., DANIELS, JUST HEALTH CARE, supra note 100, at 36-58; Ford, supra note 30, at 109-12, 129-43; Light, supra note 98, at 2507-08; Stone, supra note 98, at 290-94, 308-14; see also MICHAEL WALZER, SPHERES OF JUSTICE 86-91 (1983). For further discussion of this issue, see part III.B.5.

104. For a number of commentators, achieving a more inclusive sharing of misfortune should affect public policy decision-making on particular regulatory issues, especially when the functioning of the insurance mechanism has the effect of imposing burdens on those who historically have suffered invidious discrimination. See ABRAHAM, DISTRIBUTING RISK, supra note 14, at 22-25. See generally Jill Gaulding, Note, Race, Sex, and Genetic Discrimination in Insurance: What's Fair?, 80 CORNELL L. REV. 1646, 1674 (1995); Robert H. Jerry & Kyle B. Mansfield, Justifying Unisex Insurance: Another Perspective, 34 AM. U. L. REV. 329, 344 (1985). However, other commentators reject this approach, arguing instead that actuarial fairness, the idea that all should pay their fair share in light of their expected losses, should be the paramount value guiding the regulation of insurance. Pokorski, Use of Genetic Information by Private Insurers, in JUSTICE AND THE HUMAN GENOME, supra note 7, at 98-100; see also AMERICAN COUNCIL OF LIFE INS. & HEALTH INS. ASS'N OF AM., REPORT OF THE ACLI-HIAA TASK FORCE ON GENETIC TESTING (1991) [hereinafter ACLI-HIAA, GENETIC TESTING REPORT]. For further discussion of this issue, see parts III.B.2-3.

The distinction between all-inclusive social solidarity as an end of insurance that is imposed by public policy measures, and limited social solidarity as a public benefit that is a byproduct of the functioning of the insurance mechanism is an important distinction. Social solidarity as a byproduct of the current insurance mechanism is not only limited in the scope of those included but also in aspiration. Private insurance does not rely upon or foster a transcendent caring for or commitment to the well-being of one's fellow insureds. Rather, private insurance relies upon and fosters the desire to care for oneself and one's family members. The only public-oriented commitment relied upon and fostered is a commitment to enter into and honor the terms of an insurance contract because all parties recognize they can achieve their private ends only through contractual cooperation with others.

#### III. THE INTERSECTION OF THE HGP AND INSURANCE

#### A. The Collision at the Intersection

As the discussion in part II establishes, the environmental conditions required for the functioning of the insurance mechanism include vulnerability to disease, disability, and premature death. The conditions also include a peculiarly delicate balance of knowledge and ignorance; only when this balance is maintained are the private ends and the private and public benefits of insurance realized. As the discussion in part I establishes, the HGP offers the promise of reducing both vulnerability and ignorance in the not too distant future. This change in conditions will, no doubt, affect the long-term future of insurance.

In the meantime, information from genetic testing may be useful to individuals if they can undertake measures that will reduce their vulnerability to diseases to which they are predisposed.<sup>105</sup> Additionally, this information may be useful in allowing them to arrange their affairs to minimize the other hardships to themselves and their families.<sup>106</sup>

However, in the interim between the advent of widespread genetic testing and the development of cures, the increased knowledge obtained through genetic testing will pose a threat to the functioning of the insurance mechanism. If individuals know they are predisposed to develop genetic disease, they will be motivated to purchase insurance coverage at bargain

<sup>105.</sup> For example, this is the case with genetic testing for predisposition to breast or ovarian cancer. See Kolata, supra note 3, at A1. See generally Ray White & C. Thomas Caskey, Genetic Predisposition and the Human Genome Project: Case Illustrations of Clinical Problems, in GENE MAPPING, supra note 1, at 173 (discussing predisposition toward other diseases and possible treatments).

<sup>106.</sup> See Epstein, supra note 9, at 10.

premiums given their higher risk of disease; if they know that they are certain to develop disease, they will desire to transfer their imminent financial losses to others rather than bear the burden both of disease and the associated financial losses. Thus, if individuals gain access to this testing information, but insurance companies do not, adverse selection problems could be severe, threatening the viability of the insurance industry.<sup>107</sup>

On the other hand, if insurance companies require individuals to reveal genetic test information, another set of problems will threaten the insurance industry. Insurance companies most likely would use the information to discriminate in underwriting by charging higher premiums, excluding coverage of genetically caused conditions, or refusing to offer any coverage at all. Further, if some insurance companies seek this information, other companies would eventually follow suit to avoid attracting disproportionate numbers of high-risk insureds who do not wish to reveal this information. Thus, if permitted to do so, all insurance companies will most likely discriminate against the genetically unlucky in self-defense against adverse selection.

However, this defensive conduct also will threaten the viability of the insurance industry. As insurance companies force individuals to gain and reveal knowledge about their health futures, this increasingly will eliminate potential customers of insurance. Individuals increasingly will be forced to seek other means to manage risk, and the private benefits of insurance increasingly will be lost to them.

Not only will increasing numbers of individuals lose insurance coverage and the accompanying private benefits, but also the public benefits that the insurance mechanism yields will be threatened: (1) although efficiency may be enhanced as a result of individuals learning more about their genetic predispositions, it will not be enhanced if, as in many cases of genetic disease, they do not have the ability to affect their health futures; (2) a diminished insurance industry will lose the capacity to stimulate economic growth and health care innovation through investment; (3) an exclusionary insurance mechanism will fail to provide a private vehicle by which individuals may avoid imposition on the public purse; and (4) an exclusionary insurance mechanism will increasingly fail to yield a sharing of misfortune.

Of these social consequences, the most troublesome will be the increased likelihood that individuals predisposed to disease will be forced to rely on the public purse, and concomitantly, the reduced capacity of the insurance industry to accomplish a sharing of misfortune. An increasing population of individuals excluded from insurance coverage inevitably will demand the

attention of policymakers.<sup>108</sup> For the past several years, the number of uninsureds has been a source of serious policy concern.<sup>109</sup> If the insurance industry increasingly fails to provide a private alternative to governmental assistance for those most in need and increasingly excludes them from the community of shared misfortune, policymakers undoubtedly will question whether the insurance industry should undergo a major overhaul, and even whether a system of governmental insurance might be a more desirable alternative.

Fortunately, the HGP holds great promise for significant reductions in vulnerability to disease, disability, and premature death. Generous federal funding of the HGP in an era of tight budgets continues because policymakers perceive the enormous promise for future generations. The success of the next medical revolution also will safeguard the public purse by reducing financial losses associated with disease, disability, and premature death, and will constitute the ultimate expression of social solidarity by reducing the suffering associated with these misfortunes. But, until this success is achieved, the HGP will threaten the continuing viability of the insurance mechanism and the private and public benefits it yields, and will force a public policy response.

#### B. Proposed Policy Responses

#### 1. Introduction

Commentators have proposed, 110 and policymakers have considered and in some cases enacted, a number of measures that restrict insurer access to

<sup>108.</sup> See generally NIH-DOE WORKING GROUP ON ETHICAL, LEGAL & SOCIAL IMPLICATIONS OF HUMAN GENOME RESEARCH, GENETIC INFORMATION AND HEALTH INSURANCE, REPORT OF THE TASK FORCE ON GENETIC INFORMATION INSURANCE 2 (in which a task force organized to examine the problems posed with respect to insurance has already proposed policy measures in response to these concerns).

<sup>109.</sup> See Berry, supra note 61, at 100-11.

<sup>110.</sup> See, e.g., Billings et al., supra note 82, at 481-82; Larry Gostin, Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers, 17 Am. J. L. & MED. 109, 135-37, 143 (1991); Robert Lowe, Genetic Testing and Insurance: Apocalypse Now?, 40 DRAKE L. REV. 507, 531 (1991); Joseph M. Miller, Comments, Genetic Testing and Insurance Classification: National Action Can Prevent Discrimination Based on the "Luck of the Genetic Draw," 93 DICK. L. REV. 729, 751-57 (1989). Compare Billings, supra note 82; Gostin, supra; Lowe, supra; Miller, supra; with Pokorski, Use of Genetic Information by Private Insurers, in JUSTICE AND THE HUMAN GENOME, supra note 7, at 103-09 (asserting that the use of genetic test information will be relatively rare and that it is justified as actuarially fair) and Epstein, supra note 9, at 13, 18-23 (arguing that insurers and other third parties should not be restricted in their access to genetic information).

genetic information, including genetic test information.<sup>111</sup> However, proposals enacted to date have had little effect on the insurance industry because insurance companies, generally, have not sought to require genetic testing or to obtain the results of genetic testing voluntarily undertaken by

111. See 137 CONG. REC. H2534-35 (1991); 136 CONG. REC. H7623 (1990) (submitted by Representative Conyers, "The Human Genome Privacy Act,"); DESIGNING GENETIC INFORMATION POLICY: THE NEED FOR AN INDEPENDENT POLICY REVIEW OF THE ETHICAL, LEGAL, AND SOCIAL IMPLICATIONS OF THE HUMAN GENOME PROJECT, H.R. REP. NO. 478, 102d Cong., 1st Sess. (1991) [hereinafter H.R. REP. No. 478]; see also Gail Dutton, Genetic Testing: Should You Pay?, 14 BUS. & HEALTH 41 (1996) (surveying insurance company practices with respect to genetic information and listing proposed and enacted state legislative restrictions on the use of genetic information); Gaulding, supra note 104, at 1672-73 (listing proposed and enacted state legislative restrictions on the use of genetic information by insurance companies); Jean E. McEwen & Philip R. Reilly, State Legislative Efforts to Regulate Use and Potential Misuse of Genetic Information, 51 Am. J. Hum. Genetics 637 (1992) (presenting an overview of State Legislation). June 1996 searches in LEXIS and Westlaw state code, advance legislative service, and bill tracking data bases for 50 states revealed statutory restrictions on insurance company use of genetic information in at least 12 states and proposed restrictions in at least another 14 states.

