

Chapter Five: Limits of Health Insurance Law

A. Introduction

This Chapter examines existing laws, particularly those targeting health insurance, which generally fail to protect individuals against healthism. Although the Patient Protection and Affordable Care Act of 2010 (ACA) made considerable strides at eradicating health-status discrimination in health insurance, considerable opportunities for healthism remain. Moreover, government health care programs necessarily discriminate based on the health status of eligible beneficiaries and that feature likely would remain true even under a universal health care system.

The United States health insurance market has evolved into a patchwork of public and private programs and regulations. Thus far, our elected representatives have declined to enact a universal health plan providing government coverage for all. Instead, government health care programs cover select groups and, in a few cases, specific diseases and conditions. Government coverage is generally considered a fallback, or a safety net, for those individuals and groups for whom the private health insurance market fails. Eligibility for many, but not all, government benefits turns on health status.

Traditionally, priority for public benefits has been given to the young, old, disabled, and pregnant. A universal health care plan could be designed to guarantee certain minimal benefits for all, but it seems likely that lawmakers would continue to draw distinctions among particular subgroups based on health status, extending more generous benefits to some compared to others. Such-line drawing seems endemic to a necessarily resource-limited system; we would continue to prioritize those with the greatest health care needs. To state it more bluntly, health care rationing would be necessary even under a single-payer system.

Setting aside the possibility of a national health system in the United States, government health care programs remain the exception rather than the rule for Americans' health insurance coverage needs. The United States remains strongly committed to a private market approach for the majority of Americans. More than half of the U.S. population obtains coverage through employer-sponsored health plans, either as employees or dependents of employees. The reliance on employers to provide health insurance is an historical anachronism and anomaly among developed countries.

For those not covered by employer plans, insurance is available in the private market on an individual or small-group basis. The individual and small-group markets vary by state. Insurance is regulated at the state level, with a recently expanded overlay of federal laws and requirements. Commercial health insurance markets are local, and insurance cannot be purchased across state lines. For these and other reasons, health insurance in the United States suffers from various characteristic market imperfections. The ACA made great strides toward correcting some of those flaws, including persistent healthist

practices. But considerable opportunities for insurers to discriminate based on health status remain.

B. History of Health Insurance

Health insurance as a way to pay for health care is a relatively recent development in the United States. For much of the history of medicine, there were limited interventions available and much of that care could be provided in the patient's home. Patients and their family members would simply pay out of pocket for medical care, as they would for any other goods and services delivered to their doors. Sanitariums were available for those afflicted with infectious diseases. Charitable hospitals or almshouses existed to treat and institutionalize the seriously ill who lacked family or financial support.

But as the sciences of medicine and pharmacology advanced, services became more comprehensive and expensive. It was no longer tenable to pay out of pocket. Thus, a private market for health insurance arose. At the same time, the high cost of health care and high transaction costs of selling policies made it a difficult risk to insure on an individual basis. Group enrollment, particularly among groups of workers, was one strategy to address those challenges. Workers tended to be relatively healthy and thus a more attractive risk to insure. Moreover, it was cheaper to market plans to a few large employers than multiple individuals, and premiums could be collected readily through payroll deductions. Early insurance products covered disability or loss of income, rather than comprehensive medical expenses. Routine, preventive care was typically not covered as that did not present an unpredictable, potentially catastrophic financial risk. Large U.S. automakers were one of the first industries to provide health insurance to their workers.

The next significant pressure for expanding health insurance came from hospitals. Hospitalization was becoming more common, and the costs were increasingly burdensome on middle class families, not to mention the less affluent. Individual hospitals offered the first policies on a direct-service basis, meaning that for a few dollars a year in premiums, an individual could receive hospital care at the insuring facility without having to pay for the actual costs of care at the time received. But that model became financially untenable. The Great Depression, especially, left hospitals unable to collect patients' bills and bearing significant financial losses. Under that climate, single-hospital plans would have been even more destabilizing to the market, given the competition among hospitals.

Thus, an alternative community-wide approach, which ultimately became Blue Cross, emerged. The community-wide plans were nonprofit, offered patients free choice among participating providers, and initially covered only hospital charges. Blue Shield, covering physician services, would come later, under stronger resistance from physicians who feared loss of professional autonomy. Physician services also present a different, arguably less serious financial risk for potential subscribers; thus, the demand for the product was not as great. States fairly quickly stepped in to regulate these new hospital-

service plans as insurance products, applying requirements regarding reserves, rate reviews, composition of boards of directors, and tax-exempt status.

Blue Cross plans characteristically were community-rated, meaning that all subscribers within the same community paid the same premium rates. The alternative, experience rating, means that subscribers pay different rates, based on their individual risk profiles. Under community rating, those at greater risk for hospitalization tend to pay lower premiums because they are subsidized by those at lower risk for hospitalization. Under experience rating, each pays according to his or her own risk profile, meaning that insurance could be cost prohibitive for some individuals, especially those most in need of care. It bears emphasis that experience rating explicitly discriminates against those with greater health care needs and risks.

Health insurance solves several problems at once. For most people, paying an amount-certain every month is preferable to the uncertainty of potentially catastrophic health care bills. Health insurance also pools risks; all subscribers pay into the pool but some receive more care than their premiums would otherwise cover, while others end up receiving less care than the amount that they paid in to the pool. Large employer groups, such as the automobile manufacturers, which first offered health plans, provide a particularly attractive, ready-established risk pool of relatively low risk, healthy individuals, inasmuch as they well enough to work. Group plans typically are community rated within the group, meaning that no individual member of the group pays more based on individual risks. The entire group, however, may experience a premium rate increase based on the risk profiles of individual members.

Over time, the commercial health insurance market grew increasingly robust and competitive, with a number of for-profit companies (including formerly non-profit Blue Cross plans that converted to for-profits status) entering the market. Under that competition, the Blues' characteristic community rating gave way to experience rating, based on the expected risks of the group or individual. Through experience rating, insurers could better align their potential exposure for claims to the individual customer and set premiums accordingly. Risk-pooling operates under both community rating and experience rating, but the effect is diluted under experience rating.

