HEALTHCARE POLICY

The Basics

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the access project

The Access Project is a national initiative of The Robert Wood Johnson Foundation, in partnership with Brandeis University's Heller Graduate School and the Collaborative for Community Health Development. It began its efforts in early 1998. The mission of The Access Project is to improve the health of our nation by assisting local communities in developing and sustaining efforts that promote universal healthcare access with a focus on people who are without insurance.

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Introduction

Getting involved in the world of healthcare policy for the first time can be as exhilarating and intimidating as jumping on a moving train. Everything is in motion, change is constant, and the excitement often becomes infectious. Many people, objects, and forces attract attention, but without a clear sense of structure and purpose. Everyone appears preoccupied or busy. Many competing voices clamor for attention, often saying opposite things with equal assurance. It is difficult to make sense of it all and harder still to figure out how to become an effective agent for change within the system. At the same time, what is going on here is important, and it can be both exhausting and exciting to become involved.

Welcome to the world of healthcare policy! This book was written to help new and future healthcare activists understand the basics of the American healthcare system and to learn about ways to improve it. It is written in two parts. The first describes the basics of American healthcare policy, organized around the three key elements of the system: (1) *access;* (2) *cost;* and 3) *quality*. The second part describes ways that reformers and activists have attempted to improve the healthcare system, dating back to the creation of Medicare and Medicaid in 1965, the advent of the modern American system. This book was written because understanding these basics will enable future activists to become more effective change agents on behalf of patient and consumer rights.

This book is written in a conversational style—without footnotes—in order to be as accessible as possible to readers new to healthcare policy. A full examination of the American health system would require many volumes. That would defeat the purpose of this book—to introduce future health leaders to the key ideas and themes now shaping the system. At various points, it offers recommendations for further readings as well as suggestions for activists. While this may be many readers' first or near-first book on healthcare policy, if it achieves its objectives, it will be followed by many more.

Entering the healthcare policy world for the first time can be an intimidating experience because of the complexity and size of the healthcare industry. Thus it is important to keep in mind that there is a constant need for new community activists and leaders to emerge to join or to replace others who run out of steam. The next generation of activists will redefine America's healthcare needs for the new century: in some ways, they will build on foundations that have been laid over many years; in other ways, they will move in novel and unheard-of directions. Just as our healthcare

system will always need physicians, nurses, specialists, researchers, administrators, and other professionals, so will we always need individuals and community leaders to advocate on behalf of those for whom the system was created in the first place. These people will play an important role in transforming our system from one in which unequal access to quality health care is influenced by such factors as insurance, income, and geography, to one in which the benefits of American health care and medical care are available to everyone. Training and empowering the next generation of leaders is a principal goal of The Access Project.

So, welcome to the dynamic world of healthcare policy and politics! You have arrived just in time!

The Basics of the American Healthcare System

A crucial distinction—between health and medicine—is the best place to begin. Though called the "American healthcare system," the overwhelming share of system resources is spent on sickness, on providing care to those who are unhealthy in some important way. Only a small portion of the resources spent by our medical care system is used to keep people healthy and to prevent them from becoming sick, through health promotion, disease prevention, and other public health programs. In recent years, more people have recognized this disparity and have sought to focus more resources on disease prevention and health promotion. Meanwhile, it is still more accurate to call it the "American medical care system."

It is also important to recognize that while an important goal of the medical care system is to make sick people healthy, the most significant determinants of good health are education and income. The higher one's income and education, the more likely that one's health will be better. For example, a 45-year-old white male who makes at least $25,000 can expect to live 6.6 years longer than a white male of the same age making less than $10,000. Thus one valuable way to improve the health of the population is to work to promote good education and to raise incomes. As Dr. George Kaplan of the University of Michigan said, "We need to start thinking that economic policy is the most powerful form of health policy. As we increase people's economic well being, we increase the health of all."

There are numerous ways to present the structure of the American health system. One of the most familiar and helpful ways is to divide the discussion into three essential parts: access, cost, and quality—increasing access, controlling costs, and improving quality. These are often described as the three pillars of the healthcare system, or the three legs of the healthcare stool. While each leg is critically important in its own right, the three are interrelated in every way. Access initiatives will often affect costs and quality; initiatives to control costs usually have an impact on access and quality; and quality initiatives will have cost and access effects, both positive and negative. In the process of discussing each of these three elements in turn, we touch on the issues that are most important to know about the American healthcare system.

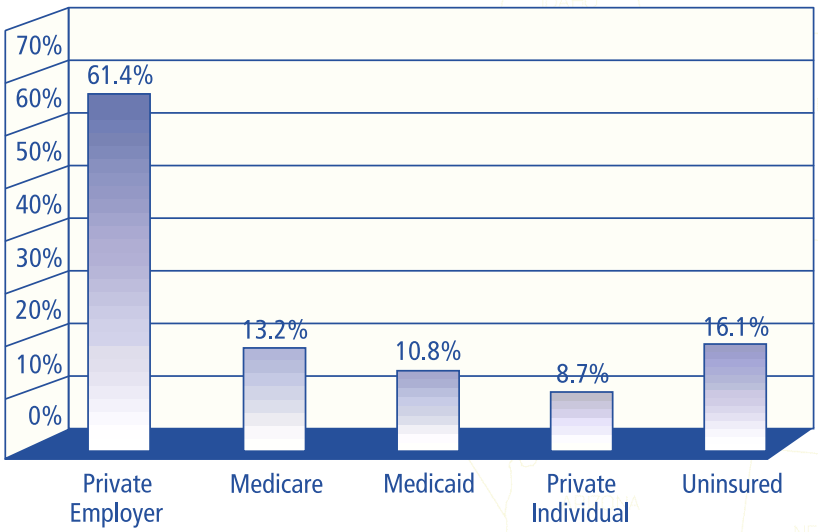
" We need to start thinking that economic policy is the most powerful form of health policy. As we increase people's economic well being, we increase the health of all."

—Dr. George Kaplan

1. Access

"America has the finest healthcare system in the world" is an oft-repeated phrase made by defenders of the U.S. healthcare system. Its truth depends on the criteria used to evaluate the system. It is undeniable that the United States has the most technologically advanced medical care system on the planet, and that that system has demonstrated extraordinary capacities to diagnose and treat disease. But it is also arguable that other nations have done a better job emphasizing health promotion, disease prevention, and primary care services. The one area in which the U.S. healthcare system undeniably falls behind the health system of every other advanced industrialized nation is in providing access to health services for all citizens. In the early 1990s, proponents of universal coverage for all Americans noted repeatedly that among advanced nations, only the United States and South Africa neglected to provide health coverage for all citizens. Since then, South Africa has embarked on the path to universal coverage, leaving the United States alone in this category. Canada, Denmark, France, Germany, Greece, Japan, and the United Kingdom all have less than 1% of their respective populations without coverage, while 16.1% of the U.S. population did not have coverage in 1997, totaling 43.4 million Americans, according to data from the U.S. Bureau of the Census.

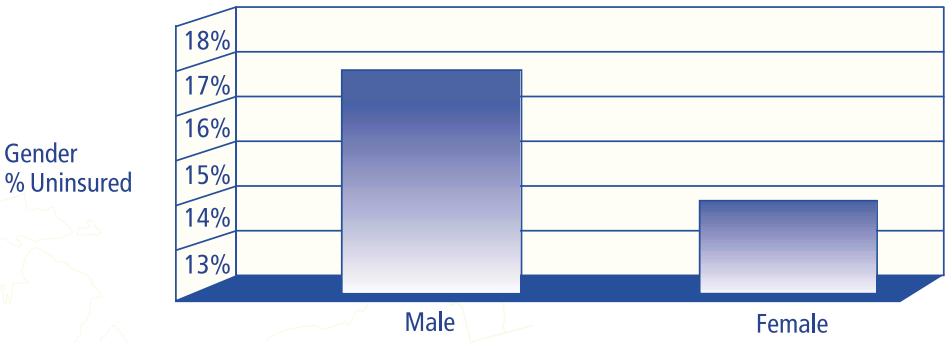
Types of Health Coverage, 1997



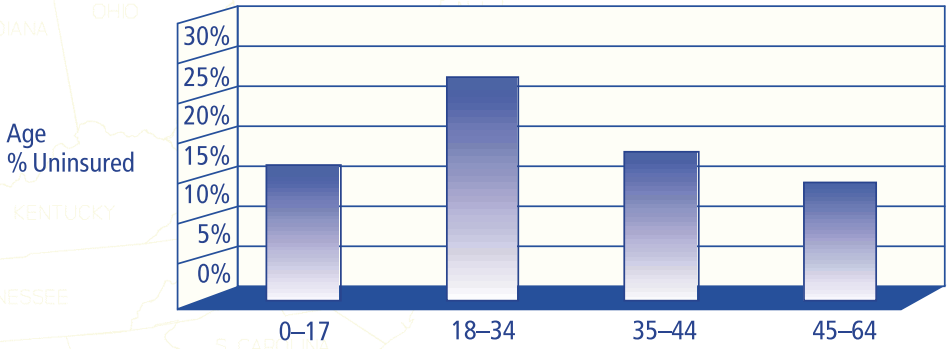
It is not just the large number of Americans without coverage that concerns policymakers, it is the persistent rate of growth in the size of this population. In 1980, the United States had about 25 million uninsured, and that number has grown by about one million per year ever since, during good and bad economic times. Recent projections indicate that by the year 2002, the number of uninsured may grow to 45.6 million, or 16.2% of the population. Using 1997 data from the U.S. Census Bureau, we know quite a lot about these uninsured Americans. (Note: these data do not account for the new federal Children's Health Insurance Program, Title XXI, established in 1997. When implemented, this program has the potential to reduce the number of uninsured children from more than ten million to about five million.)

Demographic Characteristics

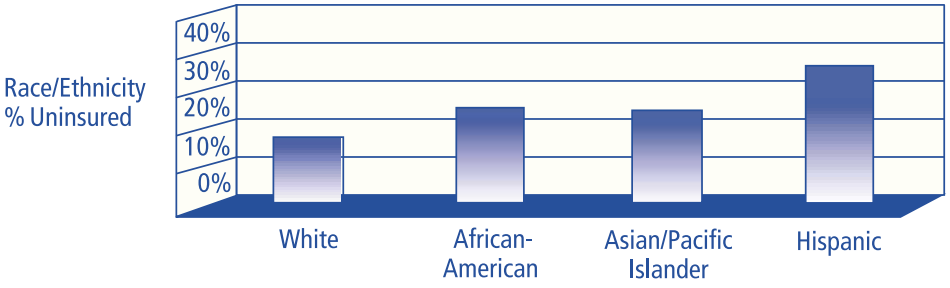
- Men are slightly more likely than women to be uninsured.



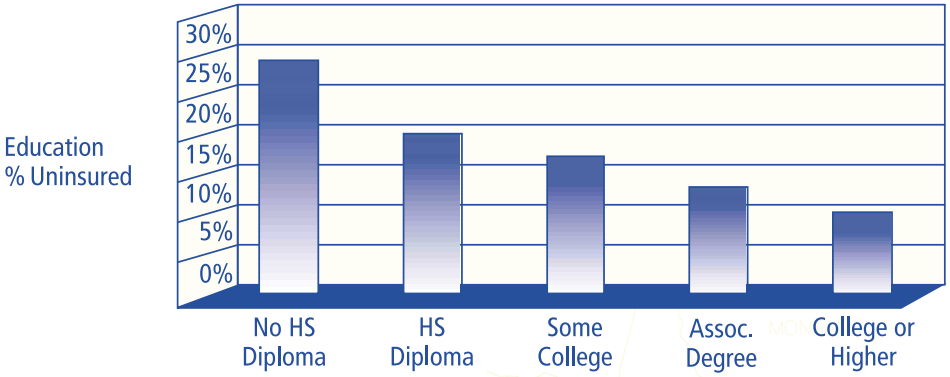
- We know that age has an impact. One-quarter of those ages 18 to 34 are uninsured.



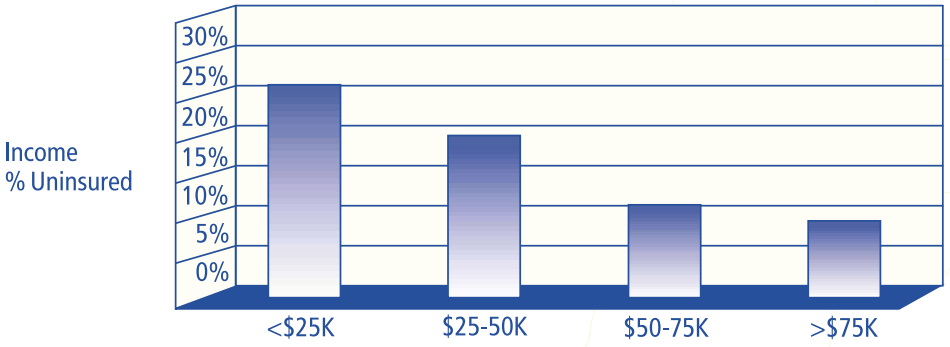
- We know that race and ethnic background have an impact. Hispanics are more than twice as likely to lack insurance as non-Hispanic whites.



- More education is associated with a higher likelihood of having insurance.



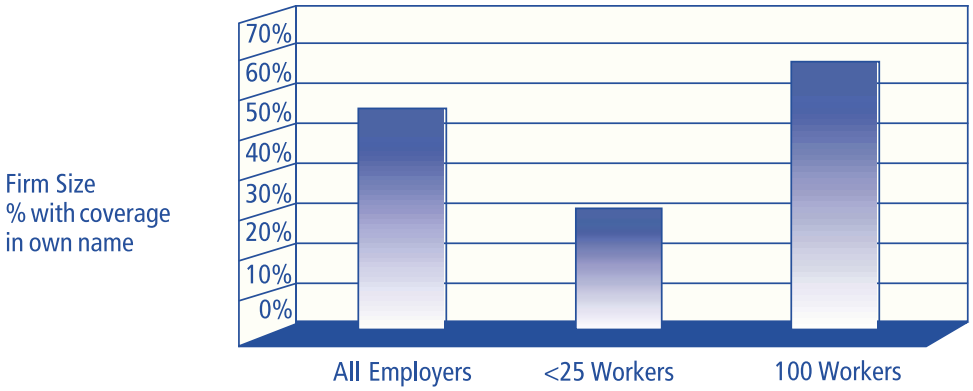
- As one's level of income rises, the chance of having no health insurance coverage generally declines. While it is clear that lower income Americans are hit hardest by the problem of uninsurance, this problem is by no means confined to lower income Americans. Indeed, health reform efforts in several states during the 1990s have focused on providing coverage for lower income Americans, leaving middle and lower-middle income Americans among the most vulnerable.