The potential application of the Americans With Disabilities Act (ADA) to the underwriting decisions of insurance companies is discussed by several commentators. See, e.g., Ostrer et al., supra note 37, at 572-74 (explaining that the ADA protects employees against discrimination in benefits and treatment, including insurance). The ADA, however, does not prohibit the use of information regarding disabilities for the purpose of underwriting or risk classification. See 42 U.S.C.A. §§ 12101-12213 (West 1991). House Report No. 485 explains that disability can be used as a risk factor so long as "refusal, limitation, or rate deferential (of coverage) is based on sound actuarial principles or is related to actual or reasonably anticipated experience." Ostrer et al., supra note 37, at 572 (quoting H.R. REP. No. 485, 101st Cong., 2nd Sess., at 137 (1990) [hereinafter H.R. REP. No. 485]). Another commentator concludes:

[T]he ADA does not restrict insurers... from carrying on their normal underwriting activities. This includes the use of pre-existing condition clauses[,]... the placing of caps or other limits on coverage[,]... or the charging of a higher premium to persons with higher risks.

... If insurers have actuarial data demonstrating a likelihood of future illness, they can limit coverage.

Gostin, supra note 110, at 135 (footnote omitted); see also Rothstein, supra note 83, at 79-81 (reviewing the legislative history of the ADA and concluding that actuarially-based discrimination is permissible in excluding pre-existing conditions, excluding coverage for certain conditions, charging higher premiums, imposing caps on coverage, and excluding dependents); Andrews & Jaeger, supra note 10, at 107 ("[I]t is not clear whether a person with an increased risk of disease due to genetic factors will be viewed as having a disability [under the ADA]."); Neil A. Holtzman & Mark A. Rothstein, Invited Editorial: Eugenics and Genetic Discrimination, 50 Am. J. Hum. Genetics 457, 457-59 (1992) (noting that the Equal Employment Opportunity Commission, which is charged with enforcing the ADA, has concluded that the ADA does not apply to individuals who are not yet symptomatic, which includes individuals who may be genetically predisposed to disease or destined to suffer disease in the future); Ostrer et al., supra note 37, at 571-72 (discussing the Employee Retirement Income Security Act (ERISA), 29 U.S.C.A. §§ 1001-1381 (West 1985) and noting that under ERISA, self-insured employers are free to exclude or limit coverage of conditions, including those caused by genetic defects).

applicants for insurance. 112

Insurers have had little incentive to actively pursue genetic test information for several reasons. Most health and disability policies are sold to groups, and because insurance companies generally experience rate these groups, they require little or no information regarding individuals. Also, genetic testing is expensive; even if insurance companies engage in individual underwriting, they can obtain comparable information more cost-effectively from other sources, such as non-genetic medical tests and patients medical records. Because genetic tests may deliver devastating news, requiring tests would raise additional public policy concerns. For example, if insurance companies require applicants to take genetic tests, perhaps the insurance companies ought to pay for adequate, contemporaneous counseling for applicants and their families. Finally, genetic testing rarely is determinative of whether an individual will suffer from a disease, and even if determinative, usually does not reveal the severity or time of onset of the disease.

Yet, commentators conclude that insurance companies will eventually seek genetic test information.<sup>118</sup> Anecdotal evidence suggests that insurers

<sup>112.</sup> Eric A. Wulfsberg et al., Alpha-AntiTrypsin Deficiency; Impact of Genetic Discovery on Medicine and Society, 271 JAMA 217, 218-20 (1994) (speculating about the possibility of insurers' use of such genetic tests in the future); ACLI-HIAA, GENETIC TESTING REPORT, supra note 104, at 5 ("No insurer — life or health — currently requires genetic tests.").

<sup>113.</sup> See ACLI-HIAA GENETIC TESTING REPORT, supra note 104, at 5 ("About 85-90 percent of health insurance is currently purchased through group plans which accept all full-time employees and dependents without evidence of insurability."); Pokorski, Use of Genetic Information by Private Insurers, in JUSTICE AND THE HUMAN GENOME PROJECT, supra note 7, at 99; see also ABRAHAM, INSURANCE LAW & REGULATION, supra note 14, at 399.

<sup>114.</sup> ACLI-HIAA, GENETIC TESTING REPORT, *supra* note 104, at 5; Wulfsberg et al., *supra* note 112, at 220 ("[A]t present, the use of genetic tests is rare because of their attendant costs . . . .").

<sup>115.</sup> See ACLI-HIAA, GENETIC TESTING REPORT, supra note 104, at 5-6; Pokorski, Use of Genetic Information by Private Insurers, in JUSTICE AND THE HUMAN GENOME PROJECT, supra note 7, at 99-100 (indicating that for individual and small group life, health, and disability insurance, insurers may request information on application forms and in physicians' statements and may obtain information through ordering medical tests as well); Wulfsberg et al., supra note 112, at 220 ("Life insurers currently use a series of tests to screen for diabetes, hyperlipidemia, renal disease, liver disease, and human amino deficiency virus infection.").

<sup>116.</sup> See Lori B. Andrews, Public Choices and Private Choices, Legal Regulation of Genetic Testing, in JUSTICE AND THE HUMAN GENOME PROJECT, supra note 7, at 46, 55 (noting the increased suicide rate among individuals who learn that they will suffer from Huntington's Disease).

<sup>117.</sup> See ACLI-HIAA, GENETIC TESTING REPORT, supra note 104, at 6; Pokorski, Use of Genetic Information by Private Insurers, in JUSTICE AND THE HUMAN GENOME PROJECT, supra note 7, at 100-05.

<sup>118.</sup> See ACLI-HIAA GENETIC TESTING REPORT, supra note 104; Billings et al., supra note 82, at 476-77, 481-82; Gostin, supra note 110, at 135-36; McEwen & Reilly, supra note 111, at 644; Ostrer et al., supra note 37, at 570-71; Pokorski, Use of Genetic Information by Private Insurers, in JUSTICE AND THE HUMAN GENOME PROJECT, supra note 7, at 103;

currently do seek genetic test information that has been voluntarily obtained by applicants for insurance and have used the information in underwriting decisions to increase premiums charged for coverage, exclude certain conditions from coverage, and deny coverage. As the cost of genetic testing decreases and its predictive accuracy improves, in insurance

Wulfsberg et al., supra note 112, at 220.

119. See H.R. REP. No. 478, supra note 111, at 558-72 (citing the testimony of the following: Dr. Paul Billings regarding the use of genetic information to determine eligibility for health and life insurance; a woman who was denied disability insurance because she was at risk for Huntington's Disease; Jeremy Rifkin, arguing for an absolute right of genetic privacy; Dr. Philip Reilly, regarding potential problems with life insurance; Dr. Nancy Wexler, regarding exclusions of genetically related conditions from coverage under health insurance policies; and a representative of the National Society of Genetic Counselors, regarding individuals refusing to be tested for fear of loss of insurance coverage); Billings et al., supra note 82, at 478-81 (analyzing the results of a survey in which he found 32 instances of insurance discrimination on the basis of genetic information); CYNTHIA CROSSON, NATIONAL UNDERWRITER CO., REGULATORS TREAD WARILY IN DEBATE OVER GENETIC TESTING 3 (Nat'l Underwriter, Life & Health/Fin. Services Ed. June 13, 1994) (regarding the Genetic Testing Working Group of the National Association of Insurance Commissioners, formed in 1994 to consider whether a model law was needed even though no insurers as of that date were known to require genetic testing); REUTER TEXTLINE, UK: DTI's "Shot Across Bows", POST MAG., May 19, 1994, at 6 [hereinafter POST MAG.] (reporting on Jonathan Spencer, the British head of the Department of Trade and Industry's Insurance Division, stating there was a need to guard against insurers segmenting the market "in ever more sophisticated ways." Spencer said that "both the [insurance] industry and [the British] Government needed to think hard about issues like genetic testing."); AM. POL. NETWORK, INC., Genetic Testing: Implications Should Be Wake-Up Call, HEALTH LINE Jan. 27, 1993 [hereinafter HEALTH LINE] (reporting an instance of refusal of health insurance coverage for two children born with a genetic disease called PKU); FIN. TIMES LIMITED, Genetic Screening Debate, WORLD INS. REP. Dec. 17, 1993 [hereinafter WORLD INS. REP.] (reporting on Dr. Ann Cavoukian, Assistant Commissioner for Information and Privacy in Ontario, Canada, speaking to the Council of Europe in Strasbourg, regarding the preparation of a European bioethics convention. She noted the "potentially devastating abuses" of genetic screening and the risk of creating new underclasses of "uninsurables."); Your Money (CNN, Inc. television broadcast, Jan. 23, 1993) (transcript no. 145-4) [hereinafter CNN, Your Money] (Dr. Paul Billings reciting 93 cases of genetic discrimination as of January 1993).