Experience rating, while advantageous for insurers, has detrimental effects for certain customers. A small employer, for example, could be faced with a dramatic premium rate increase based on one employee suffering catastrophic injury or illness in a given year. That premium increase could be unsustainable, meaning that the employer would cease offering coverage to all of its workers. Outside of the group market, the effect of experience rating was even more dramatic. Elderly individuals or others with health problems – those who arguably most need health care – might find coverage to be prohibitively expensive or simply unavailable based on their risk profiles. Moreover, insurers became increasingly probing, seeking to uncover customers' health behaviors and habits, genetic and other predispositions to disease, and other personal information tending to bear on the likelihood of illness or injury.

Group coverage, especially employer-sponsored plans, became increasingly prevalent for a variety of reasons. First, as mentioned above, for insurers, employee groups were attractive risk pools to cover and offered a single entry-point for marketing and plan administration. Also, for employers, it was good business sense to maintain a healthy workforce, reduce absenteeism, and hold down premium costs by ensuring workers' access to necessary medical care. The federal government added further incentives, allowing above-the-line deduction from gross income for contributions paid toward employee benefits. Accordingly, it is generally cheaper for an employer to offer more generous benefits than increased wages or salary to its workers. Finally, health insurance is so common in many industries that employees and applicants have come to expect it as part of their overall compensation package.

In sum, health insurance in the United States has evolved from a self-pay approach to health services to an elaborate health insurance industry, dominated by employer group plans and large insurance companies offering particular products in individual states. The Health Insurance Portability and Accountability Act of 1996 (HIPAA), better known for its privacy protections, largely eradicated healthist practices in large group plans. More recently, the ACA has dramatically changed the individual and small health insurance market. The operation of those and other federal laws are discussed more fully below.

C. Health Discrimination Under Existing Health Insurance Laws:

The United States maintains a decidedly non-system of health care delivery, with some groups entitled to government benefits, some privileged to have employers that provide health plans, some able to navigate and afford the individual market for insurance, and others left out in the cold. In each of those subgroups, health-status discrimination abounds, despite repeated calls for its elimination. Even though differential treatment based on health status is increasingly seen as unfair and wrong, competitive market pressures and pragmatic reasons related to resource limits have allowed lawmakers and insurers to continue distinguishing among individuals based on their health risk-profiles. In later chapters of this book, we will more fully consider the normative implications of the reality that we describe here, namely, that federal insurance laws offer limited protection from healthist practices.

1. Government Health Care Programs

With all the developments in the commercial health insurance market, some segments of the population were being routinely excluded: In particular, retirees, unless their employers generously allow them to stay on group coverage; those unable to work due to disability, minority, caretaker responsibilities, or other challenges; the elderly, unhealthy, and otherwise health-risky unable to afford high premiums offered by commercial insurers in the individual market. Social justice, humanitarian, and other political forces came together in the 1960s to provide government health insurance coverage for some groups being priced out of the commercial market. As the private market was evolving under union and health care provider pressures, state and federal lawmakers repeatedly

proposed various government health insurance programs, which culminated most notably in the Medicare and Medicaid programs, enacted in 1965 under Lyndon B. Johnson’s Great Society.

Medicare eligibility is based on age (65 or older) or permanent disability (including both individuals born with disabilities and those who became unable to work because of disabilities). Since 1972, Medicare also covers individuals with end-stage renal disease (ESRD). Due to cost-containment and other public policy concerns, the Medicare program has not been further expanded to disease-specific coverage. Under these categories of eligibility, Medicare is clearly healthist, limiting coverage based on health statuses of particularly severe disabilities, a specific kidney condition, and age, which operates as a rough proxy for health status, given that elderly people tend to have more frequent and severe medical issues. Unless and until Congress expands “Medicare for All,” regardless of health status or age, the program remains discriminatory.

Medicaid, as enacted in 1965 and expanded several times over its five decades limited coverage to low-income individuals who also have another qualifying condition, including pregnancy, disability, blindness, childhood, seniority, or primary caretaker of an eligible dependent child. Like Medicare, then, Medicaid also is built on health-status discrimination, at least when it comes to treatment for pregnant women, and blind and disabled children and adults. Medicaid’s basic design changed, however, with Congress’s enactment of the ACA. The ACA eliminated the categories of eligibility and extended coverage all individuals and family below a certain income threshold, regardless of health status or other eligibility criteria. Subsequently, however, the U.S. Supreme Court ruled that states must be given the option to retain the traditional categories of eligibility or expand coverage outside of the categories. A majority of states elected to retain the health-status categories of eligibility, while other states now include all individuals below 133% of federal poverty level in their Medicaid programs.

[Insert discussion of Medicaid’s equal access provision and prohibition on diagnosis discrimination]

Other federal programs, such as the Ryan White Comprehensive AIDS Resource (CARE) Act, cover specific conditions, in that case, HIV/AIDS. The Ryan White CARE Act is a payer of last resorts, meaning that coverage is available only if no other resources are available. Like Medicare’s ESRD benefit, Ryan White singles out a particular set of diagnoses for differential treatment under federal law. Also, the National Childhood Vaccine Injury Act of 1986 (42 U.S.C. §§ 300aa-1 to 300aa-34) (NVIC), provides financial compensation for vaccine-related injuries and deaths. Although not health insurance per se, NVIC does represent a federal policy that singles out a particular type of medical error and resulting illness or mortality. *[More legislative history on these programs – political debate behind and support for them. Other examples of disease-specific government programs.]*

As outlined above, lawmakers have restricted government health care benefits based on various criteria, including, in several cases, health status conditions. Those lines are

drawn for rational, pragmatic, budgetary, and ideological reasons but nevertheless perpetuate discrimination on the basis of diagnosis, age, and other health status-related conditions. As noted above, even under a national health plan, services would almost certainly be limited to some extent based on health status. Further analysis in Part III of this book will consider whether government health care programs are healthist, or whether the defining health-status distinctions are normatively acceptable under the factors that we identify.

2. Private Insurance

Government health insurance programs are available for only a subset, roughly a quarter, of the U.S. population. The remainder obtains health insurance from private companies – or not at all. From the outset, one of the challenges in serving the private market has been the problem of adverse selection; that is, the purchase of insurance by those most likely to get sick. Insurers have employed a variety of strategies to guard against adverse selection, including simply refusing to sell policies to individuals with known health conditions; charging higher premiums based on health status or health risk; and imposing various out-of-pocket costs at the time of service, including deductibles and co-payments, intended to discourage overutilization of services.