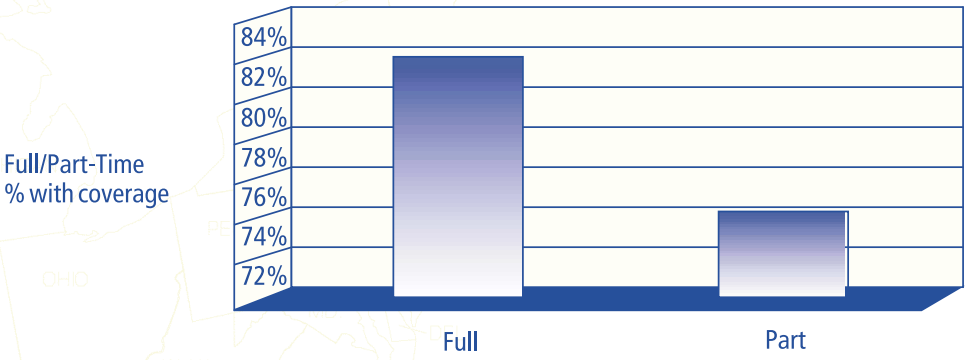
Workplace Characteristics

Several variables related to one's workplace help explain the dynamics of uninsurance.

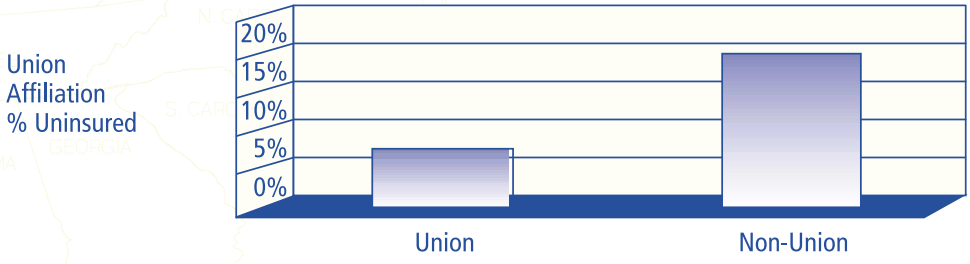
- Workers in large firms are more likely to have insurance than workers in smaller firms.



- Full-time workers have coverage much more frequently than part-time, part-year, or temporary workers.



- Workers who are not members of a union are twice as likely to be uninsured than unionized employees.



- The likelihood of being insured varies depending on the type of employer, with some sectors such as manufacturing and public service employers being more likely to provide benefits, while firms in construction and the service sector (such as restaurants) are far less likely to provide health coverage for workers.

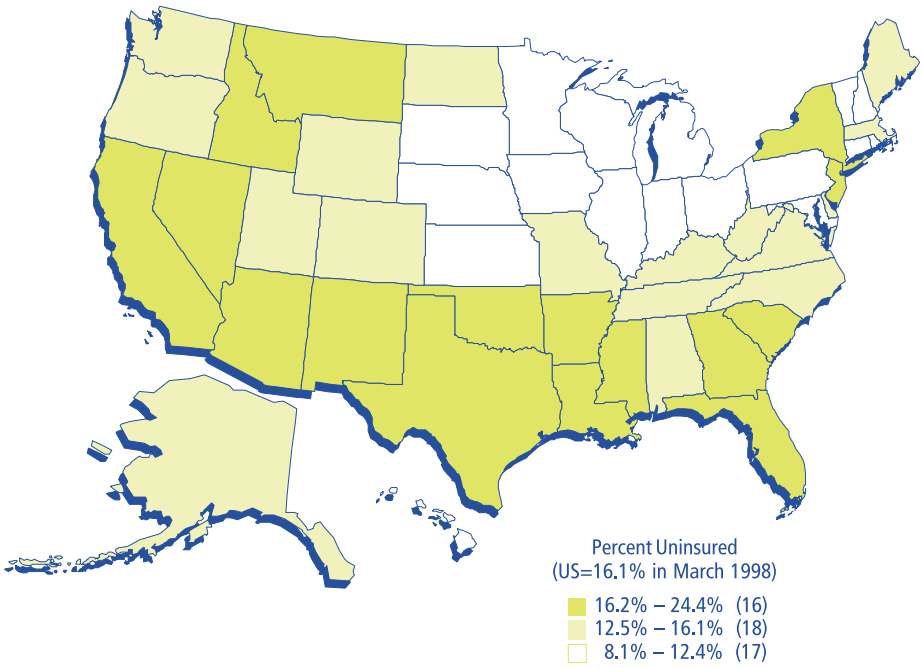
One other factor relative to employment is important in understanding the dynamics of health insurance and uninsurance. When employers began to provide coverage in large numbers, they typically paid the entire cost of premiums. The coverage offered was most frequently *defined benefit* coverage, meaning that employers agreed to pay for an agreed-upon set of benefits, whatever the cost. As the cost of health insurance premiums increased dramatically during the 1980s and early 1990s, employers began to shift many of the costs of coverage onto workers, in the form of premiums, deductibles, and co-payments. Many employers moved to *defined contribution* plans, meaning that the employer provides a fixed dollar amount, leaving the employee exposed for all additional costs above that level.

Because of this shift, increasing numbers of uninsured workers are offered coverage at their workplaces, but choose not to accept the offer of coverage because the employee share is too expensive. Some of these workers get coverage through their spouses or from other sources, but many simply choose to go uncovered because of the cost. Recent data show that while the percentage of workers who are offered coverage by their employers did not change between 1987 and 1996, the percentage of workers who are offered coverage and "take it" dropped from 88% in 1987 to 80% in 1996. Not surprisingly, workers who made the least amount of money (less than $10 per hour) were the most likely to reject employer offers of coverage.

Region

Levels of uninsurance vary depending on one's region and state. Levels of uninsurance are lowest in the northeastern and midwestern parts of the nation and highest in the southern and western regions. Levels of coverage vary substantially from one state to the next. The following map shows the states where levels of uninsurance are relatively low, moderate, and high (see Appendix 1 for the actual rates of uninsurance). It is interesting to note that some of the states with the highest levels of uninsurance among their citizens (Arizona 24.3%, Arkansas 23.1%, California 20.8%, and Texas 24.4%) have been among the least active in efforts to expand health insurance coverage.

Lack of Health Insurance by State



Children

In 1997, about 10.7 million children—15% of all people under 18 years of age—were uninsured. In terms of income, about one-third of the uninsured children were poor, in families with incomes under 100% of the federal poverty line (about $16,400 for a family of four). Another one-third were in the "near poor" category, with incomes between 100 and 200% of poverty, and the final one-third were in families with incomes above 200% of poverty. Older children between the ages of 12 and 17 were less likely to have coverage than children 11 or younger. As is true for the larger population, Hispanic children were more likely to be uninsured than African-Americans or whites.

One key difference between adults and children is the large and increasingly important role of Medicaid. As a result of federal expansions approved in the late 1980s, as well as state health reform activities implemented in the 1990s, Medicaid covers more children with family incomes below 133% of poverty than do private employers (12 million versus 7 million). More than 20% of all U.S. children are covered by Medicaid versus 11% of the full population. The State Children's Health Insurance Program (SCHIP), established by the U.S. Congress in 1997, assures that over the coming years, increasing numbers of children will be enrolled in Medicaid.

Recent research indicates that a substantial portion of the nation's 10.7 million uninsured children are eligible but not enrolled in their state Medicaid programs. How can this be? When Medicaid was first created in 1965, enrollment was linked largely to *categorical eligibility* for other programs such as Aid to Families with Dependent Children (now called Temporary Assistance to Needy Families or TANF). Beginning in the mid-1980s, Congress began to expand eligibility for Medicaid to groups of children based on their family income. However, state governments—which administer Medicaid—did not identify, reach, and enroll many of these children. A new concern has now emerged with the creation of TANF, which limits the length of time that a family may receive public assistance benefits. Because many families still qualify for Medicaid at the same time as welfare, they may believe that their Medicaid coverage ends as welfare benefits begin to expire. However, many of these families may still be eligible for Medicaid because of their low incomes, although they may not know this. Policy activists, concerned that declining welfare rolls will mean growing numbers of uninsured, are watching this situation closely.

The attention drawn to uninsured children by the enactment of SCHIP has also drawn attention to children eligible for but unenrolled in Medicaid. Many states are now establishing outreach efforts to identify children eligible for SCHIP as well as those eligible for Medicaid under prior rules.

Success in these efforts to enroll children in Medicaid and other SCHIP initiatives holds the promise of substantially reducing the numbers of uninsured children in the United States. While the attention of federal and state policymakers is focused on this challenge, it is important for activists to push hard to enroll as many children as possible.

Why Does Health Insurance Matter?

After learning so much about the uninsured, the question arises—how important is health insurance? Do people really need it? Don't the uninsured get care one way or another, anyway?

This question has been studied intensively by numerous researchers over many years. There is broad agreement that those without health insurance coverage have much more difficulty gaining access to the healthcare system than do insured people. When they do gain access—through free clinics, charity care, etc.—they receive less care and are more likely to suffer adverse consequences due to delayed or postponed care. About 17% of the privately insured population report that they lack a usual source of health care, as

compared with 33% of the uninsured. National survey data show that fully half of the uninsured have not seen a physician in the past year as compared with about 26% of the insured population.

Because they do not seek preventive services, the uninsured end up being hospitalized for controllable conditions that do not generally require hospital care. The uninsured are twice as likely to be hospitalized for diabetes, hypertension, and immunizable conditions, all problems that can be well managed in a physician's office. The uninsured also have death rates 25% higher than the insured population. Lack of health insurance can be a matter of life and death.

One further point is important to recognize: the cost of caring for the uninsured when they need urgent care is considerable, and it is passed on to the rest of the insured population through higher health costs and taxes.

Other Barriers to Healthcare Access

While lack of health insurance coverage is widely and appropriately recognized as the key barrier to accessing health services, many other barriers also exist. These can be broken down into three categories: (1) other financial barriers; (2) sociocultural barriers; and (3) organizational barriers.

What Are Co-Pays and Deductibles?

Coinsurance obligates the beneficiary to pay a fixed percent of medical bills, frequently 20%.

Co-payments are flat, per-visit fees paid by the patient.

Deductibles obligate the beneficiary to pay the first part of any medical bill up to a certain level: i.e., paying the first $200 of a $2,000 hospital bill.

1. Other financial barriers include the use of co-payments and deductibles in insurance policies that discourage patients from receiving timely and appropriate care. In the late 1970s, the RAND Health Insurance Experiment demonstrated conclusively that financial incentives and disincentives affect the amount of healthcare services that individuals and families obtain. The experiment demonstrated that low-income families, especially, will defer obtaining medically necessary care if co-payments and deductibles are too high.

2. Sociocultural barriers are increasingly recognized as substantial deterrents to healthcare access, and—even more than financial barriers—may account for much of the persistent and distressing racial disparities in health care. Some key ones are:

   Language Incompatibility: Many health facilities are not equipped to handle language differences. While language compatibility has been

demonstrated to positively affect health outcomes, many health providers and programs address this problem on an ad hoc basis, relying on family members to translate.

Provider/Staff Attitudes: Differences in the socioeconomic and cultural backgrounds of providers and patients contributes to communication difficulties. Hurried and impersonal caregiving, fostered by healthcare organizations that push providers to see large volumes of patients, leads to suboptimal care and poor outcomes.

Cultural Preferences: Little has been done to sensitize providers to patients' cultural beliefs and the need to accommodate them when possible. Fear of provider disapproval can result in lack of necessary communication that is vital to effective diagnosis and treatment.

Immigrant Status: Undocumented residents are frequently unwilling to seek service from traditional providers because of deportation fears, and legal residents may fear harming their chances for citizenship by being labeled as "public charges" if they apply for Medicaid. These fears can result in unnecessary morbidity and mortality as well as increases in healthcare costs.

3. Organizational barriers to access result from the structure of the healthcare delivery system; they are also increasingly recognized as contributors to good or poor outcomes. These barriers include:

Inadequate Capacity: Capacity issues involve shortages of health professionals, usually in rural and inner-city regions. Even when personnel are available, poorly funded and organized delivery systems can pose barriers because of long waiting times for appointments, inadequate numbers of appointment slots, inconvenient clinic hours, and an inadequate number of clinics.

Transportation Barriers: Lack of adequate transportation is closely tied to income level and poverty status and can pose a substantial barrier to obtaining appropriate healthcare services. Individuals with limited incomes who are required to travel long distances to obtain needed services may find public transportation systems inadequate or unavailable, while others are unable to afford the cost. Many individuals do not obtain necessary care because of transportation barriers.

Child Care Barriers: The unavailability of affordable and convenient child care can be a major obstacle to obtaining adequate healthcare services. Mothers may be forced to bring their children to medical appointments, which leads some to forego obtaining services.