120. Regarding the commercial development of genetic tests, one commentator observed:

While . . . insurers are unlikely to routinely use genetic diagnosis that costs, say, \$2000-\$3000 per test, as the technology becomes capable of identifying a battery of genetic conditions at a fraction of the current costs, the sheer competitive nature of . . . insurance may drive them toward increased testing.

... The emergence of commercial interests in genetic test development provides powerful incentives to lower the cost of genetic testing, placing it within the reach of ... insurance. If some insurers ... begin to make increasingly more sophisticated genetic predictions, the pressure on others to utilize the same technology may become irresistible.

Gostin, supra note 110, at 116-17.

As costs decrease, life insurance companies are most likely to seek genetic test information:

[L]ife insurance companies are perhaps the most likely to take advantage of

companies will most likely seek genetic test information, and the public policy issues raised will become inescapable. 122

Proposed public policy solutions fall into four categories: (1) proposals to prohibit the use of genetic information by insurance companies (genetic privacy proposals); (2) proposals to restrict the use of genetic information by insurance companies (actuarially justified proposals); (3) proposals to restrict the use of genetic information by insurance companies and insureds (fair limits proposals); and (4) proposals to render genetic information irrelevant to insurance companies by requiring insurance companies to engage in community rating rather than individual underwriting or experience rating (community rating proposals). Several versions of these proposals have already been enacted in various states and in other nations. Analysis of these proposals reveals that all are problematic.

#### 2. Genetic Privacy Proposals

Genetic privacy proposals would prohibit the use of genetic test information by insurance companies to discriminate in setting rates, limiting

the "benefits" of genetic tests, as life insurance, unlike disability and health insurance, is most often purchased on an individual basis. . . . Although, at present, the use of genetic tests is rare because of their attendant costs, this undoubtedly will change with the institution of efficient and cost-effective multiplex testing.

Wulfsberg et al., supra note 112, at 220.

#### 121. Pokorski concludes:

Diagnostic and therapeutic advances in the practice of medicine are both inevitable and desirable. The genetic testing one may expect in the wake of the Human Genome Project offers exactly such advances. . . . The policy adopted in the past by all countries where private insurance is sold is not to deny insurers access to medical information but rather to require that the medical information be accurate and up-to-date and that underwriting decisions be based upon sound actuarial assumptions. The same requirements are appropriate for the use of future genomic information as well.

Pokorski, Use of Genetic Information by Private Insurers, in JUSTICE AND THE HUMAN GENOME PROJECT, supra note 7, at 108-09; see also Kolata, supra note 3, at A1, A9 (discussing ethical, employment and insurance implications of the imminent marketing of simple genetic tests for predisposition to breast and ovarian cancers).

122. See H.R. REP. No. 478, supra note 111, at 558-72; Billings et al., supra note 82, at 476-66; CROSSON, supra note 119, at 3; Gostin, supra note 110, at 136-37; Greely, Health Insurance in, THE CODE OF CODES, supra note 1, at 278-79; Human Genome Project Urged to Develop Guidelines for Statutes Regulating the Use of Genetic Tests, 34(7) THE BLUE SHEET, Feb. 13, 1991, at 6-7; McEwen & Reilly, supra note 111, at 646; Miller, supra note 110, at 735-36; Ostrer et al., supra note 37, at 565-66; Mark A. Rothstein, Discrimination Based on Genetic Information, 33 GERIMETRICS J. 13 (1992); CNN, Your Money, supra note 119; HEALTH LINE, supra note 119; POST MAG., supra note 119, at 6; WORLD INS. REP., supra note 119.

coverage, or refusing coverage.<sup>123</sup> These proposals would threaten the viability of the insurance mechanism by encouraging adverse selection and would promote social consequences that are mixed.

Individuals who know as a result of genetic testing of their increased risk of disease would seek insurance at bargain premiums; the most unfortunate individuals would seek to transfer their certain or nearly certain financial losses to others rather than suffer the full burden of their health and financial misfortune. <sup>124</sup> If these individuals purchased large amounts of insurance, their insurance companies would face potential insolvency.

Insurance companies might respond to this threat by raising all premiums sufficiently, thus absorbing the increased risk of the few by spreading the costs among the many. However, they would then face an ever-increasing competitive disadvantage with other risk management devices, notably self-insurance. In addition, any unevenness in the distribution of high-risk insureds among insurance companies would cause escalating adverse selection problems. Uneven distribution could arise either by chance or by the strategic efforts of insurance companies to dissuade high-risk individuals from applying for coverage. As soon as any one insurance company suffered a significant adverse selection problem due to an uneven distribution, its competitive disadvantage could quickly lead to an adverse

<sup>123.</sup> See, e.g., CAL. INS. CODE § 10140. (West 1995) (prohibiting the use of genetic characteristics in connection with health insurance and limiting the use in connection with life and disability insurance); COLO. REV. STAT. ANN. § 10-3-1000 to -1004.7 (West 1994) (prohibiting the use of genetic test information in connection with health insurance, group disability insurance, and long-term care insurance); WIS. STAT. ANN. § 631.89 (1991) (prohibiting health insurers and governmental entities that self-insure from requiring, using or conditioning coverage or rates on the results of genetic tests and permitting life and disability insurers to use these results only if actuarially justified).

<sup>124.</sup> See supra part II.C. (describing the problem of adverse selection); see also Pokorski, Use of Genetic Information by Private Insurers, in JUSTICE AND THE HUMAN GENOME PROJECT, supra note 7, at 93-96; ACLI-HIAA, GENETIC TESTING REPORT, supra note 104, at 8; Gostin, supra note 110, at 136-37; Ostrer et al., supra note 37, at 567; Greely, Health Insurance in, THE CODE OF CODES, supra note 1, at 266.

<sup>125.</sup> Complex issues have been raised regarding discrimination in employment on the basis of genetic condition under the ADA as interpreted by the EEOC, and regarding employer incentives to self-insure and their opportunities to discriminate on the basis of genetic condition in the provision of self-insured benefits under ERISA as interpreted in Owens v. Storehouse, Inc., 984 F.2d 394 (11th Cir. 1993) (permitting a cap on coverage of benefits for the treatment of AIDS). See also sources cited supra note 111 and accompanying text. Even if insurance companies are not put at a disadvantage by adverse selection with respect to their insurance company competition, under present law, they are put at a disadvantage at least with respect to nongovernmental self-insured plans. See WIS. STAT. ANN. § 631.89 (1991) (extending Wisconsin's genetic privacy prohibition to self-insured governmental entities but not to self-insured private entities).

<sup>126.</sup> Such strategies might include, for example, offering health care policies with less coverage of benefits that high-risk insureds would disproportionately require or imposing administrative requirements that disproportionately affect high-risk insureds.

selection price spiral and insolvency. 127

19961

Genetic privacy proposals also potentially would affect the social consequences of the insurance mechanism. The net effect is mixed. First, it is debatable whether these proposals would impair efficiency. Arguably, efficiency would be diminished because these proposals would preclude insurance companies from conveying efficiency promoting information and incentives through the underwriting process. For example, absent genetic privacy restrictions, insurance companies might refuse to provide coverage to individuals who were genetically predisposed to lung cancer if they smoked or worked in asbestos factories; efficiency would be promoted if these individuals changed their respective behaviors and occupations.

However, in some cases, individuals have little or no ability to respond to information in ways that promote efficiency. For example, individuals may have no realistic alternative to working in asbestos factories, or individuals may be destined to suffer genetic diseases such as Huntington's Disease whether or not they engage in healthy behaviors or work in relatively safer occupations. Also, even if individuals were both willing and able to respond, insurance companies might well be indifferent to their responses. It may be cheaper for insurance companies to simply reject applicants with any genetic risk factors. Furthermore, in the absence of genetic privacy protection, individuals might refrain from obtaining genetic tests that would promote efficiency for fear that the results would be used discriminatorily by

<sup>127.</sup> See supra part II.C. (discussing the adverse selection price spiral). Insurance company representatives and other commentators insist that adverse selection is an inevitable result of genetic privacy proposals. They believe that if the insurance mechanism is to survive, insurance companies must have access to knowledge equal to that of their insureds, in keeping with current regulatory policy with respect to access to other important medical information. See ACLI-HIAA, GENETIC TESTING REPORT, supra note 104, at 8; Epstein, supra note 9, at 13; Pokorski, Use of Genetic Information by Private Insurers, in JUSTICE AND THE HUMAN GENOME PROJECT, supra note 7, at 94-95, 106, 108-09. Similar issues have arisen with respect to AIDS testing and have been resolved generally by permitting insurance companies to obtain information and to require testing, provided the testing is reliable and applied on a nondiscriminatory basis. See Daniels, supra note 99, at 498-99; see also Office of Technology Assessment, U.S. Congress, Medical Testing and Health Insurance (1988) (regarding AIDS testing); Gostin, supra note 110, at 136.