As health care costs steadily rose, insurers sought additional ways to limit their financial exposure, including retroactive utilization review, post-claims underwriting, and rescissions. Not uncommonly, insurers would, in the face of a potentially large claim or serious diagnosis, scour the patient’s application for errors, omissions, or other technical grounds for cancelling coverage. Insurers also commonly placed lifetime or annual limits on the dollar value of coverage. After the patients’ claims hit that mark, they would have to pay for any additional care out of pocket. Such limits tended to discriminate against patients with chronic or particularly costly conditions. By their very design, all of those techniques disadvantage unhealthy individuals by making private insurance more expensive or unavailable.

a. Health Insurance and Risk Assessment

Defined loosely, insurance is a risk-pooling arrangement designed to indemnify the contracting party against a particular kind of loss. Insurers guarantee their insureds against any number of possible harms including death (life insurance), property damage (fire insurance, flood insurance, casualty insurance, renter’s insurance), injury (disability insurance), and illness (health insurance). As part of their services, insurers must set premiums related to their insureds’ probable risks. Failing to assess risk accurately could undermine the insurance structure because the cost of claims paid would exceed the amount of premiums collected.

A sustainable, and even profitable, insurance plan thus relies on assessing accurate, calculable risks. Risk assessment is particularly difficult in the health insurance market because health is a fluid and amorphous concept, determined by a wide range of controllable and uncontrollable, known and unknown, factors. In assessing the potential

health risks of a particular applicant, insurers frequently rely on the opinions and diagnoses of health professionals, including medical experts working for their companies. Accordingly, when determining coverage and setting premiums, health insurers have historically sought detailed individual and family medical histories, in addition to demographic and behavioral factors like sex, age, weight, occupation, and smoking that statistically tend to correlate with greater health risks. Insurers' ability to gather those data is challenged by information asymmetries between the insurer and the insured, particularly, when insureds' disclosures and actions are based on their own personal knowledge of their risks. If insurers were aware of all potential risks, they could factor those risks into their underwriting and rating decisions to avoid inflating premiums artificially.

Even assuming perfect information, insurers are challenged to maintain sustainable risk pools. Just as high-risk people are more likely to purchase insurance, low risk individuals may opt out of insurance, finding it worth the gamble to have limited or no insurance once premiums rise to a certain cost. Because insuring higher risk individuals is more costly, adverse selection drives up the price of premiums. This process may, in turn, further induce lower risk individuals to leave the market. If enough low risk people leave the insurance pool, rates will again rise, driving those in the remaining group with lower relative risks to leave the market, and so on, until the market collapses. This phenomenon is known as a "death spiral."

Under those pressures, commercial insurers have employed a number of risk assessment and other profit-maximizing strategies that systematically disadvantage the unhealthy. The strategies operate somewhat differently in the individual and group markets, but differential treatment based on health status is prevalent in both settings.

In the individual market, health insurers historically engaged in risk selection, using health information in making eligibility or underwriting decisions. Underwriting is the process by which insurers evaluate applications for insurance. It involves assessing the applicant's potential risk. Once the insurer assesses the relevant risks, it may either assign the applicant to a particular rating class and offer a corresponding policy, or it may decline to offer a policy altogether. If a potential insured has a condition that puts him or her at a heightened health risk before applying for coverage, health insurers in the individual market may simply choose not to cover that particular preexisting condition. Preexisting conditions include any number of serious mental and physical health conditions, ranging from breast cancer, depression, and testing positive for HIV, to relatively minor ones, like allergies or acne.

Second, health insurers also engage in ratingmaking based on health status. Ratemaking is the process that follows underwriting. Once the insurer decides that a particular applicant is insurable, it then decides how much to charge in premiums to carry that individual's risk. That process includes assessment of the individual's health risks based on his or her current and past health conditions. Under a traditional experience rating model, those with higher risks pay higher rates. The result of these two strategies is that

those most likely in need of medical services are also those least likely to be individually insurable.

The majority of Americans with health insurance hold group policies. Group health-insurance plans, most commonly, employer-provided health insurance, distribute risk differently than individual policies. Instead of assessing the relative health risks of individuals, group health insurers look at the relative risk of the group as a whole. As a result, group plans tend to be more affordable than individual plans because the potential risk is spread over a greater number of policyholders. Group health insurance plans come in two varieties: large and small. The smaller the group, the fewer insureds available to share the risk. Thus, small group health insurance policies feel the impact of individual risk factors more acutely than large groups. Like individual health insurance providers, group health insurers disadvantage their insureds on the basis of health status, albeit less directly.

Despite spreading risk across a larger number of policyholders, group insurers also disadvantage their insureds on the basis of health status. For one, insurers in the group market may reject the group in its entirety as too risky. Group health insurers can also limit the amount and type of coverage or benefits available to similarly situated members of the group, such as providing limited or no coverage for particular health conditions. Moreover, if a particular insured develops a costly health condition, that single person's diagnosis can impact the entire group's premium or coverage. This reality, at times, has led employers to ask their employees to leave the group plan or to fire (or avoid hiring) employees with expensive conditions.

In addition to health status discrimination via premium rates, cost-sharing obligations under health insurance plans further disadvantage the unhealthy. Requiring insureds to pay some amount at the time of service, in addition to monthly or periodic premiums, relates to adverse selection but more directly addresses the problem of moral hazard. Moral hazard is the tendency of persons with insurance to engage in more risky behaviors, or higher use of health care services, than they would if uninsured. Health insurers have three main strategies for addressing moral hazard through cost sharing: (1) deductibles, (2) coinsurance, and (3) copayments. Deductibles often take the form of flat dollar amounts that the insured must pay before his or her insurer will begin coverage in any given coverage period. With coinsurance, an insured must pay a certain percentage of particular kinds of expenses covered by the insurer. Finally, copayments typically involve an insured paying a relatively small dollar amount toward each designated covered service.