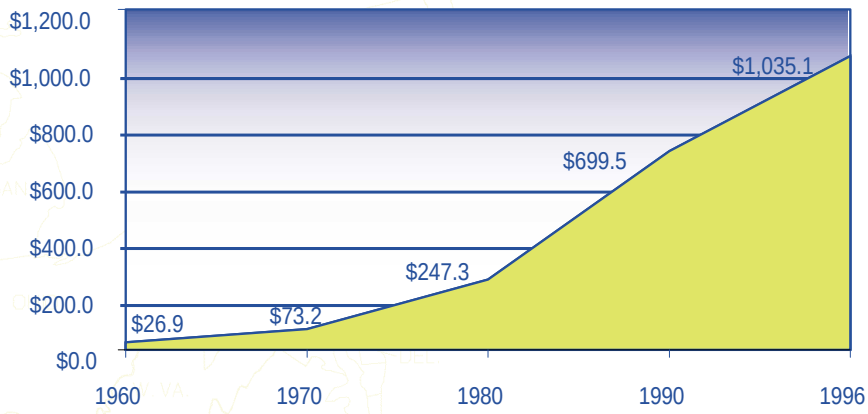
Lack of Service Coordination: Disadvantaged families and individuals often need an array of additional services related to housing, transportation, nutrition, and other social and supportive services that make the difference between obtaining and not obtaining care. Patients and systems of care can be overwhelmed by the number of competing demands and needs, all of which can result in failure to obtain needed services.

Managed Care: Some managed care plans have rigid rules requiring members to get all of their specialty care through referrals from a primary care "gatekeeper." Although coordination of care by a single physician is an ideal of managed care, in practice this can sometimes work as a barrier to seeking care.

2. Cost

If nothing else, the American healthcare system is very expensive, topping one trillion dollars in cost for the first time in 1996, up from $26.9 billion in 1960 when costs were first measured systematically. Chart 1 shows the growth in national healthcare expenditures since 1960.

National Health Expenditures $ Billions, 1960–1996

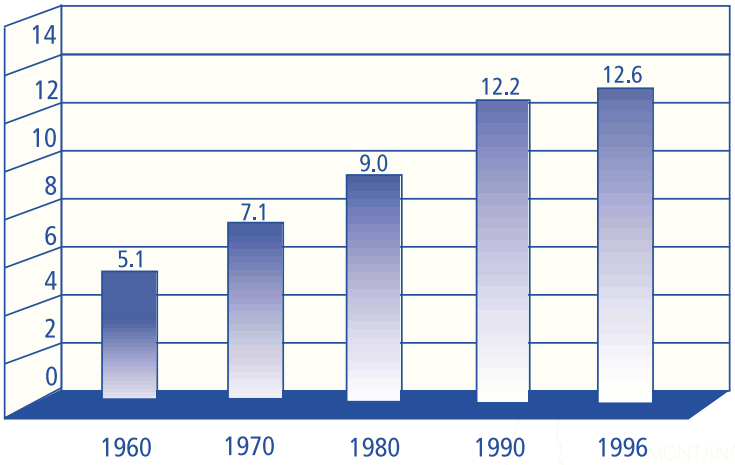


(Source: Levit, K. et al. "National Health Spending Trends in 1996"; Health Affairs, Jan-Feb, 1998, p. 38.)

Between 1960 and 1990, health spending rose at an annual rate between 10.6 and 12.9%. Since 1994, spending growth has slowed to between 4.4 and 5.6%, though few expect costs to continue to rise at this lower rate indefinitely. Another important feature of national health spending is that its rate of growth has been far greater than that of the rest of the U.S. econ-

omy. Chart 2 shows the growth in health expenditures as a percent of the U.S. Gross Domestic Product (GDP)—the accepted measure of the size of the U.S. economy. In the late 1980s and early 1990s, the annual increases in healthcare spending were so huge that some predicted expenditures as high as 20% of GDP by the year 2000. That clearly will not occur, though no one knows how long the recent moderation in health expenditure growth relative to the rest of the economy will last.

Health Expenditures as Percent of GDP, 1960–1996



(Source: Levit, K. et al. "National Health Spending Trends in 1996"; Health Affairs, Jan-Feb, 1998, p. 38.)

Another way to understand U.S. healthcare spending is by looking at comparisons with other industrialized nations. The trend that has existed for more than 30 years continues in the late 1990s: the United States leads the world in its rate of expenditures for healthcare services but shows a mediocre performance on key health status measures such as infant mortality and life expectancy. In addition, unlike the United States, the other countries provide coverage to virtually all of their citizens. Table 1 shows the performance of a number of industrialized nations on these different measures:

Table 1: United States vs. Other Industrialized Nations					
	1996 Per Capita Spending (U.S. Dollars)	1996 Percent of GDP Spent on Health	1995 Infant Mortality per 1,000 Live Births	1995 Life Expectancy at Birth (Males)	1995 Life Expectancy at Birth (Females)
United States	$3708	14.2%	8.0	72.5	79.2
Canada	$2002	9.0%	6.0	75.3	81.3
France	$1978	9.6%	5.0	73.9	81.9
Germany	$2222	10.5%	5.3	73.0	79.5
Italy	$1520	7.6%	6.2	74.4	80.8
Japan	$1581	7.2%	4.3	76.4	82.8
United Kingdom	$1304	6.9%	6.0	74.3	79.7

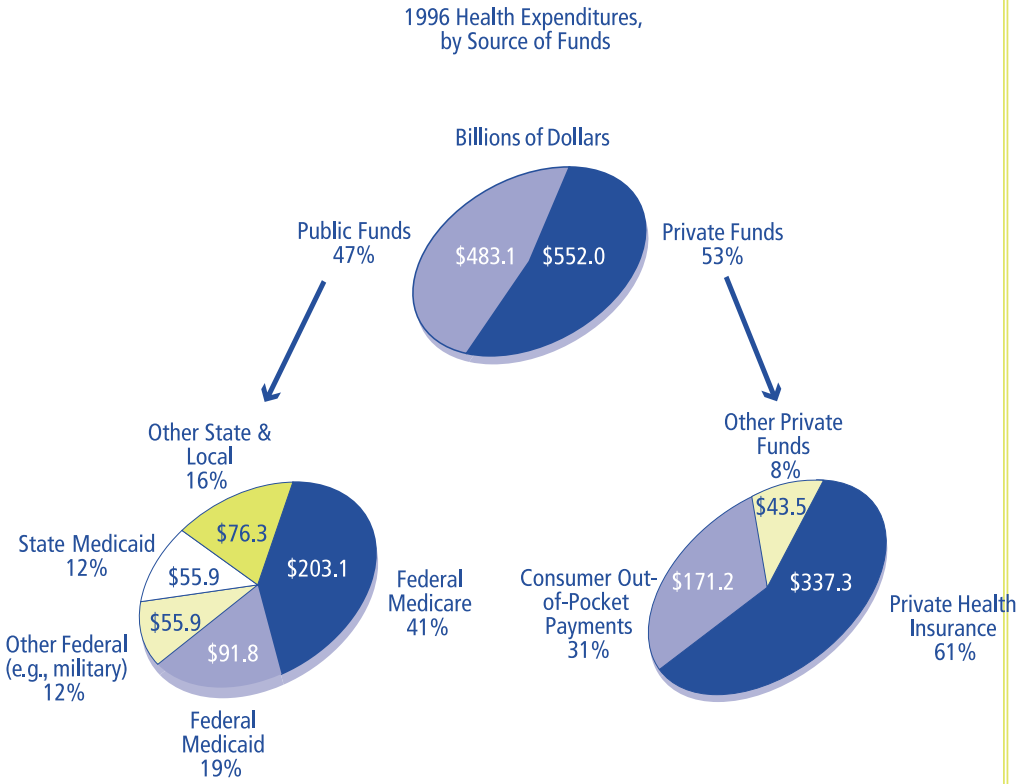
What is the "right" GDP rate?

There is no "right" rate. We do know, however, that the U.S. rate of health spending far outstrips that of other industrialized nations with better health outcomes. We also know that a nation's spending on health increases as a nation's GDP rises.

Infant mortality and life expectancy are affected by much more than the amount of resources spent on medical care. Therefore, it may not be fair to blame the medical care system for our poor performance on these measures. But these data reinforce the disconnection between investments in medicine and improvements in the health of the population.

From Where Does All This Money Come?

Many who oppose efforts to establish a national health insurance program have talked about the importance of maintaining America's private health insurance system. They are usually surprised to discover the huge portion of the system already directly financed by the government. Federal, state, and local sources accounted for $483.1 billion of the $1.035 trillion system in 1996, nearly one-half of the total cost. The following chart shows the major sources of health system funding.



(Source: Levit, K. et al. "National Health Spending Trends in 1996"; Health Affairs, Jan-Feb, 1998, p43.)

Private spending on healthcare services accounts for slightly more than half of system financing, with the bulk of it—more than $337 billion—coming from health insurance premiums paid by private employers and their employees, and by individuals who purchase coverage for themselves and their families. The cost of co-payments, deductibles, and direct consumer payments for health services is substantial—about one-half the amount spent on premiums.

What is DSH (pronounced "dish")?

Disproportionate Share Hospital spending is federal funding to assist health providers who care for very large numbers of Medicare or Medicaid beneficiaries. Medicaid DSH is funneled through state governments, though not equally, and has been a substantial source of funding, sometimes abused.

Public sources of spending fall into several basic categories. The largest public expenditure is for the federal Medicare program, which accounts for about one of every five dollars spent nationally on healthcare services. Medicare provides services to elderly persons over age 65 along with certain disabled populations. Part A pays mostly for hospital services and is financed by payroll taxes, while Part B pays for physician and other non-hospital costs

Medicare? Medicaid?

If you are confused, you are not alone. These sound-alike programs were both created in 1965 as amendments to the Social Security Act. In a nutshell:
Medicare is the federal health program for *seniors* and some disabled persons. Virtually all seniors (over age 65) are eligible for Medicare benefits, regardless of their income.
Medicaid is the federal/state program that finances health services for *low-income* families, disabled, and elderly persons. States run the program under federal guidelines (every state's program is different), and the two levels of government share the costs. Medicaid is the principal payer for nursing home and other long-term care services in the United States.

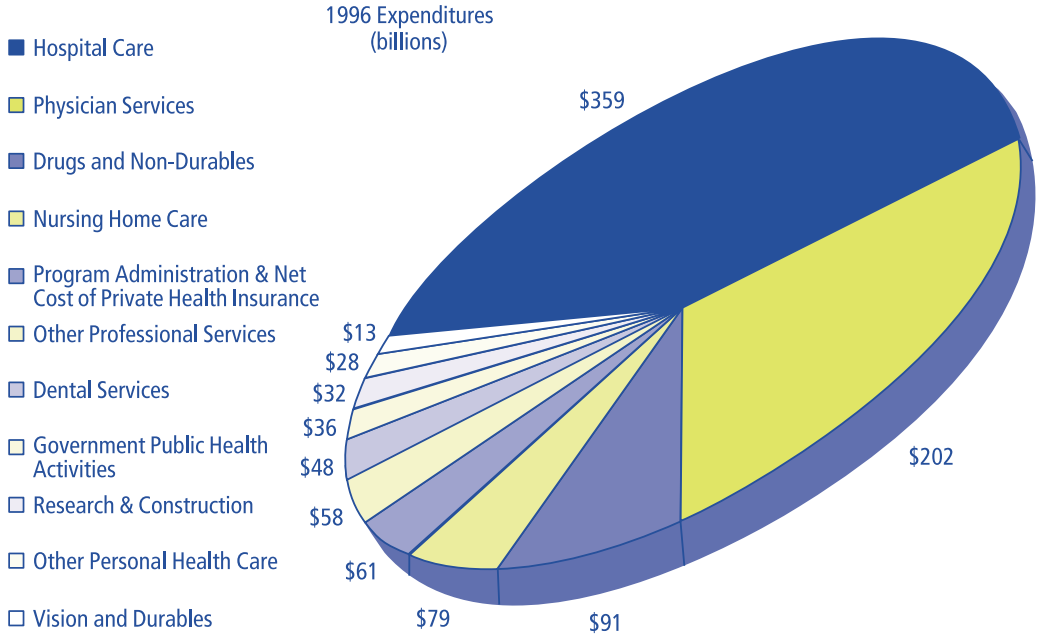
and is financed by enrollee premiums and general tax revenues. When public discussion refers to "Medicare going broke," reference is being made only to the Part A Trust Fund.

Medicaid is the other major public health services program, accounting for about one-seventh of health system spending, divided between the federal and state governments. Medicaid funds health services for various low-income groups, including welfare recipients, the disabled, and seniors in need of nursing home services who have exhausted their assets. In recent years, some states have expanded the Medicaid programs to cover larger portions of health care for other low-income adults and children. Low-income parents and their children account for three-quarters of enrollees but only one-third of program costs. This is because it is much more expensive to provide services to disabled persons and elderly persons in need of nursing home care.

Other federal spending includes health services for the military (CHAMPUS), federal employees (FEHBP), Native Americans, public health programs, and other services. Other state and local spending includes public health spending accounts, payments to safety net providers, insurance programs for public employees, and other services.

Where Does All the Money Go?

More than $1 trillion was spent on healthcare services in the United States in 1996 in a wide variety of ways. Hospital and physician services consumed more than one-half of the entire amount; drugs, nursing home services, and program administration costs followed in size:



(Source: Levit, K. et al. "National Health Spending Trends in 1996"; Health Affairs, Jan-Feb, 1998, p. 38.)

The cost of drugs has been increasing so rapidly in recent years that some predict it will outstrip the cost of physician services early in the 21st century. The $60.9 billion spent on "program administration and net cost of private health insurance" is a category that has been publicized by groups advocating the establishment of a Canadian-style "single payer" health insurance program, whereby most services are financed through taxes without the administrative costs associated with private health insurance. Others note the relatively small share of money spent on "government public health activities" for health promotion and disease prevention.

What Is GME?

GME stands for "Graduate Medical Education." The federal government (and some states) finance large portions of the U.S. medical education system through payments to teaching hospitals for direct and indirect services.

How Do We Control Health System Costs?

Because healthcare costs have risen so dramatically over the past 30 years, much public policy is focused on attempting to slow the rate of growth.

The first necessary step to controlling the growth of health system costs is to understand what drives the increases. Four factors account for most of the growth in health costs: (1) general economy-wide inflation; (2) additional inflation in medical prices; (3) increases in the quantity of health services provided to patients, including both volume and intensity of services; and (4) population growth and demographic changes. The last is a small contributor to cost increases. The other three categories loom large but vary considerably in their share from one year to the next.