Some critics of the use of this information by insurance companies in discriminating against the genetically unfortunate agree that adverse selection poses an insuperable hurdle to effective regulation through genetic privacy proposals. These commentators conclude that the only solution may be the elimination of the private, market-based insurance system, at least with respect to health insurance. See Andrews, Public Choices and Private Choices, Legal Regulation of Genetic Testing, in JUSTICE AND THE HUMAN GENOME PROJECT, supra note 7, at 62; Daniels, supra note 100, at 100. For a discussion of universal health insurance proposals, see infra part III.B.5.

<sup>128.</sup> See Wexler, supra note 9, at 212.

<sup>129.</sup> There is anecdotal evidence of insurer indifference toward documentation by individuals that their diseases are medically controlled. *See* Billings et al., *supra* note 82, at 478, 481.

insurance companies.

Finally, efficiency achieved through insurance company use of genetic test information could potentially violate important ethical principles and public policies. For example, anecdotal evidence indicates that insurance companies have attempted to pressure parents into aborting genetically defective fetuses in order to maintain coverage. Employers might discriminate against employees with genetic risk factors to avoid increased premiums imposed by insurance companies. 131

With respect to investment in the health care sector, genetic privacy proposals might divert some risk management dollars from insurance companies to alternative risk management devices. The relative attractiveness of other risk management strategies to low-risk insureds would increase as insurance companies increased the premiums of all insureds to cover the increased claims of bargain-seeking or loss-transferring insureds.<sup>132</sup>

The implications of genetic privacy proposals for protecting the public purse would be mixed. In the absence of genetic privacy proposals, some of those excluded from private insurance coverage would obtain insurance coverage through employed family members or would draw upon private resources in the event of misfortune. Others would resort to mixed funding mechanisms, such as state-sponsored, high-risk pools, which typically combine contributions from high-risk individuals rejected by private insurance companies with assessments upon insurance companies doing business in the state and sometimes with general taxpayer revenues as well. Those unable or unwilling to find support from private or mixed funding mechanisms would resort to a patchwork of federal, state, and local

<sup>130.</sup> Id. at 480-81.

<sup>131.</sup> See generally Rothstein, supra note 83.

<sup>132.</sup> These low-risk insureds might choose, instead, to apply their dollars toward reducing the risk of disease, disability, or premature death, or they might self-insure against financial losses associated with these events. This would reduce investment dollars available to insurance companies. This trend is evident in the health insurance industry. Because of the increased premiums health insurance companies must collect, in part to cover the costs of claims for which coverage has been mandated by policymakers, employers increasingly self-insure at least a portion of their employees' health risks, thereby avoiding the costs imposed by state statutes mandating coverage. Genetic privacy proposals also might contribute to this trend, a trend diminishing the public benefits that otherwise would flow from insurance company investments. See HALL, supra note 15, at 25 (discussing this phenomenon); see also SORKIN, supra note 57, at 177.

<sup>133.</sup> See Naomi Obinata, Comment, Genetic Screening and Insurance: Too Valuable an Underwriting Tool to Be Banned from the System, 8 SANTA CLARA COMPUTER & HIGH TECH. L.J. 145, 161-64 (1992) (asserting that high-risk pools can provide an appropriate mechanism for those who are excluded from insurance coverage because of genetic defects). For further discussion, see infra part IV.

governmental sources. 134

However, if genetic privacy proposals were enacted, this might encourage bargain-seeking and loss-transferring insureds to purchase greater insurance coverage, transferring their financial losses to their fellow insureds, rather than to private, public, or mixed alternative sources of support. If insurance companies were forced to raise premiums, low-risk insureds as well as lower-income insureds would increasingly drop their insurance coverage and opt for less expensive insurance coverage from other insurance companies or for alternative risk management strategies. Not only would this result in adverse selection, but also some of those who opted for alternative risk management strategies might well draw upon the public purse if they should suffer financial losses due to inadequate protection against risk, especially the risk of unpredicted, high-magnitude financial losses.<sup>135</sup>

The effect of genetic privacy proposals upon social solidarity as a sharing of misfortune would be complex. These proposals would prohibit insurance companies from discriminating against individuals by denying or restricting coverage or charging higher premiums for coverage. However, these prohibitions assume that insurance companies would continue to discriminate against individuals on the basis of other risk factors, such as age, sex, or poor health status. To the extent proponents of these proposals seek to advance social solidarity, these proponents assume that discrimination on the basis of genetic endowment is offensive to social solidarity, whereas discrimination on the basis of these other risk factors is not necessarily offensive to social solidarity. The second solidarity of the second solidarity.

There are several reasons why genetic discrimination might particularly offend social solidarity and, hence, justify this particular regulatory prohibition. One reason is that individuals' genetic endowments are beyond their control. Discrimination against individuals on the basis of characteristics that they cannot control may particularly offend social solidarity because it is discrimination on the basis of misfortune itself. In contrast,

<sup>134.</sup> These sources include: Medicare, Medicaid, SSI-Disability, and Social Security Survivor's Benefits.

<sup>135.</sup> For a variety of reasons a growing class of uninsureds increasingly resort to publicly-funded health care services. See HALL, supra note 15, at 16-31; see also the discussion of protection against unpredicted losses as a unique benefit of insurance at *infra* notes 56-58 and accompanying text.

<sup>136.</sup> ABRAHAM, DISTRIBUTING RISK, supra note 14, at 92-95.

<sup>137.</sup> However, some commentators favor genetic privacy proposals in the context of broader proposals to assure that no individuals are excluded from health insurance coverage for any reason, or at least for any reason based on health status. These broader arguments are addressed at *infra* part III.B.5. But others, for reasons explored *infra*, believe that exclusions or restrictions from health insurance or other insurance coverage that are based upon genetic information are particularly offensive to social solidarity. See Miller, supra note 110, at 741, 751-57; Gostin, supra note 110, at 143.

discrimination on the basis of individual behavior that individuals can control, such as smoking or skydiving, simply acknowledges that individuals should be held responsible for the consequences of their voluntary behavior. This argument taps into a strong current in U.S. political theory, law, and culture deploring invidious discrimination among individuals on the basis of characteristics they cannot control, such as race, sex, and age, but accepting and even encouraging discrimination on the basis of voluntary behavior.

Currently, insurance companies do discriminate on the basis of uncontrollable characteristics in denying or restricting coverage and establishing premiums. For example, insurance companies routinely use age and sex in underwriting life and automobile insurance. 138 Age and sex are easy to verify and correlate well with mortality, so age- and sex-based discrimination helps insurance companies predict their costs of claims, set premiums, and combat adverse selection. Thus, such discrimination is arguably consistent with social solidarity as a public benefit constrained by the functional requirements of the insurance mechanism. discrimination on the basis of genetic test information is similar to discrimination on these bases in that individuals cannot control their genetic endowments and in that genetic test information will be easy to verify and to correlate with mortality. 139 Hence, if discrimination on the basis of age or sex does not offend social solidarity despite the fact that they are not controllable characteristics, neither should discrimination on the basis of genetic endowment.

However, discrimination by insurance companies on the basis of sex is controversial, and the idea of discrimination on the basis of race is unthinkable, regardless of how easy race might be to verify and how well race might correlate with mortality.<sup>140</sup> Therefore, discrimination on the basis of some uncontrollable characteristics may offend social solidarity even though the discrimination contributes significantly to the functioning of the insurance mechanism. The reason for this may be a belief that burdens should not be imposed on the basis of characteristics that historically have also been the basis for imposing egregiously unjust burdens. Another reason may be a sense that the very reliability of these correlations, for example,

<sup>138.</sup> See ABRAHAM, DISTRIBUTING RISK, supra note 14, at 64-100; HALL, supra note 15, at 11, 79; JERRY, supra note 17, at 84-89.

<sup>139.</sup> This assumes that genetic tests will be sufficiently reliable and their significance properly understood and applied by insurance companies. For a discussion of these issues, see *infra* part III.B.3.

<sup>140.</sup> ABRAHAM, DISTRIBUTING RISK, supra note 14, at 92-95 (discussing sex as a suspect variable). Race once was commonly used in underwriting insurance, a practice that persisted at least through the 1950s. See Gaulding, supra note 104, at 1658-64; Leah Wortham, Insurance Classification: Too Important to Be Left to the Actuaries, 19 U. MICH. J.L. REF. 349, 360-70 (1985).

between race and mortality, reflects the legacy of that history. Although these reasons would not apply to discrimination on the basis of genetic endowment, a third reason may be that such discrimination may reinforce stereotypical views of individuals, contributing to the establishment and perpetuation of invidious discrimination.