Because individuals with health conditions require more frequent medical services and treatment, they end up paying significantly more cost sharing than individuals who have less frequent need for health care. One study indicates that having a single chronic health condition increases an individual's out-of-pocket expenses by over seventy percent, and having a second condition increases it by three hundred percent. Although intended to deter adverse selection and overutilization of medical care, cost-sharing obligations also tend to perpetuate health status discrimination. Moreover, the deterrent effect may have

the unintended effect of decreasing individual health, as patients avoid necessary treatment (including prescription drugs essential to managing many chronic conditions) because the out-of-pocket costs are too high. Moreover, as patients avoid seeking or following through with treatment, the information asymmetry increases, leaving insurers less able to accurately assess risks.

b. Regulation of Commercial Health Insurance

Although insurers undeniably have legitimate, economically rational reasons for discriminating on the basis of health status in their policies and procedures (discussed in Chapter 2), the public increasingly objected, pushing for legal protection from insurers' unfair, restrictive, and abusive practices. States, to varying degrees, and ultimately, the federal government eventually responded with a number of reforms.

Managed care plans were a particular target of state regulation because they tend to employ a variety of cost-containment strategies that tend to interfere with the patient-provider relationship in ways that typical indemnity plans do not. Under managed care, including health maintenance organizations (HMOs), preferred provider organizations (PPOs), and point of service (POS) plans, health insurance operates more as a way to prepay for medical care than to provide financial protection against unexpected risks. Managed care plans seek to keep a population of patients healthy and, thereby, decrease overall health care costs. Thus, managed care plans cover not just catastrophic health care costs, such as hospitalization, but also routine and preventive care. Medical professionals are employed as administrators, reviewing and coordinating care on behalf of subscribers. Managed care plans employ various strategies, including preapproval, gatekeeping, and utilization review, to ensure that the care for which they are paying is medically necessary, cost-justified, and appropriate.

Health care providers participating in managed care plans typically are not reimbursed on a fee-for-service basis but instead receive bundled or capitated payments, requiring the providers to bear some of the financial risk with the plan. The risk is in providing more medical care than the predetermined reimbursement amount covers. Under bundled payments, for example, the provider receives a scheduled amount determined by the patient's diagnosis or spell of illness. Under capitated payments, the provider agrees to treat a certain population of patients annually for a per-head amount. In both cases, the incentive is to provide medical care that is no more expensive than the agreed amount of reimbursement; otherwise, the provider risks under-compensation for the excess care.

Managed care's financial incentives do not explicitly discriminate based on health status, inasmuch as the bundled or capitated amounts are derived from actual claims data. Those data, however, are averaged, meaning that some patients' will surely require care that is more expensive than the predetermined amounts. Accordingly, providers may be inclined to avoid treating those "outlier" patients, unless additional, exceptional compensation is provided.

State health insurance and managed care plan regulations address a number of those typical plan features. With respect to the insurance industry, states regulate the business and professional licensure of companies and brokers. They may regulate solvency or require minimum financial reserves. There may be plan description, disclosure, and other consumer protection requirements. Plan participants typically are guaranteed certain due process rights to appeal coverage denials through internal grievance as well as external administrative and judicial review channels. Laws limit the financial incentives that plans may place on providers that risk compromising quality of patient care and professional judgment. Certain services, including emergency room care, often must be accessible without preapproval or gatekeeping. States may also mandate coverage for certain conditions and treatments. Historically, however, states tended to impose little to no regulation of underwriting and ratemaking practices, leaving those features of insurance to competitive market forces.

The federal government has authority to regulate the business of insurance, but until relatively recently Congress refrained from enacting significant substantive regulation of commercial health insurance. For decades, the most notable federal health insurance law was ERISA, the primary effect of which was to knock out, or “preempt,” state regulations and common laws bearing on the operation of employer-sponsored health plans. But ERISA imposed virtually no affirmative federal regulation in place of the state laws that it preempts.

Historically, only a few federal laws imposed specific, substantive requirements on health plans, including coverage for reconstructive surgery following mastectomy and minimum hospital stays following childbirth. Like Ryan White or NVIC, those mandates apply to certain diseases or conditions, and thus draw health-status distinctions for private insurance coverage. Additionally, the Paul Wellstone and Pete Domenici Mental Health Parity and Addiction Equity Act of 2008 (MHPAEA) generally requires health plans that cover mental health and substance abuse treatment to do so on at least as generous terms as medical/surgical benefits. The law requires parity in mental health coverage but still allowed plans to exclude mental health coverage across the board. Originally applicable only to group health plans, the ACA amended MHPAEA to extend the protection to individual health insurance plans as well. Coupled with the ACA essential health benefits (EHB) package, federal law now requires most individual and small group plans to cover mental health and substance abuse treatment. In sum, most health plans are prohibited from discriminating on the basis of mental health or substance abuse disorders.

Federal lawmakers addressed insurers’ health status distinctions more broadly with HIPAA. HIPAA was the culmination of President Bill Clinton’s (or perhaps more precisely, then-First Lady Hillary Rodham Clinton’s) attempt at comprehensive federal health care reform. The broader plan, which called for establishing corporate “regional alliances” of health providers subject to a government fee schedule, among other sweeping changes that would have radically altered the private health insurance market, was not enacted. As something of a consolation, Congress passed a more modest piece of legislation, HIPAA, which ensured that employees could maintain coverage when they

changed jobs and provided significant privacy protections for health information and standards for electronic health records.

Better known for its privacy protections, HIPAA’s portability provisions are particularly relevant here because they restrict health-status considerations in eligibility and pricing for group health plans. Group health plans include most employer-sponsored plans. HIPAA portability was enacted in response to concerns about “job lock,” that is, employees with health conditions being reluctant to change jobs for fear that they would be denied health insurance at a new employer. HIPAA was Congress’s first antidiscrimination approach to health insurance legislation. Supporters cited eliminating health-status discrimination as among the legislation’s most significant goals. Representative William Richardson explained that in addition to protecting workers’ health insurance as they change jobs, HIPAA “also prevents discrimination against those individuals with preexisting conditions.” Similarly, Senator Judd Gregg explained that HIPAA “grew out of the recognition that some basic flaws in the regulation of health care caused American families monumental problems,” including the fact that “[i]ndividuals are subject to unfair discrimination in their access to health insurance if they have a medical condition that has required treatment before they joined that health plan.”

Specifically, HIPAA prohibits employers from excluding new workers from coverage for more than twelve months based on preexisting conditions. Preexisting condition is defined as a physical or mental condition “for which medical advice, diagnosis, care, or treatment was recommended or received within the 6-month period ending on enrollment date.” 29 U.S.C. § 1181(a)(1). Conditions more remote than six months in the employee’s medical history cannot be used as a basis to deny or delay coverage. In addition, the twelve-month waiting period must be reduced by any amount of “creditable coverage,” which includes another group health plan or a government health care program. Accordingly, if a worker with a preexisting condition had been employed (and covered) at her previous job for at least a year, she would be eligible for immediate coverage at her new job. If she were at the previous job for eight months, she could be required to wait no longer than four months for new coverage.