Generally, Americans rely on the free market and the power of consumers to control the rise in costs in any sector of the economy—when a price for a good grows relative to its believed value, people change their buying practices, using less of that commodity or service. The seller of the good may respond either by lowering prices or by improving the value of the product. But market forces have not successfully controlled health prices. Economists believe several factors have accounted for "market failure" in health care. Key among these are (1) the unique nature of medical care that makes it difficult for consumers to judge its "value" (more on this in the section on quality); and (2) the prevalence of insurance that insulates consumers from paying, or even knowing, the full price for services.

Health insurance first emerged during the 1930s with the creation of Blue Cross plans to help individuals pay for the costs of hospitals and physician services. Hospitals began the earliest plans so that patients would be better able to use their services. These plans were "community rated," meaning that all participants paid the same premium regardless of their age or health status. During World War II, private employers began to buy health insurance for their workers as a way to increase compensation without violating the federal government's wage and price freeze—and thus began the important American pattern of employer-sponsored coverage.

Americans have been complaining about the high cost of medical care for most of this century. But rising costs became more of a public policy concern after World War II because of the spread of health insurance, which tended to mask cost increases. With the growing demand for health insurance, commercial for-profit insurers began selling their own policies during the post-war years. Other reasons for the cost acceleration in the post-war period were federal decisions to invest in the expansion of hospitals

What Is Meant By "Adverse Selection" and "Moral Hazard"?

These are key related terms in the world of insurance. *Adverse selection* occurs when people who know they are at high risk buy more insurance than those at lower risk. *Moral hazard* is the altering of one's behavior because one is insured.

Much of the behavior of insurance companies is related to their desire to avoid adverse selection by consumers.

through the "Hill-Burton" program, to finance medical education in order to increase the nation's supply of physicians, and to establish a major health research agenda. All of these activities have had important and valuable results. But they also fueled the cost engine in a dramatic fashion.

Prior to the 1970s, hospitals, physicians, and other healthcare providers largely were paid by insurers and consumers for whatever they did. The more they did, the more they got paid under the "fee-for-service" cost-based reimbursement structure. Beginning with the creation of the Medicare and Medicaid programs in 1965, public policymakers in Washington, D.C., and in state capitals, became more concerned about increases in health costs and the effect of those increases on the rest of the economy. Employers who paid the bulk of private costs also expressed concerns.

During most of the 1970s and 1980s, government responded to the health cost "crisis" through public sector regulation. The theory behind this response was that the government had to step in to correct what the market could not. The regulatory responses included (1) *certificate of need* (CON) laws that required hospitals to go through a state-based, public process before building new facilities or adding expensive new services; (2) *health systems planning boards* that included health providers, consumers, business leaders, and government officials to review CON proposals and to plan local health service delivery systems; (3) state *hospital rate setting programs* that required hospitals to submit to state cost control regulations; and (4) financing and support for the development of *health maintenance organizations* (HMOs). These four efforts were cooperative arrangements involving the federal government, state governments, employers, consumers, insurers, and providers. On the federal level, the regulatory response included the *Prospective Payment System* (PPS), created in 1983 to pay hospitals a set amount for services provided to each Medicare patient in a particular *diagnosis related group*, or DRG, rather than for each service individually based on the hospital's cost.

What Is Managed Care?

Managed care refers to any of several organizations in which measures are taken to provide care for a group of patients within a budget. Key examples are health maintenance organizations (HMOs), preferred provider organizations (PPOs), and point-of-service plans (POS). Over time, the distinctions among each of these forms have blurred.

What is Capitation?

Capitation is a method of reimbursement—especially prominent in HMOs—where by a provider is paid a certain amount per patient for a predetermined set of services. Opponents of this form of payment argue that, unlike fee-for-service, which has incentives to increase the amount of care provided, capitation contains incentives to provide less care.

Capitation can also provide incentives to address health problems early and to focus on prevention to avoid larger costs downstream.

Both dynamics have been observed in plans that use capitation.

Hospital rate setting and PPS both worked for a while to hold down costs, but they ran out of steam. The most aggressive hospital rate setting programs helped hold down hospital costs in the late 1970s and early 1980s but were abandoned by nearly all states in the late 1980s and early 1990s as hospitals figured out how to benefit more under new, market-based arrangements. The federal PPS/DRG model also worked to hold down Medicare's rate of growth during the 1980s and early 1990s. In recent years, however, Medicare's high rate of growth relative to private plans has led policymakers to seek other means to control that program's spending increases. The other regulatory responses—CON laws, health planning, and federal support of HMOs—were all judged to be well-intentioned failures. HMOs only took off after the federal program was abandoned and the private sector and Wall Street began to invest in them in the mid-1980s.

The Growth of Managed Care

One common criticism of health care prior to the 1990s was that those who paid the bills (insurers) had different incentives from the suppliers (providers) who gave the care. "If only we could unite the insurance and provider sides of the equation, we would have the capacity to control system costs," went the thinking. The "health maintenance organization," or HMO, is a term Paul Ellwood invented in 1970 to promote this organizational form. Prior to the 1970s, "pre-paid group practices," such as the Kaiser Health Plans in California, enjoyed modest success as organizations that collected health insurance premiums and provided services in their own networks of hospitals and clinics. President Richard Nixon adopted the promotion of HMOs in 1970 as his key strategy to restructure the health system to hold down costs. In 1973, Congress agreed to pass the HMO Act requiring employers who provided health insurance to include at least one HMO option for their workers, and providing federal funding for new HMOs that met federal standards.

Throughout the 1970s, observers predicted that HMOs would skyrocket in enrollment and popularity. But while many new HMOs were formed, real enrollment growth was miniscule. In 1981, the new Reagan administration ended all federal subsidies for HMOs. During this same period, as the nation went through a serious recession, employers began turning to HMOs in increasing numbers to hold down their employee health expenses. Without federal support, many HMOs converted from non-profit to for-profit status and obtained vitally needed capital—for computer systems, member services, marketing, and the like—from Wall Street investors. These currents led to the first explosion in HMO enrollment and popularity. The major growth during

this period did not involve the original "staff-model" HMOs where all physicians were salaried employees of the plan, but instead used looser "independent practice associations," or IPAs, that contracted with independent groups of physicians and other providers for services. HMOs, IPAs, and other network arrangements such as Preferred Provider Organizations (PPOs) all fall under the general label of "managed care."

From fewer than 20 million members in 1985, HMOs grew rapidly in membership to more than 50 million by 1995, with growth continuing into the Medicaid and Medicare populations. Managed care enrollment accelerated in the recession of the late 1980s and early 1990s and continued in the wake of the failure of President Clinton's proposal for national health insurance coverage in 1993 and 1994. In the early days of managed care in the 1970s, employers had to be compelled by federal law to offer their employees the opportunity to join an HMO. Generally, enrollees in these early days were workers with fewer health problems, attracted by HMOs' lower premiums. The result of this trend was higher premiums for those remaining in traditional fee-for-service plans and thus even more enrollment in HMOs. Increasingly, employers began dropping any fee-for-service option for their workers, giving either a choice of managed care plans or only one option for all workers.

In the mid-1990s, more and more managed care enrollees found themselves in these plans not by their own choice, but by their employers', causing a wave of enrollee dissatisfaction with the constraints of managed care. State and federal elected officials then tried to legislate protections for consumers in these plans. (More on this in the section on reform options for activists.)

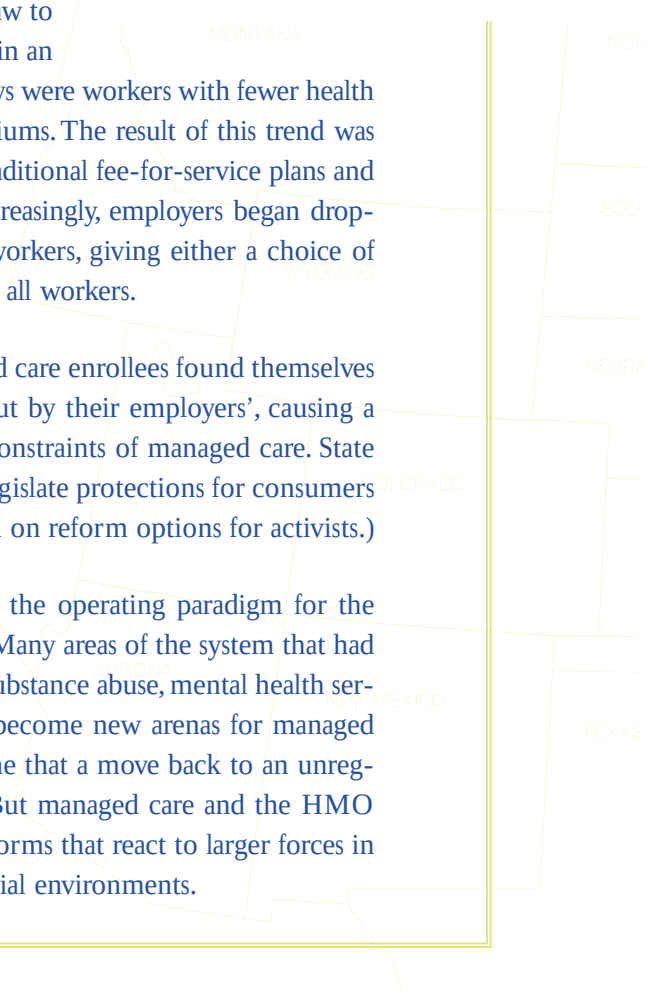
Like it or not, managed care has become the operating paradigm for the American healthcare system in the 1990s. Many areas of the system that had been bastions of fee-for-service—such as substance abuse, mental health services, dental care, and many more—have become new arenas for managed care growth and development. Few imagine that a move back to an unregulated fee-for-service system is practical. But managed care and the HMO are not static concepts. They are evolving forms that react to larger forces in the healthcare, economic, political, and social environments.

What Is "Public Health"?

While medical care focuses on the individual patient, public health focuses on the health of populations. Its interests include assessing and monitoring health problems, developing and enforcing health protection laws and regulations, implementing and evaluating population-based strategies to promote health and to prevent disease, and ensuring the provision of essential health services.

Public health professionals include nurses, sanitarians, physicians, epidemiologists, statisticians, health educators, environmental specialists, industrial hygienists, food and drug inspectors, toxicologists, lab technicians, veterinarians, economists, social scientists, attorneys, nutritionists, dentists, social workers, administrators, and managers.

They work in government but also in clinics, academic institutions, health centers, and community-based institutions.



3. Quality

In addition to broad statements, such as "the United States has the finest quality health system in the world," another commonly recited refrain about health care is that "no one knows what quality is." In fact, substantial progress has been made in defining and understanding quality over the past 30 years. As this section will make clear, we still have a long way to go. While activists appropriately devote great attention to financing and access issues, it is important to understand this key aspect of the healthcare and medical systems.

The Institute of Medicine, in a widely praised study on Medicare published in 1990, suggested that quality is *"the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge."* Several aspects of this definition are worth noting. First, the definition encompasses care for both *individuals* and *populations*, clearly and appropriately linking public health to the overall health system functioning. Second, the definition focuses on *outcomes* as the key measure of the system's effectiveness as opposed to *process* measurements; we will learn more about outcomes versus process and other evaluative tools shortly. Third, the definition recognizes that our understanding of quality health services is constantly evolving and changing by including the word *current* with professional knowledge. In the 1950s, for example, the best professional knowledge suggested that most children should have their tonsils surgically removed; today, we view that practice as unnecessary and, in most cases, an example of poor-quality medical care.

A shorter definition of quality is less precise, though a little bit more memorable. Quality is "*doing the right thing, and doing it right.*" This definition can apply to the quality of almost anything, including health care. It incorporates the two key elements of good service—choosing the most appropriate and effective intervention and applying that intervention in the best way. Not explicitly stated in this definition is a recognition that our understanding of the "right thing" evolves over time.

Understanding the Nature of Quality

Writing in the 1960s, Avedis Donabedian of the University of Michigan identified three key attributes that laid the foundation for how researchers still analyze and understand healthcare quality today. *Structure* is the physical environment in which care is delivered as well as other setting characteristics (provider credentialing, staffing patterns, ownership arrangements,

etc.). *Process* attributes are the components of the encounter between the patient and the provider, including what treatments were used, how well they were administered, and how well or poorly the provider communicated with the patient. *Outcome* is the result of the encounter and the patient's subsequent health status.

Think of these attributes in evaluating the quality of your favorite restaurant. The *structural* aspects include the physical environment, location, availability of parking, candles, air quality, and more. The *process* aspects include the politeness of the staff, waiting time for food, drinks, and the bill to be delivered, etc. The *outcome* aspect involves the quality of the food and whether you left satisfied. In fact, the Donabedian framework can be used to evaluate a wide array of services according to essential quality criteria.

While the Donabedian framework is a useful starting point to explain and understand quality issues, it also illuminates the difficulties in evaluating quality. The easiest part of a framework to judge is the *structural* aspect because elements such as appropriately marked emergency exits, or the holding of necessary credentials, are easily recognizable and determinable. *Process* aspects can be more difficult but are obtainable: patients can fill out surveys that determine how well physicians and other providers followed appropriate processes; studies on waiting and treatment times can be conducted. The problem is that neither aspect necessarily determines whether the patient received quality care. One can visit a sparkling, modern medical facility and receive excellent service, yet still obtain poor-quality technical care and have an adverse outcome. In fact, survey data show that patients who receive poor-quality technical care from a provider with good interpersonal skills will rate that care more highly than excellent technical care from a physician with poor personal skills.

Frustrations with the recognized inadequacies of structure and process measures lead many to favor *outcome-based* measures: let's just evaluate whether the encounter led to a better health result. The problem here is that one can receive excellent technical care from someone with great personal skills and yet still have a poor outcome, as well as the converse. Simply put, we do not know how well most medical practices actually heal or prevent illness. Though much effort is now being applied to investigating and understanding what works, we still have a long way to go and will continue to rely on a mix of all three elements to evaluate healthcare quality.