This third reason has been advanced by critics of sex discrimination in insurance.<sup>141</sup> Critics argue that people apply crude stereotypes to members of the respective sexes rather than assessing each as an individual. Because discrimination on the basis of sex in insurance perpetuates invidious sex discrimination, it should be prohibited, at least if the costs of prohibiting the discrimination are reasonable in light of the benefits of the prohibition.<sup>142</sup> Yet, discrimination on the basis of sex persists; it is generally considered such an inexpensive and reliable risk factor that it is not worth the cost of prohibiting its use in underwriting.<sup>143</sup>

Perhaps discrimination on the basis of genetic endowment is more akin to race discrimination than sex discrimination in its potential to reinforce stereotypes that help establish and perpetuate invidious discrimination. If insurance companies begin to demand genetic information, this could be the first step toward the creation of a new class of individuals branded inferior

<sup>141.</sup> See ABRAHAM, DISTRIBUTING RISK, supra note 14, at 92-95. The historical discrimination and legacy of historical discrimination arguments potentially apply to sex discrimination as well, but these arguments have carried less force. See Gaulding, supra note 104, at 1661-64 (noting that most states "tolerate the use of sex as a classifier as a form of fair discrimination"); Wortham, supra note 140, at 360-70 (arguing that although sex discrimination in insurance is not, it "should be treated like race, color, religion, and national origin").

<sup>142.</sup> See, e.g., MONT. CODE ANN. § 49-2-309 (1991) (prohibiting sex discrimination in all insurance underwriting). Federal law also prohibits discrimination on the basis of sex in pension benefits. See Arizona Governing Comm. v. Norris, 463 U.S. 1073 (1983); Los Angeles Dep't of Water & Power v. Manhart, 435 U.S. 702 (1978); ABRAHAM, INSURANCE LAW & REGULATION, supra note 14, at 141-142, citing 42 U.S.C. § 2000e-2(a)(1).

<sup>143.</sup> Insurance companies most likely will continue to discriminate on the basis of sex unless prohibited by law. Insurance companies use sex as a proxy for causal risk factors that are not fully understood and would require the expenditure of resources to develop. An insurance company is not likely to invest in discovering these risk factors because any marginal competitive advantage that the superior accuracy of its predictions might bring most likely would be outweighed by the costs of development. Furthermore, other insurance companies quickly would eliminate any competitive advantage by adopting these risk factors without having invested in their development. Hence, if policymakers determine that the use of sex is sufficiently offensive, for example, because it reinforces stereotypes, they most likely would require cooperative insurance company investment in discovering risk factors, or acceptable proxies, with any incurred cost to be shared by all insureds in the form of increased premiums.

Some commentators argue, with supporting examples, that insurance company discrimination on the basis of sex does not reflect the commonly asserted justification of actuarial reasonableness. *See* Gaulding, *supra* note 104, at 1661-64; Wortham, *supra* note 140, at 375-77.

on the basis of their genetic endowments. Employers, health and educational institutions, and the justice system potentially may engage in invidious discrimination on the basis of genetic stereotypes.<sup>144</sup>

But it also is true that discrimination in insurance on the basis of genetic endowment is potentially anti-discriminatory in the sense that it can reduce the use of invidious kinds of discrimination in the insurance industry. Discrimination on the basis of genetic information, performed according to actuarially sound principles, constitutes discrimination that is anything but invidious in that it is neither irrational nor founded in the legacy of any historical or stereotypical discrimination. Genetic information potentially is an accurate, readily verifiable basis for predicting risk according to biological data that are directly relevant to health status. Unlike family health histories. genetic information accurately indicates whether or not individuals have inherited genetic risk factors. Unlike self-reported health status, genetic test information is readily verifiable. Unlike race or sex used as proxies for causal factors, genetic information pertains directly to the underlying biological mechanisms that affect health status. 145 Thus, genetic test information avoids reliance upon factors that may be sociological in origin and related to a history of invidious discrimination or factors that may perpetuate stereotypes. If it is granted that insurance companies must make accurate predictions of future claims, the use of genetic test information may be less offensive to social solidarity than the use of other information.

# 3. Actuarially Justified Proposals

Actuarially justified proposals would permit insurance companies to discriminate on the basis of genetic test information if the discriminatory use is actuarially justified according to the standards set forth in these

<sup>144.</sup> See sources cited supra note 10 and accompanying text. One of the premises of the recently enacted Americans with Disabilities Act is that stereotypical responses to disability, or perceived disability, are commonplace. See 42 U.S.C.A. §§ 12101-12213 (West 1995); see also Keller, supra note 8, at 281; Nelkin, The Social Power of Genetic Information, in THE CODE OF CODES, supra note 1, at 177-90.

<sup>145.</sup> In the same way that a positive HIV test pertains directly to the biological mechanism involved in AIDS, whereas homosexuality is only a crude proxy reflecting a higher risk of having AIDS. Given concerns about invidious discrimination against homosexuals, policymakers generally have opted to prohibit the use of lifestyle information but permit the use of HIV test information in insurance underwriting. For a similar discussion, see Obinata, supra note 133, at 156-59. See Eric C. Sohlgren, Note, Group Health Benefits Discrimination Against AIDS Victims: Falling Through the Gaps of Federal Law—ERISA, the Rehabilitation Act and the Americans with Disabilities Act, 24 Loy. L.A. L. Rev. 1247, 1250 n.7 (1991) (summarizing state statutes pertaining to HIV testing and HIV/AIDS coverage); see also Daniels, supra note 99, at 498-99; Gostin, supra, note 110, at 136.

proposals. 146 The most significant result would be to impose upon insurance companies and, hence, their insureds the costs of justifying the use of genetic test information according to the underwriting standards specified in the proposals. 147 Assuming these costs of compliance were the same as the costs insurance companies already incurred in ensuring that the information they use is actuarially justified, the effects upon the functioning of the insurance mechanism and its social consequences would be minimal.

Presumably, insurance companies could predict financial losses and combat adverse selection quite effectively by using this actuarially justified, genetic test information. The requirements of these proposals would help to ensure that the risk factors applied in insurance underwriting were justified as accurate predictors of future claims.<sup>148</sup>

With respect to the social consequences of these proposals, efficiency presumably would be enhanced if actuarial standards were improved by these proposals at the minimal cost of compliance. Concerns would remain,

<sup>146.</sup> See ARIZ. REV. STAT. § 20-448 (1992) (forbidding discrimination in life and disability insurance on the basis of a genetic condition, unless claims experience or actuarial projections establish that substantial differences in claims are likely to result from the genetic condition); MD. ANN. CODE of 1957, Art. 48 A, § 223 (1986) (forbidding discrimination in life and health insurance contracts unless there is actuarial justification for it); MONT. CODE ANN. § 33-18-206 (1991) (forbidding discrimination in life and disability insurance unless the insurer can demonstrate, based on claims experience or actuarial projections, that substantial differences in claims are likely to result from the genetic condition); WIS, STAT. ANN. § 631.89 (West 1991) (regarding life insurance); Human Genome Project Ethical Recommendations Are One to Two Years Away, NIH Tells Congress, 34(43) THE BLUE SHEET, Oct. 23, 1991, at 7-8 (W. French Anderson, Chief of the Molecular Hematology Branch at the National Heart, Lung and Blood Institute, in congressional testimony noted the concern that insurance companies might misuse genetic information because "[g]enetic information is complex and it can be easily misused totally unintentionally."); Sheryl Stolberg, Insurance Falls Prey to Genetic Bias; The DNA Revolution is a Blessing and a Curse, L.A. TIMES, Mar. 27, 1994, at A1 (citing Jonathan Beckwith, a Harvard University Geneticist, regarding genetic information: "It is not precise information. And yet insurance companies are already using that information to deny insurance or hike insurance rates."); Ostrer et al., supra note 37, at 575 (concluding that standards of accuracy, validity and predictive value must be developed for purposes of determining whether genetic tests can be used in insurance underwriting); Pokorski, Use of Genetic Information by Private Insurers, in JUSTICE AND THE HUMAN GENOME PROJECT, supra note 7, at 108-09 (asserting that use of genetic information should be limited to use that is actuarially justified). There have been legislative responses to HIV testing that generally prohibit discrimination except if actuarially justified or justified by claims experience. See Sohlgren, supra note 145, at 1250 n.7; see also Gostin, supra note 110, at 135-137; see generally Daniels, Insurability and the HIV Epidemic, supra note 99.

<sup>147.</sup> To the extent that insurance companies must show "a substantial" justification, these costs might be significant. All states currently prohibit insurer discrimination that is not justified by sound underwriting principles; the genesis of these mandates was opposition to the rebating practices of insurance agents. See Ostrer et al., supra note 37, at 571; Wortham, supra note 140, at 384-86.