HIPAA further prohibits group health plans, or insurers offering group health plans, from basing eligibility or individual premium rates based on the following list of health status-related factors: health status, medical condition (both physical and mental illnesses), claims experience, receipt of health care, medical history, genetic information, evidence of insurability (including a history of domestic violence victimhood), and disability. In short, HIPAA established guaranteed issue and community rating rules for group health plans. An individual employee cannot be discriminated against on the basis of health status with respect to participation in or price of group coverage. Nothing in HIPAA, however, prevents employers or insurers from increasing the premiums on the group as a whole. Therefore, employers and co-workers still have a vested interest in the individual health of other group members. An employee with diabetes, cancer, hypertension, or multiple pregnancies could increase the premium rates for all.

Moreover, an insurer conceivably could offer a plan that excludes coverage across-the-board for a particular condition or treatment, such as infertility treatment or in vitro fertilization. Such an exclusion would be facially neutral but could have a disparate impact on some employees. State law coverage mandates may not apply to some employer-sponsored health plans as a matter of ERISA preemption, depending on particulars of whether the employer itself bears the risk or purchases insurance on behalf of its employees, transferring the risk to an insurance company.

Although focused on employer group plans, HIPAA also provides some protections from health status discrimination in the individual and small group markets. First, in the individual market, all applicants with eighteen or more months of creditable coverage, and no more than a sixty-three-day gap between losing that coverage and applying for an individual policy, must be offered a plan (“guaranteed issue”) and the plan must be renewed (“guaranteed renewal”). Insurers could not impose preexisting condition exclusions on those applicants. For example, if an employee, who had been employed for two years and covered by his employer’s health plan for at least a year and a half, applied for individual coverage, the insurer would have to write a policy. HIPAA’s individual market protection, however, in no way restricted the amount that the insurer could charge. Moreover, insurers were not required to comply with those rules if the state had adopted an alternate approach to covering uninsured individuals, which the vast majority of states did. Insurers also often engaged in practices to circumvent the requirement, such as refusing to pay brokers’ fees for selling those policies or delaying processing of applicants long enough to cause a sixty-day gap.

In the small group market, HIPAA also imposes guaranteed issue and renewal for all employers who applied for small group coverage, and all individuals employed by such employers who opted for coverage. Again, there was no rate regulation with respect to the small group market. Therefore, the plans offered could easily be cost-prohibitive, especially if the group included an employee with a serious or chronic medical condition. A number of states did voluntarily address premium insurance rates in the small group market, especially after HIPAA. As of 2012, thirty-nine states limited the range of premium rate variation (e.g., 2:1) based on claims experience, health status, or duration of coverage. Thirteen states prohibited any premium rate variation within the small group market based on those health status-related factors. New York also prohibited premium rate variation based on age. *[See Furrow, Greaney at 649]* Those state laws augmented the federal protections under HIPAA but left significant pockets of health-status underwriting practices to persist nationwide.

The important thing to recognize about HIPAA is that most Americans, meaning those covered by employer-sponsored group health plans, have long enjoyed fairly good protection from insurers’ potentially healthist practices. Accordingly, the highly publicized and popular provisions of the ACA actually were not terribly dramatic, at least for those with employer-sponsored coverage. But for the relatively small segment of the population who historically lacked coverage entirely or struggled to obtain and maintain coverage on the individual market, the ACA was a revolution.

Advocates of the health care reform debate that culminated in the ACA in 2010 characterized existing health insurance practices that systematically disadvantaged unhealthy people not as rational business practices but as insufferable discrimination. Representative Louise Slaughter described preexisting condition exclusions as “cruel,” “capricious,” and “done only to enhance the bottom line.” Representative Edward Perlmutter, in reference to his daughter who was uninsurable at the time because of epilepsy, alleged that excluding her from insurance coverage is not only “wrong” but also “probably unconstitutional under the [Fourteenth] Amendment to the United States Constitution.” Other reform proponents likened denial of health insurance based on health status to race discrimination. On several occasions, Representative Steven Kagen described preexisting condition exclusions as discrimination on the basis not of skin color but of “skin chemistry.” Senator Patrick Leahy put things simply: “Insurance companies can and do discriminate against sick people.”

Trumpeted as a “Patients’ Bill of Rights,” the ACA expands HIPAA’s protections and ensures that all Americans with pre-existing health conditions gain coverage and keep it. It also bans insurers from placing lifetime or annual dollar limits on coverage, requires coverage without cost-sharing for preventive care, protects patients’ choice of physicians, guarantees appeal rights for coverage denials, among other protections. Specifically, insurers may not establish rules for eligibility (including continued eligibility) based on the same list of health status-related factors as in HIPAA: health status, medical condition (both physical and mental illnesses), claims experience, receipt of health care, medical history, genetic information, evidence of insurability (including a history of domestic violence victimhood), disability. In addition, the statute delegates to the Secretary of HHS the discretion to recognize other health status-related factors that may not be the basis of eligibility determination. 42 U.S.C. § 300gg-4. The ACA’s total ban on preexisting condition exclusions is more protective than HIPAA’s restriction on waiting periods for coverage. Also, under the ACA, insurers may not decline to renew coverage based on an undisclosed or later diagnosed health status, unless the patient fraudulently or intentionally misrepresented material facts under the terms of the coverage. 42 U.S.C. § 300gg-2; see also 42 U.S.C. § 300gg-3 (“Prohibition of preexisting condition exclusions or other discrimination based on health status”).

The ACA also imposes a modified form of community rating, meaning that insurers generally may not vary premium rates based on health status or other health-related habits, indicators, or profiles. 42 U.S.C. § 300gg. The rule applies to small group and individual plans, thus restoring the historical underwriting practice of the Blues. Individuals in a given community must all be offered the same sorts of plans, at the same rates, without regard to their own health-risk profiles. That provision of the ACA is somewhat less protective of health-status discrimination than HIPAA’s analogous community rating provision by allowing at least four notable exceptions, which seem to reintroduce health-status considerations. Those exceptions are discussed further below in the section on the Limits of Existing Health Insurance Laws to address healthism.