How Good Is the Quality of U.S. Medical Care?

Think of the U.S. airline industry and how rarely an airplane crashes. While we often think that a 99% success rate is good, for airlines that rate would mean 1 of every 100 flights ends in a disaster. Health researchers who have critically examined the extent of error in medical care have concluded that if the airline industry had the same quality performance as the medical sector, we would see two jumbo jet crashes in the United States every three days.

It is undeniable that the United States has a technologically advanced medical system that can create wondrous cures and that saves lives every day. But it is also true that our system is rampant with examples of poor quality. In 1998, President Clinton's Advisory Commission on Consumer Protection and Quality in the Healthcare Industry (which included many health sector leaders) concluded that ". . . too many patients receive substandard care. . . . These shortcomings endanger the health and lives of all patients, add costs to the healthcare system, and reduce productivity." The major quality problems they identified include:

1. Avoidable errors in the practice of medicine. A 1990 study of New York hospital discharges found that adverse events occurred in 3.7% of hospitalizations, and that 27.6% of them were due to negligence and resulted in more than 3,000 unnecessary patient deaths annually. Errors in the administration of medications led to more than 7,000 unnecessary deaths in 1993 alone.

2. Overuse of unnecessary services. One study of hysterectomies found that 16% of the 510,000 performed in 1994 were unnecessary. Several studies have documented that many thousands of radical mastectomies are performed each year on breast cancer victims when far less severe lumpectomies lead to the same outcomes. A study on the appropriateness of carotid endarterectomies (a procedure to remove harmful material from heart arteries) found that 18% were inappropriate, 49% were of uncertain clinical value, and 33% were appropriate.

What is "Defensive Medicine"?

The practice of ordering additional—and unnecessary—procedures or tests to avoid potential lawsuits. There is disagreement on how much goes on and whether it is good or bad.

3. Underuse of needed services. 1995 data show that only 76% of children had received the appropriate set of immunizations by 18 months of age. Among adults over age 65, only 52% received an annual influenza vaccine and only 28% received a pneumococcal vaccine, despite

compelling evidence of the ability of these vaccines to save lives. Another study found that between 20 to 30% of patients with depression were prescribed antidepressant medications and among those prescribed, 30% received a subtherapeutic dose.

4. Inexplicable variation in the practice of medicine. In 1994, hospital admission rates were 49% higher in the Northeast than in the West, and lengths of stay were 40% higher. Ceasarean section rates varied from 19.1% to 42.3% in a study of affluent women cared for by different obstetricians at the same community hospital. Children with asthma in Boston have a 3.8% chance of being hospitalized, while children in New Haven have a 2.3% chance.

In the airline industry, pilots are encouraged to report near misses and other safety problems. The first assumption is always that problems are tied to *systems* rather than to *individuals*. When something goes wrong, the question is: What is the problem with this system that needs to be fixed?

In the healthcare industry, the assumption has been that when something goes wrong, it is some individual's fault, and the challenge is to identify and punish that person—a practice sometimes called the "bad apples" approach to healthcare quality. Prior to the 1990s, hospitals typically had a department in charge of "quality assurance." The assumption behind the term is that quality already exists, and that a separate administrative team is needed to "assure" that quality levels are maintained. The Report of the President's Advisory Commission on Consumer Protection and Quality in the Healthcare Industry makes clear the inadequacy of this approach.

Over the course of this decade, a new approach has taken hold within the healthcare industry that is more helpful and hopeful. This approach recognizes that healthcare quality is not where it could be. It recognizes that problems are found in systems more than in individuals, that the practice of medicine is complex, and that practitioners need to be encouraged to report quality problems in a supportive environment. This approach has several names, including total quality management (TQM) and continuous quality improvement (CQI). Its assumption is that however good or bad any organization may be, there is always room for *improvement*—and the challenge is to create an environment in which professionals and consumers encourage and support each other in finding and fixing these opportunities. The health industry has moved away from the notion of "quality assurance" and toward "quality improvement."

Who's Minding the Store?

A large number of organizations—both governmental and non-governmental—have responsibilities for monitoring the quality of healthcare services delivered in the United States.

1. GOVERNMENTAL: At the federal level, the largest health-related entity is the U.S. Department of Health and Human Services (HHS). This department contains numerous agencies responsible for measuring and monitoring the quality of health care, in addition to financing, regulating, and directly providing it. All of these agencies can be helpful to healthcare and community activists, depending on the need. Key agencies within HHS include the Healthcare Financing Administration (HCFA), which enforces quality standards in the Medicare and Medicaid programs it administers; the Agency for Healthcare Policy and Research (AHCPR), which funds and conducts research on how to measure quality; the Health Resources and Services Administration, which focuses on expanding the capacity of health professionals and facilities providing care to underserved and vulnerable populations; and the Centers for Disease Control and Prevention (CDC), which conducts research and provides services that promote public health and the prevention of disease, injury, and disability. A longer list of HHS agencies involved in various aspects of the healthcare system is in Appendix 3.

HHS also has ten regional offices with officials from many of its constituent agencies. These offices can be useful in addressing a variety of health system issues and problems, including quality of care concerns.

Every state also has a set of agencies with some role in quality of care, though every state organizes these responsibilities among their agencies differently. Usually, the following responsibilities will be addressed within each state bureaucracy, each with a quality monitoring function:

Public Health: Every state has some agency in charge of public health functions that may include health facility licensure for hospitals, nursing homes, and other health institutions. Revoking a facility's license is one of the most serious steps taken to address quality of care deficiencies.

Physician and Other Professional Licensure: Every state has some administrative structure to license physicians, nurses, and other health professionals. Licensure is a key governmental power. All licensure boards were created in response to pressure by the affected group of professionals seeking licensure to control entry into their profession—this process helps keep poor-quality providers out and also enhances the earning power of licensed professionals. Licensure boards are invariably dominated by the affected

professionals. Disciplining of licensed practitioners varies enormously from board to board and state to state.

Medicaid and Other Health Reimbursements: Every state has some entity that manages the federal/state Medicaid program. Because Medicaid is so important to many providers, it makes an enormous impact by requiring its providers to meet certain quality standards. For many other providers, however, Medicaid is not an attractive program, is a small part of the provider's income base, and can be easily ignored.

State Insurance Departments: Because the "business of insurance" has been left to the states, each has its own insurance department that can have significant impact monitoring the activities of insurance companies and managed care entities such as HMOs. Traditionally, these departments have focused most of their attention on insurer solvency issues, making sure that the companies can pay claims. In recent years, many of these departments have aggressively asserted themselves into quality of care concerns. Insurance commissioners are either appointed or elected—either structure can be a plus or minus for consumer activists depending on the individual's orientation.

Attorneys General: Every state has an attorney general who enforces its consumer protection statutes. Additionally, attorneys general usually oversee a state's not-for-profit, charitable corporations. These officials can be important allies in holding accountable healthcare providers and insurers, both for-profit and not-for-profit.

2. NON-GOVERNMENTAL: A panoply of private organizations also hold responsibility for monitoring the quality of care in various sets of healthcare organizations. Two of the more important ones include:

The Joint Commission on Accreditation of Healthcare Organizations: JCAHO accredits hospitals across the nation and is jointly sponsored by the American Hospital Association and the American Medical Association. Many states and the federal Medicare program require that hospitals have JCAHO accreditation.

The National Committee on Quality Assurance: NCQA accredits managed care plans and developed the most widely used "report card"—an instrument called "HEDIS" (Health Plan Employer Data and Information Set)—to compare and evaluate HMOs and other managed care organizations. NCQA was established by the managed care industry but has separated itself in order to act more independently.

Healthcare Reform—American-Style

Throughout the twentieth century, Americans have joined together from diverse backgrounds and perspectives to reform the healthcare system. The first of many unsuccessful attempts to establish national health insurance took place during the World War I/Progressive era in American politics. Another major push took place during the Great Depression/New Deal era of the 1930s, though President Franklin Roosevelt ultimately decided to push for enactment of Social Security without health benefits, hoping the latter could be added in the future. President Harry Truman made a strong, failing effort to establish national health insurance in 1948. In each of these efforts, reformers faced strong opposition from the American Medical Association and other powerful interests. It was during this period that other industrialized nations such as Great Britain and Canada set up their national health frameworks. Enactment of a national system during the post-World War II era in the United States would have been less disruptive of existing arrangements than establishing such a structure today.

In the 1960s, American reformers achieved their greatest success with the creation of Medicare for senior citizens and Medicaid for some portions of the poor. The architects of these programs explicitly hoped that expansion of coverage for all Americans would follow shortly. It did not happen. President Nixon proposed in 1974 the establishment of a national "employer mandate" to require all employers to cover their workers, but he was opposed by reformers seeking a nationalized, "Canadian-style" health system without employer coverage. There were further efforts to legislate a national health plan in the late 1970s, but without presidential support.

What Is Community Rating?

Community rating is a system of insurance pricing where everyone in a certain area is charged the same rate, regardless of health history or personal characteristics. It is in contrast to "experience rating" where a person or group is charged a different rate depending on health history or demographic characteristics. "Modified community rating" permits some differentiation, usually based on age or geography.

The next major reform push came in 1993 and 1994 with the election of Bill Clinton as President. His proposed "Health Security Plan" would have imposed a national employer mandate and reorganized all health insurance into regional pools based on community rating, mandatory enrollment, and strict government regulation and standards. Fierce opposition from the small business community and the health insurance industry, combined with lack of consensus among the Democratic majorities in the House of Representatives and the Senate, kept any proposed legislation from reaching the floor. The subsequent election of Republican majorities in the House and Senate in the

1994 mid-term congressional elections removed comprehensive reform as a viable policy option for a still-unknown number of years.

But all action on healthcare reform is not necessarily comprehensive and not necessarily federal. Most major health reforms—whether federal, state, or local—have been incremental or step-by-step. Sometimes incremental reforms are used to slow down or thwart efforts to win more comprehensive change. At other times, incremental reforms help to win comprehensive change in pieces over a longer period. It's important for activists to think about whether a particular reform opens up avenues for future change—or helps to thwart them.

Part I of this volume described the problem of lack of health insurance in the United States and the characteristics of the uninsured. Many of them are employed; some are not. They do not have insurance because it is not available through an employer or other means, or because they cannot afford it. This lack of coverage is documented to lead to a lack of access to timely, quality health care, which in turn means poorer health. Federal and state governments consider this connection an important enough issue of public concern to have instituted policies, in a variety of categories, to address the problem.

This section outlines some of the major reforms that have been implemented, and the reform opportunities that are available for healthcare activists to invest their commitment, energy, and resources. It is divided into four sections: 1. Access initiatives, 2. Managed care consumer protections, 3. Senior citizen healthcare needs, and 4. Other healthcare reform opportunities. These reforms look both to the private sector, to expand or improve coverage through market mechanisms, and to the public sector, to cover or provide care to more of the uninsured. Suggestions for future activists are included at the end of each section.

1. Initiatives Promoting Access to Coverage

Expanding Coverage in the Private Sector

One focus of recent public policy has been private health insurance markets. The federal and some state governments have attempted many reforms and implemented some of them. Senior citizens are a particular group that could benefit from further reform.

What Are "Self-Insurance" and "ERISA"?

Employers who self-insure assume the risk of insuring their employees and use insurer-intermediaries for administrative purposes only.

The Employee Retirement Income Security Act of 1974 (ERISA) prohibits states from regulating employers who self-insure. It has also been interpreted to prevent states from mandating that employers provide specific benefits or coverage to their employees.

Because it limits the reach of state insurance laws, ERISA has been a major impediment to comprehensive state health reform.

Health Insurance Market Reforms In the late 1980s and early 1990s, when many were seeking comprehensive health system reform, others argued that simple market corrections to health insurance would solve the most pressing problems. Two parts of the health insurance market required reform: first, the "small group" market for employers with fewer than 50 employees; and second, the "individual" or "non-group" market for persons not eligible for employer coverage. As the cost of health insurance rose, insurance companies increasingly avoided the riskiest consumers. To insurers, the small group and individual markets were the most risky, unlike the large employer market where large numbers of enrollees minimized the cost impact of a major illness to any one worker.

During the 1990s, many states implemented insurance market reforms to address problems faced by small businesses and individuals in obtaining and keeping private health insurance. Generally, states sought to provide: (1) *guaranteed issue*, ensuring that individuals or businesses that met appropriate criteria could obtain coverage from insurers; (2) *guaranteed renewal*, ensuring that individuals or businesses that met appropriate criteria could not be denied renewal; (3) *modified community rating*, ensuring that all policy holders within certain defined groups would be charged the same rate; (4) *limitations on pre-existing condition exclusions* that insurers used to deny coverage to persons who may cost the plan large sums of money; and more.

In 1996, Congress and the President approved the Health Insurance Portability and Accountability Act of 1996 (HIPAA) to increase the access, portability, and renewability of private health insurance by setting minimum standards for individual, small group, and large group markets. In essence, Congress applied the reforms enacted in some states to all 50, imposing a degree of uniformity and consistency. Additionally, employers who self-insure are exempt from all state-imposed health insurance regulations because of a law passed in 1974 known as ERISA (see box). Under HIPAA, these employers must adhere to the same standards that apply to traditionally state-regulated markets.

When HIPAA and many state insurance reform laws were passed, supporters claimed that the new law would solve critical problems facing consumers and would drastically reduce the numbers of uninsured. In fact, insurance reform

by itself has led to no drops in any state in the numbers of uninsured. Most of the uninsured lack coverage because of affordability, not availability. HIPAA did not impose any affordability requirements on insurers, and many sidestepped the new mandates by pricing their products at unreasonable levels. Those who thought they could buy health reform on the cheap were kidding their constituents—or themselves.

What Is "Cost Shifting"?

Cost shifting is the process of shifting the costs of taking care of some patients onto another group more able to pay. For example, when Medicare or Medicaid reduces its payments to hospitals, hospitals simply charge more to privately insured patients to make up their losses.

Under managed care, providers have been less able to shift costs. Their flexibility varies substantially from market to market.