<sup>148.</sup> See Pokorski, Use of Genetic Information by Private Insurers, in JUSTICE AND THE HUMAN GENOME PROJECT, supra note 7, at 98-100.

however, with respect to the violation of other important ethical principles and public policies. For example, employers might seek to reduce costs by refusing to employ high-risk individuals rather than by supporting and promoting improvements in employee health.<sup>149</sup>

Investment would be minimally affected. Any reduction in investment would reflect the loss of premium dollars resulting from increased premiums to cover the costs of compliance.<sup>150</sup>

Because these proposals would help assure that those excluded from the insurance mechanism were those individuals most likely to suffer misfortune, they would probably cause increased reliance upon the public purse as well as private sources of support by these high-risk individuals. Thus, as with genetic privacy proposals, these proposals would change the characteristics of the insured and uninsured populations. But whereas genetic privacy proposals would increase the number of high-risk insureds and increase the number of low-risk and lower-income uninsureds, these proposals would increase the number of low-risk insureds and increase the number of high-risk uninsureds. The most likely consequence would be increased reliance on public resources by those with relatively greater health care needs.

The effect upon social solidarity would be to reduce invidious genetic discrimination based upon ignorance or prejudice and to encourage genetic discrimination based upon accurate predictions of future claims. Current anecdotal evidence indicates that insurance companies do engage in invidious genetic discrimination, that is, genetic discrimination that is not actuarially justified. However, the extent of this conduct is unknown. Thus, if these proposals reduced invidious discrimination, this would contribute to the sharing of misfortune in a manner consistent with the functioning of the insurance mechanism.

However, even in the absence of such proposals, the mutual interests of the parties to insurance contracts generate powerful incentives to squeeze out invidious discrimination.<sup>153</sup> When incidents of invidious discrimination occur, other insurance companies have every incentive to insure those discriminated against and gain a market advantage.

Perhaps further evidence will reveal entrenched prejudice toward or widespread ignorance regarding certain genetic endowments such that normal marketplace incentives are insufficient to protect against invidious

<sup>149.</sup> See discussion, supra part III.B.2.

<sup>150.</sup> See discussion, supra part III.B.2.

<sup>151.</sup> See Billings et al., supra note 82, at 479-81; Ostrer et al., supra note 37, at 571.

<sup>152.</sup> Billings, supra note 82, at 477 (indicating that evidence of use of genetic information, including invidious use of this sort, is purely anecdotal at this point); see also Epstein, supra note 9, at 18-19 (questioning the extent of invidious discrimination.)

<sup>153.</sup> See Epstein, supra note 9, at 18 (arguing to this effect).

discrimination. Or perhaps actuarially justified proposals should be preferred in any event because they preempt invidious discrimination rather than relying upon the exercise of initiative by an insurance company to discover and capitalize upon invidious discrimination. Discriminating invidiously on the basis of characteristics that cannot be controlled and under circumstances that may reinforce harmful cultural stereotypes may be judged to justify such a preemptive governmental response.<sup>154</sup>

Although these proposals thus might contribute to a sharing of misfortune consistent with the functioning of the insurance mechanism, they certainly would not contribute to social solidarity in the all-inclusive sense. These proposals would, in fact, help assure that the most unfortunate are excluded from the sharing of misfortune among insureds.

#### 4. Fair Limits Proposals

A third regulatory approach would impose genetic privacy prohibitions on the use of genetic information by insurance companies only with respect to specified fair limits of insurance coverage. If an individual sought coverage in amounts exceeding these fair limits, then no restrictions would apply to an insurance company's use of genetic information. To date, these proposals have been devised only for life insurance. These proposals would limit the effects of adverse selection and would have minimal social consequences.

Fair limits proposals mute the effects of adverse selection by permitting insureds to seek bargains or transfer loss but only within limits. If high-risk insureds were evenly distributed among insurance companies, adverse selection would not pose significant problems. Even if there were an uneven distribution, the limits of coverage imposed upon high-risk insureds might well be sufficient to protect insurance companies against adverse selection price spirals. Furthermore, the increased premiums that insurance companies would be required to charge to cover their increased costs of claims most

<sup>154.</sup> For comparison, see the discussion at supra part III.B.2.

when the insurance industry adopted a ceiling of \$100,000 in U.S. dollars as an appropriate life insurance fair limit. This reflected the policy of the Netherlands' Health Counsel that insurance companies should not obtain access to genetic information provided that the insurance sought by an individual is "appropriate to [his or her] financial and social circumstances," but if an individual sought coverage "above this ceiling of real need," the individual would be obliged to disclose genetic information to insurers. See International Standards for Access to Genetic Test Results Urged at Conference Sponsored by NIH, 34 (23) THE BLUE SHEET, June 5, 1991, at 2-3; see also Lowe, supra note 111, at 523 ("For example, a state could bar insurers from discriminating against life insurance applicants on the basis of genetic tests but allow a \$100,000 coverage limit. Such a rule would limit the effects of adverse selection on insurers.").

<sup>156.</sup> See Lowe, supra note 111, at 523.

likely would be modest because of these limits. Hence, these proposals would only modestly increase the desirability of alternative forms of risk management.<sup>157</sup>

The effects of these proposals upon efficiency would be minimal. Although insurance companies would have no incentive to communicate information particular to a genetic disease, the general information communicated to all insureds with coverage below the fair limits also would be useful to those predisposed to genetic diseases. Furthermore, individuals probably would not be dissuaded from obtaining the potentially useful knowledge provided by genetic tests because they would be assured access to at least a limited amount of insurance coverage regardless of the test results.

Similarly, investment would be affected only modestly. Insurance companies would be forced to raise premiums to cover the increased claims attributable to those who suffer genetic diseases. Other forms of risk management might then become more attractive to low-risk insureds, causing insurance companies to lose premium dollars. But if the fair limits were established at a fairly low ceiling, the increased claims could be absorbed with relatively small premium increases, thus minimizing any effects upon investment.

As with genetic privacy proposals, fair limits proposals would ensure that most of the financial losses of high-risk insureds would be distributed among members of insurance pools rather than absorbed individually or distributed among various private and public sources of support. However, unlike genetic privacy proposals, fair limits proposals would limit the premium increases that insurance companies would have to impose, thereby limiting the number of low-risk or low-income uninsureds who might be forced to draw upon the public purse.

The major appeal of fair limits proposals lies in the limits they impose upon satisfaction of the bargain-seeking and transfer of loss motivations of those unlucky in the genetic lottery. These proposals would assure that these individuals would have only a modest impact upon the functioning of the insurance mechanism while permitting their inclusion, subject to fair limits restrictions, in the sharing of misfortune with fellow insureds. The inaccessibility of genetic information regarding those whose coverage was beneath the fair limits also would reduce the potential for invidious discrimination on the basis of genetic endowment. Thus, these fair limits proposals would contribute to social solidarity, however conceived, in that they would include more of the genetically unfortunate in the sharing of

<sup>157.</sup> Compare the much more serious problems posed by genetic privacy proposals discussed at *supra* part III.B.2.

misfortune. However, as with genetic privacy proposals, proponents of these programs assume that the exclusion of individuals on the basis of non-genetic factors is acceptable or more acceptable than exclusion of those who suffer genetic misfortune.

## 5. Community Rating Proposals

The last category of proposals for solving the problems raised by the introduction of widespread genetic test information would make this information irrelevant by requiring insurance companies to use community rating.<sup>158</sup> Presently, these proposals have been developed only for health insurance and are of two types. The first type would require all health insurance companies within a given geographical area to charge each individual within the community the same or a similar premium<sup>159</sup> based upon the predicted claims of all members of the community. The second type would establish a national health insurance plan that would employ community rating in some form.<sup>160</sup>

[T]he Human Genome Project could help move medical insurance back to a community-based scheme. The more that is learned about the human genome, the more will it become obvious that everyone is susceptible to some kind of genetic disease or disability; everyone carries some genetic load and is likely to fall ill in one way or another. Of course, the cost and severity of the illnesses will vary, but everyone's being aware of his or her genetic jeopardy might well increase interest in a rating system that emphasizes equality rather than equity, that expresses what the Europeans call solidarity . . . .

Social insurance — that is, national health insurance — is the ultimate form of solidarity, and the Human Genome Project, by revealing how everyone is in genetic jeopardy, might contribute to bringing about some form of it in the United States.

Daniel J. Kevles & Leroy Hood, Reflections, in THE CODE OF CODES, supra note 1, at 300,

<sup>158.</sup> See Mark A. Hall, Health Insurance: Community-Rating or Experience-Rating?, 2(4) RESPONSIVE COMMUNITY 79, 79-82 (1992) (discussing policy issues regarding mandatory community-rating); see also HALL, supra note 15, at 38-39 & n.8 (discussing proposed and implemented plans of community rating in Maine, New York, New Jersey, and Washington and modified community rating in Louisiana, Florida, Maryland, Massachusetts, Oregon, and Vermont). See supra part II.B for a discussion of the underwriting process.