The potential for health insurance markets collapsing under the death spiral of adverse selection drove lawmakers in 2010 to enact a mandate that disallows most Americans

from gambling on no or minimal health insurance coverage. In short, the ACA mandates that most individuals maintain insurance as part of a larger strategy to stabilize the insurance market for higher risk individuals. With insurers now required to sell policies to people who are already ill or injured, the potential for adverse selection was considered very high. If an individual were not inclined to purchase insurance, he could simply wait until he needed health care and purchase a policy at that time. The ACA's modified community rating rule partially averts the death spiral by prohibiting insurers from charging differential premiums based on health status. But without the individual mandate, insurance might still become unaffordable if only higher risk individuals were purchasing insurance. That said, nothing in the ACA prohibits insurers from raising rates on everyone in the community-rated risk pool, although there are disclosure requirements and state rate review for large premium increases.

[Add discussion of 1557, which extends existing federal antidiscrimination laws including Title VI of the Civil Rights Act, Title IX of the Education Amendments of 1972, Section 504 of the Rehab Act of 1973, and Age Discrimination Act of 1973, to health insurance and government health care programs. Effect is to prohibit discrimination on the basis of race, color, national origin, sex, age, or disability in any health program or activity that receives any HHS funding (which virtually all do); any health program or activity that HHS administers (e.g., Medicare and Medicaid); and the Exchanges and plans offered on the Exchanges). Section 1557 is well in keeping with our project's aim of reducing discrimination in health insurance but because it merely extends protection for already recognized categories to a new context, rather than including health-status as a newly protected category within the health insurance realm, it fails to fully address healthism in health insurance. Chapter Four provides more detail on the limits of disability discrimination laws, in particular, to address healthism.]

D. The Limits of Existing Health Insurance Laws

As the previous section explained, a number of state and federal laws incrementally addressed the prevalence of health-status discrimination in health insurance. The ACA was billed as a civil rights triumph, a victory over healthism. But this section explains, many hidden pockets of potential healthist practices remain within the ACA's laws regulating health insurance and within other existing laws.

Perhaps the clearest instance of health-status discrimination is within the ACA's community rating laws. The ACA expressly allows insurers to vary premium rates based on a few, specified factors. First, insurers may charge different rates based on whether the plan type (individual or family). Plans also may be priced differently in different geographic areas (that is, community rates may vary by community). In addition, the elderly and tobacco may be charged more, up to a point. 42 U.S.C. § 300gg. The ACA specifies that premium rates may vary based on age, up to 3:1, and tobacco use, up to 1.5:1. Finally, a separate provision of the ACA allows plans to offer discounts, rebates, or reduced cost sharing for participation in "Programs of Health Promotion or Disease Prevention" (popularly know as "wellness programs"). Two of these factors are explicitly based on health-status and two could easily be proxies for health status.

The plan-type allowance does not seem particularly likely to perpetuate health status discrimination. There is an argument, however, that geographic variation reintroduces health status into the underwriting process. In one sense, that allowance is eminently practical. Insurers could hardly be expected to sell policies for the same amount statewide (accepting, for now, that there is no national market for health insurance), given the tremendous variation in health care costs, labor costs, and other inputs. Nevertheless, there could be some rough correlation between poor health and geography.

For example, individuals living in urban areas exposed to worse air pollution and more stress may experience adverse health effects vis-à-vis more rural dwellers. People living in low-income areas – particularly the urban poor and individuals in rural communities – on average experience more health risks, combined with less access to health care. Thus, depending on how states draw the boundaries of the rating areas, allowing health insurers to engage in community rating will continue to disadvantage low-income people who live in the inner city, as well as people in rural areas. The ACA merely provides that the areas are “adequate” and authorizes the Secretary of the U.S. Department of Health and Human Services (HHS) to review the rating areas and provide further definitions. Consequently, the federal government’s definition of adequate will determine whether cordoning off low-income, high-risk populations is an acceptable practice. If adequate means “nondiscriminatory,” higher premiums would be unacceptable. But if adequate means “accurate for risk assessment purposes,” poorer, unhealthier communities could end up pay higher health insurance premiums.

Under the Secretary’s final regulations, states may establish one or more rating areas, based on existing geographic divisions, including counties, three-digit zip codes, or urban and rural regions. Consistent with the rules, some states effectively banned geographic rating by adopting single rating areas for the entire jurisdiction. Other states adopted rating areas that aligned with pre-ACA state requirements, thereby minimizing market disruption. In some cases, that meant a single rating area for the entire individual market. In other cases, the rating areas corresponded to single-county areas, which could be fifty or more per state. Policymakers in other states had difficulty designing rating areas that reflected existing regional health care costs without baked-in pricing mechanisms that could systematically disadvantage particular subpopulations. At least one state representative was attuned to the concern identified above, namely that segmenting the market too finely could isolate communities with greater needs, resulting in higher rates, contrary to the ACA’s anti-discriminatory objective. On the other hand, adopting relatively few rating areas could result in premium shocks for many residents, if previously low-cost areas were now required to share risks more broadly. There was also concern that insurers might exit the market in expensive regions, depressing competition and further increasing rates. [*Cite Commonwealth Fund report, Dec. 2014*]

The ACA does contain other provisions that may address the income differential and related effects of geographic rating areas. Two tax code provisions subsidize the cost of health insurance for lower income individuals, thus making it more affordable. First, tax subsidies are available to lower amount that lower income individuals are required to pay

in health insurance premiums. Second, a slightly lower income group of individuals may qualify for further federal assistance to offset other out-of-pocket costs, including deductibles and copayments. Both forms of federal tax assistance are paid directly to the insurance companies on the eligible individuals' behalf and operate on a sliding scale, with greater assistance to lower income individuals. But both forms of assistance are capped at a certain income level (400% of federal poverty level (FPL) in the case of premium assistance tax subsidies, and 350% of FPL in the case of cost-sharing reduction payments). Accordingly, particular middle-income populations – the “near poor” – might still experience disadvantage.