At the same time, these insurance reforms—small and non-group—have enabled many individuals to obtain coverage who otherwise would have been unable to, and have allowed many ill individuals to retain coverage. The reforms have also led to premium increases for young and healthy individuals whom insurers desire because they cost so little. For these reasons, many commercial insurers continue to fight these laws and seek ways to subvert these reforms.

ADVICE FOR ACTIVISTS

Evaluate your state's health insurance market consumer protections and look for opportunities to expand availability and affordability, especially to those most vulnerable to the market—those in poor health or with small group or individual coverage.

Employer Mandates and Single Payer Proposals In the late 1980s and early 1990s, America's health system faced dual crises the likes of which it had never seen—rapidly expanding costs and rapidly expanding numbers of uninsured. Employers had been trying a variety of means to hold down exploding employee health costs; government budget writers were unable to stem a tidal wave of red ink; across the nation, the sense grew that "nothing seemed to work." In this context, a window of opportunity appeared to consider and promote more far-reaching health reform proposals.

One set of proposals mandated that all employers provide health insurance to their workers and associated families. All other industrialized nations, in one way or another, required employers to pay part of their nation's health bill. Even President Nixon, no radical reformer, embraced the concept of a national employer mandate in 1974—albeit to avoid proposals for more far-reaching reform.

In 1974, wrongly anticipating the passage of a national employer mandate, Hawaii became the first state to pass a law requiring all employers to cover

their workers. The law required individual—not family—coverage and exempted those working fewer than 20 hours per week. During the 1980s, the law was aggressively enforced as the state sought to expand coverage to as many islanders as possible. In the early 1990s, the state entered a long economic recession and relaxed enforcement. Currently, the Hawaii mandate is not enforced, and many employers hire workers for only 19 hours to evade the requirement.

In 1988, Massachusetts passed the second employer mandate in the form of a "pay or play" statute. All employers were assessed a new $1,680 per-worker tax, though employers who bought insurance coverage for their workers were exempted. The revenues from the tax would be used to finance coverage for uninsured workers and their families. In subsequent years, Oregon, Washington, and Minnesota all passed their own forms of employer mandates. None of these four was ever implemented, and all have been subsequently repealed. Small business opposition was critical in altering the political consensus within each state.

In 1993, President Clinton included a national employer mandate as a key component of his ill-fated "Health Security Plan." The campaign for passage began with support from several national business organizations, including the U.S. Chamber of Commerce. Over the course of the political debate over his plan, most of these business groups reversed their position to opposition.

No state has considered adopting an employer mandate since 1993. The examples from the states that did pass mandates suggest that it is not likely to be a successful path in the near future. The change in the composition and structure of the nation's workforce—with more workers placed in "consultant" and part-time positions—makes potential enforcement of such a requirement less feasible. In addition, employers who self-insure (a significant percentage of employers providing health insurance in most states) are exempt, under the federal ERISA law, from any state-imposed mandates. The likelihood of a state obtaining an ERISA exemption from Congress is extremely remote.

The progress of Canadian-style, single-payer proposals has been even less encouraging. In the late 1980s and early 1990s, a handful of states saw single-payer plans pass one legislative chamber or the other, most prominently in the Democratic-controlled New York State Assembly in 1990. In 1992, the State of Vermont created a new health commission and directed it to produce two alternatives for the legislature by 1994, either a Canadian-style single payer, or a German-style multipayer—both with universal coverage. The commission

met its mandate, and the legislature ultimately adopted neither. In November 1994, California voters had the opportunity to select a single-payer system through a statewide ballot referendum. Voters rejected the ballot question by a margin of 73% to 27%. No state has passed, much less attempted to implement, a single-payer model.

Big-picture, comprehensive health reform has been the Holy Grail for healthcare activists throughout the 20th century. Perhaps the 21st century will be more kind to these efforts. But it is difficult to escape the conclusion that the real progress made in expanding health access and services to those in need has been accomplished with an incremental, step-by-painful-step approach.

ADVICE FOR ACTIVISTS

Those who want to work for broad-based comprehensive reform need to maintain a long-term perspective but not neglect opportunities for incremental progress that present themselves on a more frequent basis.

Senior Citizen Healthcare Needs "Seniors have Medicare—they've got it made—they'll drive the rest of the economy bankrupt taking care of them! What more do they need?"

Actually, quite a bit.

The Medicare program, established in 1965, has had an enormously positive impact on the health and financial well-being of senior citizens, providing medical services that have helped to lengthen considerably their life expectancy and to avert financial disaster for many.

But Medicare has not kept pace with the changing needs of the elderly population or with developments in medical care. Today, for example, access to prescription drugs is an essential component of good medical care, yet Medicare does not pay for outpatient prescriptions. While Medicare covers a range of medical services, it also requires a series of premiums, co-payments, and deductibles for its many services, and most seniors covered by Medicare pay *more* out of pocket each year than do insured folks under the age of 65. Recent changes brought on by the Balanced Budget Act of 1997 will shift even greater costs onto Medicare beneficiaries in the next five years.

To make up for Medicare's inadequacies, many seniors purchase Medicare supplemental—or Medigap—policies. Medigap policies that cover prescription drugs are costly—drugs are the major cost not covered by Medicare

besides long-term care. Policies based on fee-for-service and freedom of choice are also more expensive than managed care plans that restrict choice. Seniors with incomes under 130% of the federal poverty line are eligible for governmentally subsidized Medigap policies (the Qualified Medicare Beneficiary—QMB—and Specified Low-Income Medicare Beneficiary—SLIMB—programs), though large numbers of eligible seniors fail to take advantage of this option. In every state, a significant number of seniors have no Medigap coverage either because they do not know about the special subsidy programs or because their incomes are too high to qualify, yet too low to afford many commercially available products.

Access to Medigap Policies. Markets for Medigap insurance are regulated by federal and, in some cases, additional state requirements. States can do a much better job reaching out to eligible seniors to enroll them in subsidized Medigap programs. States can also develop their own subsidies to increase access to Medigap plans by vulnerable seniors.

Access to Prescription Drugs. A number of states have established programs to help eligible seniors buy prescription drugs. The programs can be expansive or limited and have been funded by a variety of sources, including lottery funds in Pennsylvania, casino revenues in New Jersey, and cigarette taxes in Massachusetts. States without such a program can create one—states with such a program can expand it. In the context of a rapidly changing Medicare market, states can look at redirecting the revenue stream to subsidize purchase of more comprehensive Medigap policies by eligible seniors.

Long-Term Care. Medicare provides seniors with only a very limited benefit for either home-based or nursing home care that is needed for a short time following a hospitalization. To pay for long-term care in a home or institutional setting, seniors must either use their own savings and contributions from family members, rely on a small private insurance market, or divest themselves of most of their resources to qualify for their state's Medicaid program. Medicaid is currently the primary source of funding for long-term care for the elderly, accounting for nearly half of expenditures on nursing homes in 1997.

ADVICE FOR ACTIVISTS

Connect with senior citizens' advocates in your state to identify key health needs for senior citizens. Senior citizens can be enormously effective lobbyists and advocates—linking their issues with other health needs for the under-65 population can help improve services for both populations.

Expanding Coverage in the Public Sector

For certain people, no amount of reform in private insurance markets will make health coverage accessible. Federal and state governments have undertaken equally ambitious efforts in the public sphere to reach some of these populations.

Medicaid Reforms During the 1992–94 national health reform debate, Medicaid was not considered a reform option. During the economic recession of the early 1990s that preceded the reform period, Medicaid was the universal "budget buster" of state spending, leaving governors and state legislatures in no mood to consider expansion. Medicaid was historically structured as a "categorical entitlement" for persons who fit into categories such as welfare, SSI disability insurance, and a limited number of others. When state economies went sour and the numbers of unemployed rose, soaring welfare populations also spilled into Medicaid programs, depleting already tight state budgets. Added to this were a series of congressional mandates passed in the late 1980s requiring states to gradually cover all children under the age of 18 up to 100% of the federal poverty level ("FPL"; about $16,000 for a family of four) by the year 2002.

In response to the cost increases, states moved to enroll most Medicaid recipients into managed care plans that gave states more fiscal control. As healthcare inflation lessened between 1993 and 1997, concerns about the cost impact of Medicaid expansion began to diminish. Also, Medicaid has built-in advantages—substantial federal cost sharing and a pre-existing administrative structure—that became more apparent. As states looked for ways to expand coverage to growing numbers of uninsured persons, the option of using Medicaid, and specifically seeking a Medicaid Section 1115 research and demonstration waiver (or simply a "1115 waiver"), became the option of choice for many.

States have used Medicaid 1115 waivers to reinvent their programs, moving away from "categorical" eligibility under which some poor are

The **TennCare** program, Tennessee's Section 1115 Medicaid waiver initiative, provides comprehensive managed care coverage to Tennesseeans who (1) were previously eligible for Medicaid; (2) were uninsurable as a result of an existing health condition; or (3) are not eligible for an employer-sponsored or other government-sponsored health plan. This policy implies a judgment that the best way to insure the continual financial support for TennCare and its 1.29 million enrollees is to enroll middle- and upper-income, working (and voting) uninsured families, in addition to families who are poor. TennCare currently covers 1.29 million people, using the same amount of money that at one time provided coverage for only 750,000 poor families.

Tennessee used its purchasing power to ensure provider participation. Providers cannot ignore one-quarter of the state's population in TennCare: 490,000 uninsured working citizens (the "expansion" population), as well as 800,000 working or disabled poor citizens (the "Medicaid" population). In the TennCare design, enrollees with moderate or high incomes receive the same benefits as people of low income. Politically, it is very difficult to cut or reduce funding for a program when it serves a significant group of higher income enrollees.

covered but many are not, to a structure where Medicaid is open to nearly all uninsured individuals below a certain income level. Some states have used 1115 waivers for limited purposes only to expand Medicaid managed care, but other states have used savings to finance major expansions in health insurance coverage for the uninsured.

Medicaid 1115 waivers differ from traditional Medicaid in two ways that make state policymakers less leery of using them for expansions: (1) The 1115 programs are not structured as entitlements, meaning that enrollment can be suspended when program funds are used up; and (2) The programs can vary the amount and scope of benefits provided to beneficiaries, again giving program and budget managers more flexibility. While these attributes are reasons for vigilance on the part of activists, they are key concessions that have led policymakers to implement significant access expansions.

As of April 1999, 19 states had implemented 1115 waiver programs, while another 16 states had applied but not yet implemented them. See Appendix 2 for a list of the status of Medicaid 1115 waiver applications in 35 states.

Most 1115 waivers are simply creative ways to place existing Medicaid recipients into managed care/capitation plans. But the most creative waiver plans have used the process to generate additional federal revenues that can be used to expand coverage to a significant number of uninsured residents in ways that are politically palatable to policymakers. Some of the more creative state initiatives include waiver programs in Tennessee, Oregon, and Massachusetts.

ADVICE FOR ACTIVISTS

Learn about the status of your state's Medicaid program, particularly its 1115 waiver status. Learn about how other states have used waivers to expand coverage. Identify ways that your state could develop its own waiver or else strengthen and expand its existing one.

Non-Medicaid Access Expansions A number of states have identified sources of funding to establish their own healthcare insurance programs to provide coverage for uninsured residents. Some states have combined these initiatives with their Medicaid programs to enhance their market clout, to minimize administrative costs, and to maximize federal matching revenues.

One of the premiere examples is in Minnesota, where the MinnesotaCare program, established in 1993, is open to uninsured families with children and incomes up to 275% of the federal poverty level, and to childless adults with incomes up to 175% of the federal poverty level. The program is

financed by a 1.5% tax on healthcare providers and insurers, as well as by co-payments and premiums paid by enrollees. The program has been used to provide insurance coverage to more than 100,000 state residents who otherwise would be uninsured. The program is required to operate within its annual approved budget and thus has a waiting list of families and individuals seeking coverage.

The Washington Basic Health Plan is another example of a successful state-subsidized program that helps uninsured persons obtain coverage. The BHP provides subsidized coverage for adults and children up to 200% of poverty and permits anyone with an income over 200% to buy into the program at full cost.

Benefits for both programs are broad, though MinnesotaCare strictly limits inpatient hospital expenditures to discourage individuals from dropping private employer coverage to gain access to the program. Everyone in both programs is required to be part of a managed care organization, and premiums/co-payments are required for many services. Both programs have more applicants than available slots because of budget limitations.

ADVICE FOR ACTIVISTS

If your state is looking for a way to expand access for the uninsured, make sure that they examine programs such as MinnesotaCare and the Washington Basic Health Plan.

Children's Access Initiatives There was a period in the early to mid-1990s when cynics proclaimed that nothing special could come out of Congress or state legislatures for the exclusive benefit of children because "kids don't vote." They were wrong. After more than 20 states created their own programs to expand health insurance coverage for uninsured children, Congress in 1997 approved Title XXI of the Social Security Act, the State Children's Health Insurance Program (SCHIP), a state-federal partnership designed to expand insurance coverage to large portions of the nation's 10.7 million uninsured kids.

SCHIP provides an enhanced federal match to states that develop new programs to cover uninsured children in accordance with federal rules. For example, states that normally receive a 50% federal Medicaid match can receive a 65% match under SCHIP. About $24 billion is available between 1998 and 2002 to support this initiative. States have a choice of expanding their Medicaid programs or establishing/expanding state-only programs.

Federal SCHIP rules require states applying for the enhanced funding to include in their plans a strategy for *outreach*. Many of the plans involve collaboration with community resources—using facilities (in addition to hospitals and community health centers) in which to outstation state workers, or entering agreements with community groups to provide information and assistance to potential enrollees. Part of the $24 billion in SCHIP funds is designated specifically to support outreach work. Most of the outreach initiatives that states are establishing to bring kids into their SCHIP programs will also help identify and enroll currently eligible children. Importantly, several million of the 10.7 million uninsured children are *already* eligible for Medicaid under existing program rules—states do not receive an enhanced match for enrolling these kids.