<sup>159.</sup> Proposals for community rating generally are for modified community rating rather than pure community rating, that is, the premium charged would be modified to some extent to reflect the age, health status, or other factors affecting the risk of the individual insured. See Hall, supra note 15, at 72-75 (discussing the rationale for modified community rating); see also William R. Jones et al., Pure Community Rating: A Quick Fix to Avoid, J. AM. HEALTH POL'Y, Jan.-Feb. 1993, at 32 (proposing a variety of reforms to ensure continuing coverage regardless of health status and proposing modified community rating, according to actuarially justified variables, such as geographic area, age, sex and industry but not according to claims experience, health status, or duration of policy); Gene Steuerle, Community Rating of Health: How Much Is Appropriate?, 59 TAX NOTES 1269, 1269-70 (1993) (discussing a variety of approaches to modified community rating requirements).

<sup>160.</sup> As Kevles & Hood argue:

In its early history, health insurance was community-rated, 161 but community-rated insurance soon proved nonviable in competition with individually underwritten and experience-rated insurance. As insurance companies gained predictive knowledge regarding differential risks posed by individuals based on age, health status, and other characteristics, they quickly applied it to their advantage in the marketplace. These insurance companies could offer insurance coverage at lower premiums to low-risk insureds and still make profits. Community-rated plans, faced with competition from these insurance companies, were overwhelmed by adverse selection of high-risk insureds, and therefore, were largely abandoned. 163

Community-rated plans would face a similar problem today. Unless alternative forms of risk management, including experience-rated plans and self-insured plans, were eliminated, these plans would, once again, attract the risk management dollars of low-risk insureds, presenting community-rated plans with ever-increasing adverse selection problems.<sup>164</sup> As community-rated plans raised premiums, increasing numbers of employers might choose to eliminate health care coverage altogether if not compelled to provide such benefits.<sup>165</sup> Unless other alternatives for accomplishing risk management were foreclosed by law, marketplace competition for risk management dollars would render community-rated insurance nonviable.<sup>166</sup>

Adverse selection forced Blue Cross to abandon community rating in favor of experience rating for groups, and it is now destroying the market for individual and small-group insurance as subscribers select against the Blue Cross community-rated pools. Adverse selection has impeded the development of a significant market in private long-term health care insurance, since younger people with little need decline to purchase, and older subscribers cannot afford the high premiums.

#### Id. (footnote omitted).

Hall notes that many of the effects of adverse selection can be mitigated by modified community-rating plans that take into account age or health status to some extent. *Id.* at 40-44.

- 164. See discussion of various forms of risk management in supra part II.A.
- 165. See Jones et al., supra note 159, at 30-31.
- 166. See Hall, supra note 158, at 80-82 (noting that several states have enacted community-rating requirements in some form, and concluding that unless all employers are required to purchase community-rated health insurance, those with less risky employees will self-insure); see also Aaron, supra note 100, at 32 (noting that about half of employees who have health care plans are covered by employers who self-insure); HALL, supra note 15, at 39.

There are no examples of adverse selection in a market that is entirely communityrated, which would require those opting out to go without insurance. Nevertheless, we know from experience in markets that are experience or risk rated that many average-to-good risk individuals and employers opt out because of the price of insurance. This tendency can only be aggravated by community-rating, which will

<sup>324-25.</sup> 

<sup>161.</sup> For a description of the history of health insurance, see supra part II.C.

<sup>162.</sup> See Aaron, supra note 100, at 32-33.

<sup>163.</sup> HALL, supra note 15, at 40.

If proposals for community rating are to succeed, they will do so only in a regulatory environment in which competition for risk management services is eliminated. Hence, many commentators favor proposals of the second type, that is, the implementation of community rating in conjunction with a universal, mandatory system of health insurance. These proposals for social insurance would eliminate the problem of competition with experience-rated health insurance and other forms of risk management.

The functioning of the social insurance mechanism would differ somewhat from the private insurance mechanism. Insurance companies or government payers would still be forced to combat adverse selection and moral hazard to avoid bankrupting the social insurance system, but the battlelines would be drawn differently. Adverse selection problems might arise if high-risk insureds sought coverage from insurance plans that offered the best access to costly services. Moral hazard problems might arise if the absence of experience-rated premiums led to careless over-use of health care services without fear of financial repercussions. In the absence of opportunities to discriminate against insureds by increasing premiums, restricting coverage, or refusing coverage, insurance companies or government payers would combat adverse selection and moral hazard by imposing administrative controls, such as pre-admission approvals for hospitalization.

The social consequences of the functioning of the social insurance mechanism also would differ. Promotion of efficiency would not be accomplished through the marketplace incentives created by underwriting. Insurance companies, nonetheless, might seek to reduce claims by broadly promoting risk-reducing conduct among their insureds. The efficacy of such measures in the absence of financial incentives generated by experience-rated premiums would most likely be reduced.

Investment in the health care economy would be redirected. The desirability of the current level of investment certainly is debatable, given the component of investment attributable to governmental tax incentives and to

produce dramatic price increases for the youngest (and therefore lowest paid) groups and individuals.

Id. at 42.

<sup>167.</sup> See Arrow, supra note 14, at 964 (noting that community rating cannot thrive in a genuinely competitive market).

<sup>168.</sup> See Aaron, supra note 100, at 31 (concluding that universal health insurance coverage should be the goal of national health care reform and community rating should be implemented in any such plan); see also Daniels, The Genome Project, Individual Differences, and Just Health Care, supra 99, at 112-20 (arguing that justice requires the sharing of risks and the abandonment of underwriting practices that place extra burdens upon those at higher risk); HALL, supra note 15, at 62-75 (assuming mandatory purchase of health insurance and comparing pure community rating and community rating by class); Light, supra note 98, at 2503; Stone, supra note 98, at 287; Stone, supra note 99, at 19.

moral hazard. <sup>169</sup> But a system of social insurance would substitute greater governmental involvement in determining the nature and level of investment. The experience of other nations indicates that investment in innovative technological and pharmaceutical products that primarily benefit those who are sickest tends to diminish under social insurance systems. <sup>170</sup> Although the overall level of investment would be difficult to predict, it is most likely that investment would be redirected toward more broadly accessible routine health care services, and away from innovative technologies that primarily benefit the sickest. Thus, the public benefit of broader access most likely would be advanced and the public benefit of increased innovation in service of the sickest most likely would be diminished under a system of social insurance.

As with genetic privacy proposals, the primary rationale for adoption of a social insurance system would be to achieve the goal of social solidarity as an all-inclusive sharing of misfortune. Social insurance proposals aim to achieve this goal through a calculated and coordinated nationwide redistribution of financial losses from the sick to the well, accomplished through universal coverage and community-rated premiums.<sup>171</sup>

Social solidarity, in this all-inclusive sense, is a controversial end of public policy.<sup>172</sup> There is debate among those who favor governmental redistribution in some form about whether the wealthy sick should benefit at the expense of the middle and lower income healthy; whether the redistribution should favor the few very sick with very expensive health care needs who would benefit most from investment in innovation, or the very many with relatively modest health care needs.<sup>173</sup>

In addition, there is good reason to doubt whether social solidarity, in

<sup>169.</sup> See discussion at supra part II.D.

<sup>170.</sup> See Robert Baker, The Inevitability of Health Care Rationing: A Case Study of Rationing in the British National Health Service, in RATIONING AMERICA'S MEDICAL CARE: THE OREGON PLAN AND BEYOND 208, 213 (Martin A. Strosberg et al. eds., 1992) (noting severe problems with lack of innovation under the British National Health Services).

<sup>171.</sup> See Daniels, supra note 99, at 497; Light, supra note 98, at 2503; Stone, supra note 98, at 287; Stone, supra note 99, at 19-20.

<sup>172.</sup> HALL, supra note 15, at 64-65 (noting studies by several researchers indicating that lower-income individuals in lower-age groups pay thousands of dollars more to subsidize actuarially undervalued health care coverage for older and wealthier individuals); see Daniels, supra note 99, at 497; HALL, supra note 15, at 65-67 (exploring alternative arguments that young, low-income individuals would not object because in effect they would be assuming higher costs at a younger age in order to enjoy lower cost at an older age when they would be less healthy. Hall observes that given income differentials and differentials between occupations, this is not a plausible argument with respect to the actual desires of actual individuals); Stone, supra note 98, at 287; Stone, supra note 99, at 19-20; see also Arrow, supra note 14, at 959-60 (discussing theory of ideal insurance and lifetime health care expense).

<sup>173.</sup> Berry, supra note 61, at 100-20.

this all-inclusive sense, could be achieved. It assumes a motivation among members of society to share social goods and misfortune on terms agreed upon through the political process. There is abundant historical evidence of motivation to share among family members and others bound by ties of affection and loyalty or transcendent commitment, but little evidence of such a motivation among those bound together only by ties of state or national affiliation.<sup>174</sup> The history of social insurance in the United States and elsewhere suggests that when social insurance systems are enacted, they tend to serve the ends of those who vote and who pay the taxes that sustain social insurance, that is, the middle class. The motivations are the same as those revealed in the history and current functioning of the private insurance mechanism: motivations to manage risk, to obtain bargains, and to transfer loss. Thus, social insurance systems tend to look much like private insurance systems with the question of who receives better and who receives worse insurance coverage determined by largely political processes rather than economic processes.