Congress designed the ACA to cover individuals at almost all income levels, ensuring near universal coverage. The lowest income individuals and families, those with household incomes below 133% FPL, would be eligible for government health care through Medicaid. The next income tier would have to obtain private insurance, either from an employer-sponsored plan or on the individual market. For employer-sponsored plans, individual enrollees could not be expected to spend more than 9.5% of their income on the plan. For individual market plans, government tax subsidies and credits would be available to reduce the cost of obtaining those plans. Individuals above 400% of FPL who are not offered employer-sponsored plans and who are not otherwise eligible for Medicare or other government programs (e.g., Veteran's benefits), bear the full cost of private market plans but may purchase through the regulated marketplace Exchanges. Finally, some individuals, whose income is below the tax-filing threshold or for whom the cost of the lowest-cost subsidized commercial market plan exceeds 8.13% of household income, may be exempt from the individual mandate to maintain insurance. They would not be subject to a tax penalty for failing to have coverage but would likely remain uninsured.

The U.S. Supreme Court, however, created a very significant income gap at the lowest end of the spectrum, but, in a different case, rejected a challenge that would have created a middle-income gap. The Court's 2012 decision in *National Federation of Independent Business v. Sebelius* allowed states the option to decline Medicaid expansion to all low-income individuals and instead to hew to their pre-ACA categorical eligibility rules with varying income levels. Most states pre-ACA eligibility rules refused to provide any coverage for childless adults, regardless of income levels. Those that provided some coverage for caretaker parents or childless adults did so at much lower income levels than 133% of FPL. Although states continue to alter their elections, mostly in favor of expansion, currently nineteen states have declined expansion while 32 states including the District of Columbia have expanded. [Cite KFF as of March 14, 2016; <http://kff.org/health-reform/slide/current-status-of-the-medicaid-expansion-decision/>; see also stateforum.org, <https://www.statereform.org/Medicaid-Expansion-Decisions-Map>] Accordingly, in more than a third of states, a significant portion of the indigent population remains uninsured and vulnerable to various health conditions based on their inability to access care.

In a subsequent 2015 case, *King v. Burwell*, the Court declined to rule that the federal tax subsidies for plans purchased on the Exchanges would be available only in states that

established their own Exchanges, as opposed to states that allowed the federal government to establish and operate the Exchange within the state. At present, twenty-seven states have federally facilitated exchanges. Had the court accepted the argument, all residents of those states would have been ineligible for tax subsidies, creating a devastating middle-income gap, leaving millions of people without insurance. There is ample health equity literature *[cite]* tracking the effect of economic disparity on health status. Our essential premise is that law and society, in various ways, systematically discriminate against the unhealthy. Thus, the ACA's overt income tiers and gaps will likely worsen the problem of health inequity and, accordingly, the incidence of healthism.

Additional, more obvious, avenues for healthism to persist are with the ACA's allowance for premium rate variation for the elderly and tobacco users. As people age, their needs for health care services tends to increase. Older individuals have a higher likelihood of developing degenerative diseases such as age-related hearing and vision loss. Similarly, age may result in compromised immune and other systems, which leads to an increased risk for other kinds of health conditions and illnesses. In short, the older a person becomes, the more likely he or she will be to require health-care services. The inverse is also true: on average, younger people tend to experience fewer health-related problems. Recognizing that tendency, the ACA also allows individuals under age 30 to satisfy the individual health insurance mandate with bare-bones, or "catastrophic coverage." Those plans have low monthly premiums but very high deductibles. But only young people are allowed to take the gamble of avoiding routine medical care and having coverage only for serious injury or illness. Therefore, the ACA's allowance for premium rate variation based on age, and for catastrophic coverage only for the young, perpetuate potentially healthist underwriting and coverage practices.

Lastly, tobacco use is highly correlated with health status. Indeed, it is hard to imagine any other reason for allowing such discrimination to persist, other than perhaps pure animus. Smokers face heightened risks for several health conditions, including various kinds of cancer, cardiovascular and respiratory disease, and the loss of bone marrow. Tobacco use thus communicates a higher likelihood of either currently having – or at some point developing – those associated health conditions. Smokers also experience diminished overall health, leading to more time away from work and a heightened consumption of medical services. Moreover, tobacco use also correlates with other health disadvantages: Lower-income individuals are statistically more likely to use tobacco. As with community rating, varying premiums based on tobacco use will likely disadvantage poorer individuals.

In addition to statistically rational reasons for discriminating against smokers, animus could explain why that particular health status-related behavior is singled out for disadvantageous treatment under the ACA's otherwise sweeping health-related antidiscrimination banner. Tobacco use enjoys little social privilege or acceptance and has been a target of various policies designed to reduce both second-hand smoking effects on non-users and paternalistically protect users from the health effects of the behavior. Smoking bans are common in workplaces and other private businesses and facilities open to the public.

To sum up, although Congress eliminated explicit considerations of health status, the ACA’s modified community rating exceptions negatively affect some of the same individuals who faced health status-related disadvantage previously. Geographic variation, to the extent that factor correlates with low-income, reveals health status discrimination. In addition, being elderly and using tobacco correlate highly with health risks. Thus, those exceptions to the ACA’s otherwise across-the-board community rating rule crudely approximate health status. Allowing health insurers to take those factors into account will produce a disparate impact on the basis of health status. As a result, the new health-care system disadvantages the same populations as its predecessor, just through a different, more indirect, process.

The new modified community rating criteria are not the only features of the ACA that perpetuate existing disparities. The same provision of the ACA that generally prohibits discrimination against individuals based on the list of health status-related factors, 42 U.S.C. § 300gg-4, also expressly allows group health plans to give preferential treatment to individuals participating in approved health promotion or disease prevention programs (commonly referred to as “wellness programs”). Specifically, group health plans, and health insurers offering group health insurance coverage, are permitted to offer premium discounts or rebates or modify otherwise applicable copayments or deductibles in return for adherence wellness programs. Subsection (b)(1).

The statute and implementing regulations distinguish two types of wellness programs. Subsection (j). Programs with rewards that are merely participation-based, such as the employer paying the cost of gym membership or smoking cessation program (even if the worker does not use the membership, attend the class, or stop smoking); waiving copayments or deductibles for preventive care, such as prenatal or well-baby visits; or offering incentives for participation in wellness seminars, health profiles, or screening tests, are not subject to particular requirements, other than that the program must be made available to all similarly situated individuals. The reward may be in the form of a discount or rebate of a premium or contribution, a waiver of all or part of a cost-sharing mechanism (such as deductibles, copayments, or coinsurance), the absence of a surcharge, or the value of a benefit that would otherwise not be provided under the plan.