By December 1998, all but two states (Washington and Wyoming) had submitted SCHIP proposals to the Healthcare Financing Administration. The two remaining states have until the fall of 1999 to submit and receive approval for their programs or else forfeit their funds for distribution to other states. States are also permitted to revise their programs over the course of the five-year plan, expanding or contracting their initiatives. Many states have not taken advantage of the full amount of federal money available for the program.

ADVICE FOR ACTIVISTS

Find out what your state is doing to implement SCHIP. Understand how much federal funding is available and what state action would be required to draw the full amount. Investigate ways that you can help to maximize federal funding to expand and broaden your state's program to cover more children and to provide a better benefit package. Explore innovative outreach strategies used in your and other states to attract eligible residents to SCHIP and Medicaid.

2. Initiatives Promoting Access to Care for the Uninsured

In spite of these many efforts to expand insurance coverage to those with no or inadequate insurance, there is still a large and growing number of uninsured who need access to care. There has been significant public policy and community activity in this area as well.

Hospital Community Benefits Most U.S. hospitals and healthcare organizations are organized as not-for-profit organizations. They do not pay taxes and are exempt from numerous requirements that apply to for-profit organizations

that must pay taxes and, in the case of investor-owned corporations, report to and comply with Securities and Exchange Commission (SEC) requirements. Not-for-profit corporations usually fall under the oversight jurisdiction of state attorneys general.

Local communities are not permitted to collect property taxes from not-for-profit groups. Various other state and federal taxes also do not apply. In some states, the continuation of tax-exempt status has been a matter of political controversy. Healthcare institutions suggest that providing medical services to sick people (including uncompensated care to uninsured persons) and jobs to local community residents is the essence of their critical community benefit. Critics suggest that hospitals and other institutions amass significant amounts of wealth and then provide little in return to local communities.

In various states and communities, public officials and activists have demanded (sometimes in the form of legislation) that not-for-profit organizations document the amount and extent of community benefits provided to localities. Some requirements have gone beyond the not-for-profit institutions and included for-profit organizations as well, noting community obligations in the banking and utility industries as models. Nationally, the hospital industry has made explicit efforts to document the extent of community benefits provided. In some cases, hospitals have simply documented what they have been doing and listed dubious items under this category. In other instances, institutions have made genuine efforts to expand and enhance the services and programs provided to the broader community.

Advice for Activists

Find out what your state is doing with regard to holding hospitals and other institutions accountable for their community benefits. Use this information to develop organizing campaigns to expand services available to uninsured persons and disadvantaged groups.

Not-for-Profit Conversions

Not-for-profit hospitals and insurers have long been dominant forces in the American healthcare system. During the 1990s, a substantial number of hospitals and health plans converted to for-profit status. This process has raised concerns about care for the uninsured and indigent as well as opportunities for activists.

Before 1997, the vast majority of U.S. hospitals were either not-for-profit or public. In 1985, there were 3,349 not-for-profit hospitals, a number that decreased to 3,191 in 1990 and to 3,092 in 1995. The number of conversions to for-profit status increased during the mid-1990s: 34 in 1994 and

59 in 1995; in 1997 the number of conversions began to drop. The most significant for-profit conversions among health insurers have involved Blue Cross and Blue Shield plans. In 1994, the Blue Cross/Blue Shield Association eliminated its longstanding requirement that its licensees be not-for-profit, leading to conversion controversies in California, Colorado, Georgia, New York, and Virginia.

Concerns related to hospital and insurer conversions involve access to services and coverage for various vulnerable populations, as well as the rights of local communities that have supported these entities over long periods through charitable giving and exemption from various state and local taxes. Generally, courts of law have the final say over not-for-profit conversions. Attorneys general in most states also become heavily involved in each issue. Legislatures have entered the arena by seeking to rewrite the laws governing conversions, instituting additional requirements on those seeking to change their status.

ADVICE FOR ACTIVISTS

Take the opportunity to become involved in specific conversions and engage attorneys general and legislatures in discussions to establish more rigorous procedures to review future conversion activity.

Maintaining the Safety Net As long as the categories of "uninsured" and "underinsured" exist in the United States, there will be a need for "safety net" mechanisms to provide ways for needy persons and families to obtain necessary medical services—and a need for healthcare activists to organize and advocate for continuation and expansion of these supports. The term "safety net" encompasses a wide array of providers, institutions, programs, and funding sources that differ dramatically from state to state, county to county, and community to community. Healthcare activists need to understand the nature of their local healthcare safety net, and to reach out to the providers and other professionals/volunteers who maintain it. These dedicated persons have important information and insight—and sometimes resources—and are valuable and important allies in any campaign to expand access. Following are some key aspects of the healthcare safety net that can be found in different parts of the nation:

1. *Hospitals:* The most common destination for ill and uninsured persons is a local safety net hospital. That hospital may be state-, city-, or county-owned (33%); a not-for-profit, a large academic medical center (57%); or a private, for-profit entity (10%). In 1996, the Georgetown Institute for Healthcare Research identified 369 "urban safety net hospitals."

Other surveys have developed different estimates, but all agree that less than 10% of U.S. hospitals fit the "safety net" designation. These institutions are often seriously underfunded and overcrowded. In the 1980s, as healthcare competition began to accelerate, the practice of "hospital dumping"—whereby one hospital would send uninsured patients to safety net hospitals—resulted in action by the U.S. Congress to require all acute care hospitals to provide services to persons needing emergency care and to women in labor regardless of their ability to pay. While reports of hospital dumping have fallen, they have by no means ended.

2. *Community Health Centers:* One of the few remaining elements of 1960s "Great Society" programs is the nation's network of community health centers that provide comprehensive preventive and primary care to diverse, underserved populations across the nation. About 825 federally-qualified health centers provide services in nearly 3,000 sites in rural and underserved communities to more than 9.3 million persons, including 3.5 million Medicaid recipients, 1.8 million Medicare recipients, and 3.8 million uninsured persons.

   The situation facing health centers is similar to that faced by many safety net hospitals: chronic underfunding, lack of capital resources, and difficulties in recruiting and training qualified staff. Some federal agencies, notably the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services, provide direct federal dollars to assist center operations, in amounts between $350,000 and $1 million per center. In 1995, state, local, and private sources provided nearly $400 million—or 16% of all revenues—to community health centers.

3. *Free Care and Uncompensated Care Pools:* All hospitals provide some amount of free or discounted service to uninsured or underinsured persons. "Uncompensated Care" consists of charity care provided to persons who are uninsured and bad debts from underinsured persons who are unable to pay deductibles or co-pays that are part of their insurance arrangement. Some states have explicit laws that provide rights to certain persons unable to pay for their hospital care, though these vary widely in applicability and enforcement. A small number of states (Connecticut, Maryland, Massachusetts, New Jersey, and New York) maintain a system of explicit "uncompensated care pools" from which hospitals can obtain resources to help them pay for their uncompensated care costs. Each of the pools in these five states vary markedly from the others; they are artifacts of a mostly abandoned form of regulation called hospital rate setting. No state has considered setting up a pool in

more than a decade, though it has proven to be a highly useful safety net mechanism in the states that maintain them.

4. *Voluntary/Donated Services:* The healthcare safety net often is composed of more than hospitals and community health centers. Physicians, nurses, other professionals, and citizen volunteers play vitally important roles in many communities. Most physicians provide some amount of below-cost or no-cost service to medically needy persons. Many physicians, dentists, nurses, and other professionals volunteer services at clinics and in other settings to provide care to those without resources. In some cases, concerned individuals have established formal programs to channel volunteer services in more effective ways. For example, in the northwestern Massachusetts community of North Adams, Ecu-Health Care has provided a means for uninsured individuals to obtain services from a highly organized network of volunteer practitioners working for partial or no pay. Another example is Project Access of the Buncombe County Medical Society in North Carolina that uses county indigent care funds to recruit physician volunteers to accept indigent care referrals, leveraging over $3.5 million in free care services for medically needy persons. Similar models include the Community Supported Medicine network in the Southern Berkshire region of Massachusetts and the Free Clinic in Roanoke, Virginia.

5. *Dedicated Local Tax Levies:* Some communities have organized to provide explicit public financing to sustain and develop safety net services. One of the most noteworthy examples is the Hillsborough County Healthcare Plan in Florida, financed by a half-cent sales tax increase adopted in 1991 to establish a comprehensive managed care plan for about 24,000 uninsured county residents. The $77 million cost of the plan includes $51 million from the sales tax revenue and an additional $26.8 million from county property taxes. This program was a 1995 winner of the Innovations in American Government award by the Kennedy School of Government at Harvard University.

ADVICE FOR ACTIVISTS

Take the time to find out the structure and nature of the healthcare safety net in your community and state. Form relationships with the professionals and others working in those systems. When expansion of insurance coverage is not attainable, explore possibilities to shore up and expand the healthcare safety net for those in need.

3. Managed Care Consumer Protection Reforms

Throughout the 1970s and 1980s, managed care in general and HMOs in particular were the darlings of many seeking health system change. By emphasizing prevention and combining the insurance and delivery aspects of care, they offered the promise of more cost-effective and higher quality care than was evident in the unmanaged, fee-for-service environment. HMOs were the "little engine that could," with health system reformers cheering them up the high hill. The entry of shareholder/investor ownership of HMOs beginning in the mid-1980s, however, began to alter this perception. Capitation, which in one respect gives a health plan the incentive to emphasize real prevention and to provide holistic and effective care, also was revealed to give plans an incentive to skimp on care and to engage in risk-selection practices to avoid enrolling those with serious health problems. In the 1970s and 1980s, employers generally offered their workers a menu of health plan choices, one of which was organized on a fee-for-service basis, usually at a higher cost. In the 1990s, employers increasingly gave workers one option—a managed care plan that limited choice of providers and controlled utilization.

These trends, along with others, resulted in a consumer backlash against managed care that reverberated in the U.S. Congress and in all 50 state legislatures. Between 1994 and 1998, nearly all states had passed various laws to protect consumers in managed care and to give various healthcare providers some power in negotiating with plans. The most common and significant of these measures include:

- Access to Emergency Services Requiring insurers to pay for individuals who present themselves at hospital emergency departments if a "prudent layperson" could reasonably consider that the health problem was an "emergency."
- Continuity of Care Requiring managed care plans to provide current enrollees the opportunity to continue to obtain services—for a period—from a provider that has been terminated or that disenrolls from the plan.
- Direct Access Providing individuals in managed care plans direct access (without prior plan approval) to some classes of providers that are not classified as "primary care." The most common form of this requirement allows female patients to have direct access to OB/GYNs. Other groups approved for direct access in some states have included chiropractors, dermatologists, optometrists and ophthalmologists, and all classes of specialists.

- **Bans on Financial Incentives** Prohibiting managed care plans from using financial incentives that compensate a provider for ordering or providing less than medically necessary and appropriate care to enrollees—usually aimed at specific cases of the form of payment referred to as "capitation."
- **Point of Service** Requiring plans to permit members to see providers who are not part of the managed care plan, usually for a higher-than-normal fee. In some cases, the option has been made for only specific benefits, and in other cases, more generally.
- **Freedom of Choice** Restricting or eliminating the right of plans to narrow members' selection of providers in return for a price discount.
- **Bans on Gag Clauses** Prohibiting provisions that outlaw providers from discussing treatment options with patients.
- **Grievance and Appeal Procedures** Establishing requirements to permit plan members to appeal access denials and other benefits. A special case is the requirement of an expedited appeals process when a person's health would be jeopardized if she had to wait more than a short time to receive care. In some cases, the laws establish requirements for the internal processes within plans. Many states have also established external appeals and grievance processes, often located within a government office.
- **Insurer Liability** Traditionally, only providers, not health plans, could be sued by consumers for malpractice. Because of the intrusive nature of managed care activities, legislators in many states have filed bills—and at least three states have passed laws—to permit consumers to sue plans for malpractice.
- **Comprehensive Consumer Bill of Rights** In numerous states, lawmakers have moved away from piecemeal managed care regulation and have introduced and passed "omnibus" managed care regulatory measures addressing the range of issues listed above. In 1998, President Clinton's Advisory Commission on Consumer Protection and Quality in the Healthcare Industry formally recommended the establishment of a consumer bill of rights for managed care enrollees but could not agree on whether these rights should be guaranteed in federal law. Congress considered a host of legislative initiatives in 1997-98 to establish comprehensive protections in federal statute.

As these proposals have been debated, various sides have offered estimates of the cost impact on health premiums. Supporters of increased regulation cite studies showing a small cost impact, while opponents cite their own studies predicting huge cost impacts. In general, proposals that more directly protect consumers have been found to have a lower cost impact than

proposals that more directly aid providers. In general, all cost estimates should be regarded with skepticism-predicting the future with regard to healthcare costs has always been and continues to be notoriously unreliable. Also, while most states have passed some laws to protect managed care enrollees, no states have taken advantage of all possible options.

ADVICE FOR ACTIVISTS

Find out where your state stands in terms of protecting consumers in managed care plans. Find out who are the key public officials and health providers working in this arena. Choose your reform targets with care.

Managed care consumer protection remains a high-profile health reform issue. Many states have passed protections, and other states and the federal government are still considering them. One side benefit of this attention is that this issue has returned health care to near the top of the public policy agenda across the country. Activists can seize this opportunity and can also use it to cast the spotlight of reform not just on those who have coverage and face access problems, but also on those whose access problems result from having no coverage at all.