174. In examining the motivational foundations of the welfare state, Robert E. Goodin and John Dryzek conclude that altruism certainly pervades family relationships but does not explain the motivations revealed in the welfare state. "It is one thing to care for those particular individuals, known and beloved to us, that constitute our own families. Extending such sentiments from those who share our genes to all those who merely happen to share the same colored passport is another thing altogether." Robert E. Goodin & John Drysek, Risk-Sharing and Social Justice: The Motivational Foundations of the Post-War Welfare State, in NOT ONLY THE POOR, supra note 15, at 37, 39. With respect to other social groups displaying transcendent commitment, Richard J. Neuhaus, reviewing BERTRAND DE JOUVENEL, THE ETHICS OF REDISTRIBUTION (Liberty Press 1989), describes Jouvenel's comparison of the transcendent commitment of a monastic community with efforts to establish a socialist community. Neuhaus states that, according to de Jouvenel:

The ideal of the brotherly city should not be dismissed as utopian. Monastic communities have embodied that ideal for centuries. Their members unhesitantly share material goods, because such goods are devalued. The desires of those in the community "are not addressed to scarce material commodities, and thus competitive; they are addressed to God, who is infinite. In short, they are members of one another not because they form a social body but because they are part of a mystical body. Socialism seeks to restore this unity without the faith which causes it."

Richard J. Neuhaus, *Redistribution: Selfish Socialism*, THE PUBLIC INTEREST, No. 101, Fall 1990, at 109 (reviewing BERTRAND DE JOUVENEL, THE ETHICS OF REDISTRIBUTION (1989)). 175. See Goodin & Le Grand, *Not Only the Poor, in* NOT ONLY THE POOR, supra note 15, at 203-27 (concluding that the non-poor in Great Britain, the United States, and elsewhere, benefit extensively from the welfare state "because they support universalist programs rather than programs that target the poor, or because they have infiltrated programs originally designed for the benefit of the poor."); see also Baker, supra note 171, at 217-21 (analyzing the Oregon Plan for Medicaid coverage as redistributing resources from the poorest to the relatively less poor); BUCHANAN & TULLOCK, supra note 103, at 193 (asserting that all social insurance reflects the desires of the middle class for risk management). For further discussion, see supra note 13-18 and accompanying text.

### IV. THE NEXT INTERSECTION AND BEYOND

The insurance mechanism has proven to be quite adaptive in satisfying the risk management motivations of individuals and the profit motive of insurance companies, but at a price. The price is discrimination against those who are most vulnerable, if insurance companies gain knowledge of their vulnerability. As the HGP progresses and genetic testing advances in its wake, the class of those excluded from the benefits of insurance will grow. Policymakers will inevitably face hard choices about appropriate responses.

In formulating their responses, policymakers should note that private insurance provides valuable benefits that include both immediate private benefits to insureds and a number of public benefits. Insureds manage risk and enjoy the distinctive benefits of reduced vulnerability to chance financial losses and, potentially, reduced vulnerability due to the communication of risk-reducing information and incentives. In addition, insureds benefit from the administrative savings and financing benefits of group health insurance and the savings opportunities in life insurance. Society as a whole benefits from any efficiencies realized, the increased wealth and innovation that flow from investment, the opportunity for individuals to take personal responsibility for the financial needs of their families, and the preservation of social solidarity that allows a limited sharing of misfortune.

Genetic privacy proposals threaten the functioning of the insurance mechanism for the sake of assuring that genetically high-risk individuals are able to obtain bargain premiums from or transfer their losses to a private pool of insureds. This is a high price for gains that appear modest in light of other alternatives. Such proposals would be more defensible if they were tailored to prohibit insurance companies from requiring individuals to obtain genetic tests rather than broadly drafted to prohibit insurance companies from obtaining access to genetic test information voluntarily obtained by individuals. Adverse selection problems with respect to the latter are potentially severe, whereas, prohibiting insurance companies from requiring tests would, at worst, entail continued use by insurance companies of less accurate and potentially more offensive classifications of risk. Given the potential harm attendant upon requiring individuals to obtain tests that may reveal devastating and unwanted information about their health, proposals prohibiting insurance companies from requiring tests are certainly defensible.

Actuarially fair proposals may well impose minor costs that would be of little consequence to the functioning of the insurance mechanism. But whether these costs, including governmental enforcement costs, would be worth the modest gains, is questionable.

Fair limits proposals would assure that individuals at high risk because of their genetic endowments would be able to obtain limited amounts of life insurance at bargain premiums with their losses distributed among private pools of insureds. The price in terms of interference with the functioning of the insurance mechanism would be moderate in exhcange for modest gains.

Adoption of a social insurance system is the most troublesome of the proposals. Such a system would substitute a governmentally designated end, that is, achieving social solidarity in the all-inclusive sense, for the private ends that currently drive the private insurance mechanism. Yet, the history of private and governmental insurance reveals that the motivations of individuals, whether expressed in the economic or the political marketplace, are quite constant. Individuals would continue to seek to manage risk, social insurance companies would continue to seek to make money. A social insurance system would simply displace the public benefit of shared misfortune as a byproduct of the cooperative pursuit of private ends under private insurance with a politically-defined and implemented version.

If the ultimate expression of solidarity is the conquering of disease, the private insurance mechanism, for all its flaws, supplemented by regulatory measures to expand coverage of all high-risk insureds and a system of universal catastrophic insurance, offers the best complement to the promise of the HGP. The private insurance mechanism can continue to yield private and public benefits even as the scientists of the HGP proceed to conquer the vulnerability and ignorance that give rise to the risk management motivation. The substitution of a social insurance system would be precisely the wrong step at the worst time. The pursuit of a dubious concept of social solidarity would divert risk management dollars from their best use in promoting efficiency and innovation on the threshold of the next medical revolution and direct these dollars into a social insurance system that would offer few benefits in exchange for its costs.

In this interim period before the next intersection of the HGP and insurance, when cures for disease at reasonable cost will bring about the end of insurance as a significant aspect of social and economic life, policymakers should respond cautiously and incrementally to the problems posed by the imminent influx of genetic information. The insurance mechanism can thrive only in an environment characterized both by vulnerability and mutual ignorance, but it could adapt to gradual increases in mutual knowledge if permitted to do what it does best, that is, discriminate among risks and distribute risks. Policy measures that acknowledge and accommodate these aspects of the functioning of the insurance mechanism can help it adapt in ways that make it more inclusive of those who are relatively more vulnerable in an era of increased knowledge. A supplementary system of universal catastrophic insurance would serve the needs of those most vulnerable, regardless of the causes of their vulnerability.

Policy measures should provide a regulatory framework that encourages insurance companies to insure relatively high-risk individuals. Such a

framework would facilitate distribution of these risks across larger pools of insureds formed through cooperative arrangements among a number of insurance companies.<sup>176</sup> Because the increased costs of insuring relatively risky individuals would be distributed more broadly, they would not significantly harm any single insurance company or the insurance mechanism itself. Hence, the private and public benefits of the insurance mechanism would be preserved, and social solidarity would be incrementally improved because of the willingness of insurance companies to insure higher risk individuals, including those with genetic defects.

In addition, to ameliorate the most significant financial consequences of misfortune for individuals and their families whether due to genetic disease or any other illness or injury, policymakers should devise and implement a compulsory, universal, catastrophic insurance plan. A compulsory plan that assured protection against catastrophic losses in the event of disease or disability would address the gravest threat to the financial security of the middle class and to access to health care for those who suffer the most serious health misfortune.<sup>177</sup> In addition, it would relieve much of the pressure on private insurance companies to discriminate against high-risk individuals by eliminating the catastrophic portion of the risk that private insurers otherwise would bear. Thus, a catastrophic plan devised to serve the risk management motivation of the majority of voters could be politically viable and could both preserve and enhance many of the private and public benefits of the underlying insurance mechanism.

These proposals to facilitate broader distribution of risk while preserving the private insurance mechanism would anticipate and welcome the next intersection of the HGP and insurance. At the next intersection, the promise of the HGP for curing disease will be realized, and much of the suffering and the financial losses associated with disease, disability, and premature death will be significantly diminished. The demand for protection against catastrophic losses will remain, but much of the vulnerability and ignorance that drive the current insurance mechanism and permit it to function will disappear. Thus will come about the proper end of insurance.

<sup>176.</sup> See HALL, supra note 15, at 44-47 (discussing various approaches to accomplishing this broader distribution of risk through reinsurance, including high-risk pools currently functioning in several states).

<sup>177.</sup> See Kenneth E. Covinsky, The Impact of Serious Illness on Patients' Families, 272 JAMA 1839 (1994) (discussing the threat of cascading financial problems within families following the catastrophic illness of a family member); see also James F. Blumstein, Health Care Reform: The Policy Context, 29 WAKE FOREST L. REV. 15, 17 (1994) (arguing that a catastrophic plan would best serve the interests of the middle class in protecting their assets and the poor in obtaining access to high cost treatment, and asserting that a catastrophic plan has not been enacted because of ideological opposition founded in the preference of many commentators and policymakers for a social insurance system).