Additional statutory and regulatory requirements apply to programs with incentives based on achieving a certain health status, such as weight loss, body-mass index, blood pressure, cholesterol level, smoking cessation, or other biometric indicators. For those programs, employers may not offer rewards that, in total for all wellness programs, exceed thirty percent of the cost of employee-only coverage under the plan. In addition, the employer must offer reasonable alternative standards for those with medical conditions that would make it unreasonably difficult or medically inadvisable to satisfy the otherwise applicable standard. Despite those accommodations, individuals with disabilities, older individuals, and low-income workers will likely experience more limited opportunities with regard to wellness programs. Consequently, wellness programs may perpetuate healthism, despite the ACA’s purported antidiscrimination

objective. Rather than discriminating against the unhealthy, wellness programs discriminate in favor of the healthy.

[Add discussion of even greater concern about wellness programs in Medicaid]

The ACA further discriminates in favor of the healthy through its preventive care coverage rules. An element of the essential health benefits (EHB) package, which individual and small group plans (both those sold on the new regulated marketplaces, or Exchanges, and those sold outside of the Exchanges) are required to cover is preventive care. The EHB requirement does not apply to large group plans, including employer plans, which are presumed to provide services at least that comprehensive. Both group and individual plans must cover preventive care services “first-dollar,” meaning, without regard to deductibles, copayments, or coinsurance that otherwise would be required under the plan. The rationale is fairly straight-forward and the opposite of the adverse selection concern that justifies cost-sharing requirements in other contexts; insurers actually do not want to discourage insureds from taking steps to protect their health or detect conditions at an earlier, easier to treat stage. The policy, however, does favor the healthy, *i.e.*, people who are not yet sick, over the unhealthy, *i.e.*, those who have already been diagnosed with various health conditions. Those individuals will still have to satisfy the cost-sharing requirements under their plans before they can receive care. As noted earlier, cost sharing falls particularly heavily on the unhealthy, who are likely to access medical treatment more frequently than healthy individuals.

The ACA was highly anticipated as something of a *Brown v. Board of Education* for health-status discrimination in health insurance; differential treatment based on health status would be all-but prohibited nationwide. Under the statute, federal law would protect individuals from being denied or charged more for health insurance because they were unhealthy or at risk of developing health conditions. Although similar protection has been available since the 1990s for individuals covered under group health plans, the ACA expanded that protection into other markets. The ACA, however, included a number of exceptions and other provisions that may largely perpetuate healthism.

First, the statute’s modified community rating provision allows insurers to charge different rates to the elderly and tobacco users, two statuses highly correlated with greater health problems and risks. Also, insurers are allowed to vary premiums within geographic areas, which could correlate with income level, a factor widely recognized to produce health disparities. The income differential under the ACA is explicit in other provisions, with some receiving government health insurance; others receiving federally subsidized commercial insurance; some being exempt from the requirement based on income or unaffordability; and the remaining middle to upper-income individuals obtaining group or individual commercial coverage through regulated marketplaces. Other provisions of the ACA discriminate in favor of the healthy. Workplace wellness programs allow plan sponsors and insurers to offer discounts, rebates, waivers of cost-sharing, and other rewards based on good health status or habits tending to produce better health outcomes. More broadly, the ACA requires coverage of preventive care without deductibles or cost-

sharing, thereby favoring those seeking to avoid or detect health conditions over those with already recognized conditions for which they are receiving treatment.

Recognizing the ACA's disappointment as an antidiscrimination law, we might consider alternate approaches to address healthism in health insurance. One alternative would be to recognize health care as a universal right, as most other developed countries do. That would require a fundamental paradigm shift in the United States' concept of rights; most of the rights we recognize are negative, meaning rights to be free of governmental intrusion. Our positive rights are non-constitutional and much more narrowly circumscribed, such as the right to public education. Even if we could surmount that conceptual hurdle, there are definitional challenges to the content of the right. What is the minimum level of care that all Americans should be guaranteed? Does the ACA's EHB package capture the essence of a health care right? Does the Medicare package of benefits (including Parts A, B & D)? Does the traditional Medicaid benefits package, and all its individual state variations, as well as the ACA's allowance for "benchmark" plan coverage for the expansion population?

These queries themselves highlight the fact that our current approach to health care is anything but universal; the content of the health benefits guaranteed to individuals varies by eligibility, plan type, geography, and a host of other factors. Even if the United States were to embrace a single-payer, government-run, Medicare-for-All health care program, it seems highly likely and rational that the coverage would be more generous for some populations and some conditions than for others. The reality of scarce resources and necessity of rationing would seem to dictate that result. Lawmakers could opt to provide a leaner but uniform package of benefits, or provide services tailored to subgroups of the population, similar to existing government health programs that prioritize the young, old, and disabled. It might be defensible to exclude coverage for an entire set of services, such as treatment for infertility or gender reassignment surgery. But those policies clearly discriminate on the basis of diagnosis or condition.

Moreover, given our country's deeply enshrined free market history, it seems likely that individuals still would be allowed to purchase additional health care services and coverage, above the government-provided minimum. Accordingly, the income differential and related health equity effects would persist. The bottom line is that health-status discrimination would remain a feature of the U.S. health care system even if it were reoriented to a rights-based view.

E. Conclusion

In sum, although the ACA prohibits health insurers from explicitly considering health-related factors when making their determinations, the statute allows them to weigh characteristics that closely parallel health status. Older individuals, individuals in low-income areas, and tobacco users all face higher health risks and are, therefore, more likely to be unhealthy. In addition, through the ACA's wellness program exception, insurers can still distinguish between individuals who represent good and bad risks. Moreover, first-dollar coverage for preventive care favors the healthy and disfavors the

unhealthy who have to pay deductibles and copayments for the care that they receive. Put simply, the new health-insurance system outlined by the ACA still disadvantages the unhealthy, albeit in some cases by proxy.

Universal health care, in theory, could be designed to eliminate healthism, providing uniform benefits across the board, without regard to health status. But even if lawmakers elected to cover everyone through a government program, they would almost certainly be forced to make choices about what services to cover and whether to vary the coverage for certain subgroups of the population. Therefore, the possibility of eradicating healthism by recognizing a right to health care seems limited.