CONCLUSION

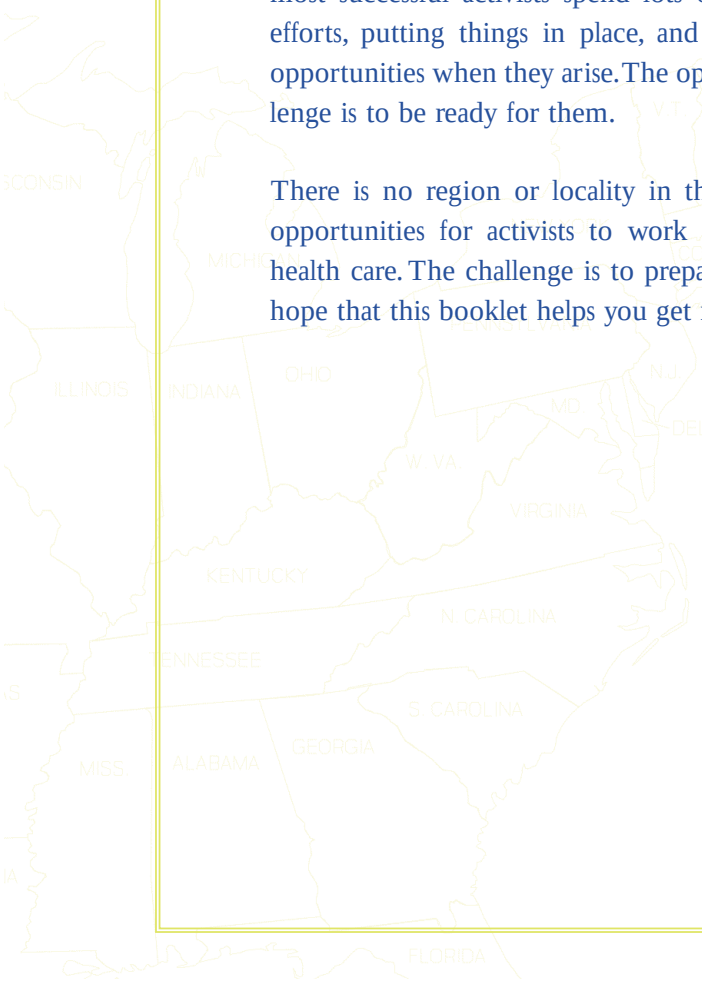
There are many ways for activists to engage the system. There are always new issues emerging that generate conflict and create opportunities for principled, disciplined activists to expand access and to strengthen the rights of patients and consumers. There are several points to keep in mind:

First, *the broadest possible coalitions create the greatest opportunities for change.* Throughout the system, depending upon the issue, there are many groups and individuals who will want to join with and help in new campaigns. Keeping the door open and the welcome mat out is vitally important to successful organizing.

Second, *be fixed in your goals, but flexible in your means.* It is extremely difficult to predict the outcome of any particular political conflict because one can never predict at the start who else will get involved. Thus it is important to be adaptable and flexible in devising strategy and implementing campaigns.

Third, *remember that luck usually only comes to those who are ready for it*. The most successful activists spend lots of time and energy organizing their efforts, putting things in place, and getting ready to take advantage of opportunities when they arise. The opportunities always emerge—the challenge is to be ready for them.

There is no region or locality in the United States that does not hold opportunities for activists to work successfully to improve and expand health care. The challenge is to prepare to do so ably and successfully. We hope that this booklet helps you get ready!



The Author

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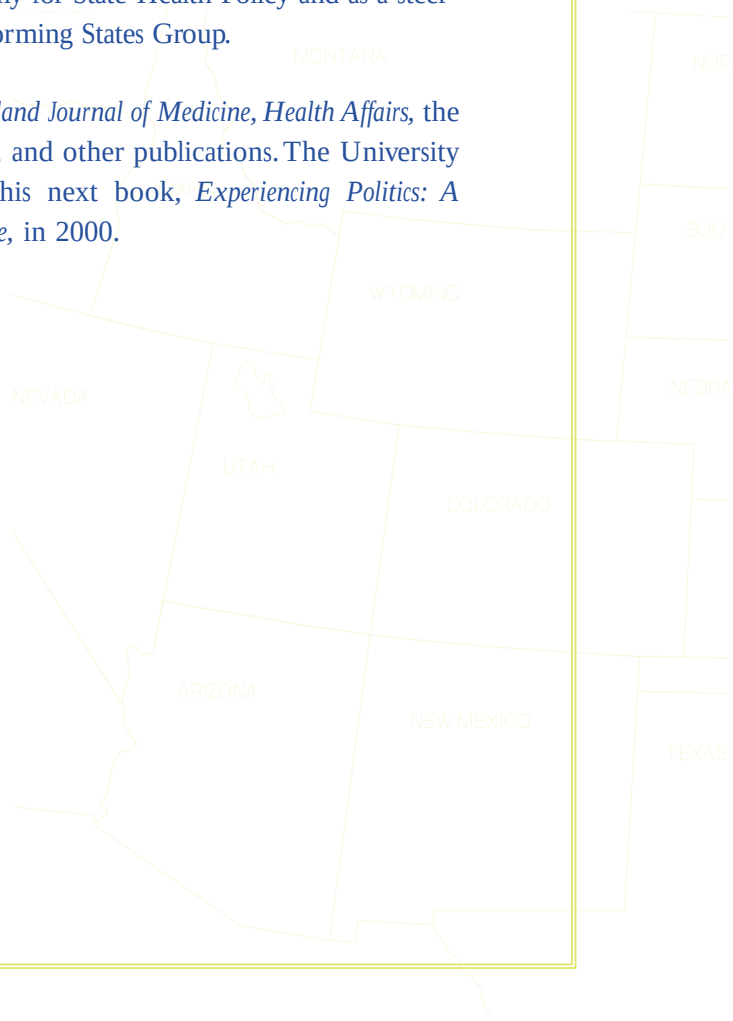
John has published in the *New England Journal of Medicine*, *Health Affairs*, the *American Prospect*, the *Boston Globe*, and other publications. The University of California Press will publish his next book, *Experiencing Politics: A Legislator's Stories of Health and More*, in 2000.



Lack of Health Insurance Coverage, by State, 1996–97

State	Total Population, 1997 (thous.)	Percent Not Covered
Alabama	4,247	14.2
Alaska	641	15.8
Arizona	4,655	24.3
Arkansas	2,622	23.1
California	32,987	20.8
Colorado	3,929	15.9
Connecticut	3,299	11.5
Delaware	750	13.3
District of Columbia	518	15.5
Florida	14,399	19.3
Georgia	7,647	17.7
Hawaii	1,183	8.1
Idaho	1,257	17.1
Illinois	12,098	11.9
Indiana	5,865	11.0
Iowa	2,830	11.8
Kansas	2,590	11.6
Kentucky	3,922	15.2
Louisiana	4,250	17.9
Maine	1,225	13.5
Maryland	5,057	12.4
Massachusetts	6,004	12.5
Michigan	9,794	10.3
Minnesota	4,767	9.7
Mississippi	2,737	19.3
Missouri	5,322	12.9
Montana	894	16.6
Nebraska	1,662	11.1
Nevada	1,724	16.6
New Hampshire	1,200	10.7
New Jersey	7,977	16.6
New Mexico	1,827	22.5
New York	18,143	17.3
North Carolina	7,352	15.8
North Dakota	639	12.5
Ohio	11,230	11.5
Oklahoma	3,338	17.4
Oregon	3,298	14.3

State	Total Population, 1997 (thous.)	Percent Not Covered
Pennsylvania	11,922	9.8
Rhode Island	944	10.1
South Carolina	3,815	17.0
South Dakota	712	10.7
Tennessee	5,542	14.4
Texas	19,751	24.4
Utah	2,085	12.7
Vermont	581	10.3
Virginia	6,752	12.6
Washington	5,748	12.5
West Virginia	1,747	16.1
Wisconsin	5,126	8.2
Wyoming	491	14.5
UNITED STATES (1997)	269,094	16.1%

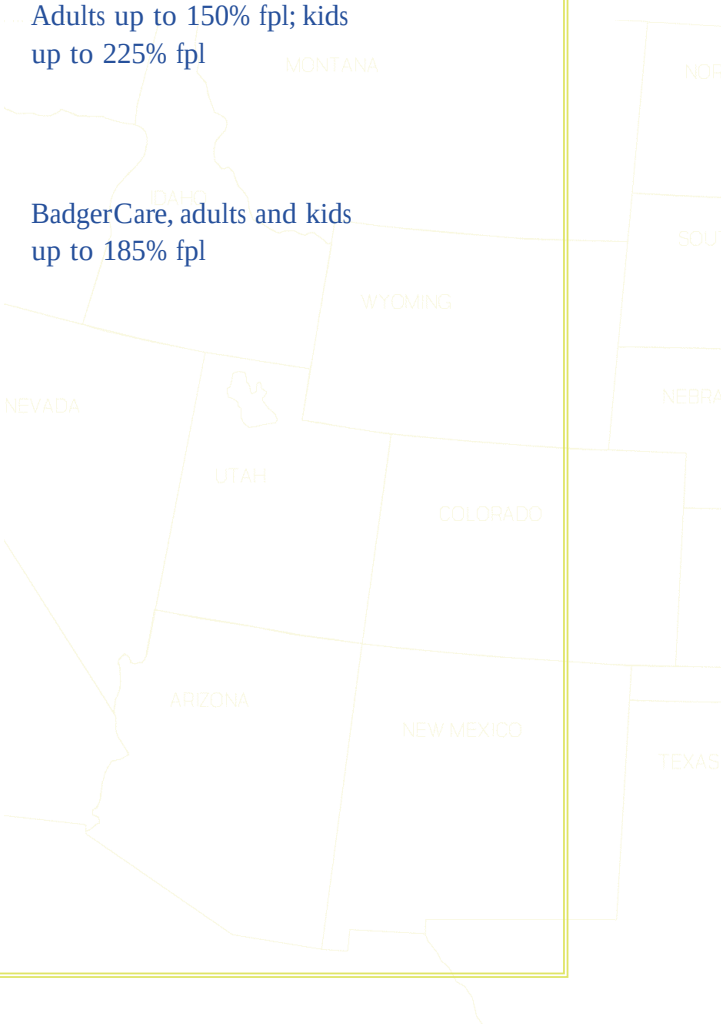
Source: U.S. Bureau of the Census, Current Population Survey

Section 1115 Medicaid Waivers: Status as of April 1999

State	Status	Program Information
Alabama	Implemented 5/97	Better Access for You
Arizona	Implemented 1982, amendment pending	Arizona Healthcare Cost Containment System (AHCCCS)
Arkansas	Implemented 9/97 Amendment pending	ARKids First; covers kids up to 200% fpl
California	Implemented 7/95	Los Angeles County Health Dept. only
Colorado	Under development	
Delaware	Implemented 1/96	Diamond Health Plan; covers adults and kids up to 100% fpl
District of Columbia	Submitted 10/98	
Florida	Legislature rejected 7/94	
Georgia	Pending w/ HCFA	For behavioral health services only
Hawaii	Implemented 8/94 Amendment pending	Covers certain adults and kids up to 300% fpl
Illinois	Approved/suspended	MediPlan Plus
Indiana	Under development	
Kansas	Withdrawn	
Kentucky	Implemented 11/97	Kentucky Healthcare Partnership
Louisiana	Conditionally rejected 6/95	LA Health Access, would cover adults and kids up to 250% fpl
Maryland	Implemented 6/97 Amendment pending	HealthChoice
Massachusetts	Implemented 7/97	MassHealth, covers most adults and kids up to 133% fpl
Minnesota	Implemented 4/95 Amendment pending	PMAP Plus, combined with MinnesotaCare (see next section)
Missouri	Implemented 2/99	Kids up to 300% fpl; adults up to 100% fpl
Montana	Submitted 9/98	Medical savings accounts
New Hampshire	Pending	

State	Status	Program Information
New Jersey	Approved, Unimplemented	
New York	Implemented 10/97	The Partnership Plan
Ohio	Implemented 7/96	OhioCare
Oklahoma	Implemented 7/97 Amendment pending	SoonerCare
Oregon	Implemented 2/94	Oregon Health Plan
Rhode Island	Implemented 8/94	RiteCare, kids up to 250% fpl
South Carolina	Approved, Unimplemented	
Tennessee	Implemented 1/94	TennCare, adults and kids up to 400% fpl
Texas	Pending	State of Texas Access Reform
Utah	Pending	
Vermont	Implemented 1/96	Adults up to 150% fpl; kids up to 225% fpl
Virginia	Under development	
Washington	Pending	
Wisconsin	Pending	BadgerCare, adults and kids up to 185% fpl

FPL: Federal Poverty Line



Key Health Agencies of the U.S. Department of Health and Human Services

Healthcare Financing Administration (HCFA) HCFA is the federal agency that administers the Medicare, Medicaid, and Children's Health Insurance programs. In addition to providing health insurance, HCFA also performs a number of quality-of-care related activities, including certification and quality improvement.

Food and Drug Administration (FDA) The FDA is an agency within the Public Health Service, which in turn is a part of the U.S. Department of Health and Human Services. It is charged with protecting American consumers by enforcing the Federal Food, Drug, and Cosmetic Act and several related public health laws.

Health Resources and Services Administration (HRSA) The HRSA directs national health programs that improve the health of the nation by assuring quality health care to underserved, vulnerable, and special-need populations and by promoting appropriate health professions' work force capacity and practice, particularly in primary care and public health.

National Institutes of Health (NIH) The NIH helps prevent, detect, diagnose, and treat disease and disability. It conducts research in its own laboratories; supports the research of non-federal scientists in universities, medical schools, hospitals, and research institutions throughout the country and abroad; helps in the training of research investigators; and fosters communication of biomedical information.

Agency for Healthcare Policy and Research (AHCPR) The AHCPR is the lead agency charged with supporting research designed to improve the quality of health care, reduce its cost, and broaden access to essential services.

Administration for Children and Families (ACF) The ACF is responsible for federal programs that promote the economic and social well-being of families, children, individuals, and communities. Under the rubric of welfare, it runs the Temporary Assistance for Needy Families program, (formerly AFDC and JOBS), as well as Welfare to Work, Refugee Assistance, and Repatriation. As part of Children and Youth programming, it administers foster care, adoption assistance, child abuse and neglect programs, Head Start, child care, and Development Funds. Other responsibilities include social service block grants, low-income home energy assistance programs, developmental disabilities, the President's Committee on Mental Retardation, and the Administration for Native Americans.

Indian Health Service (IHS) The IHS is the principal federal healthcare provider and health advocate for the more than 550 federally recognized tribes in the United States. It operates a comprehensive health service

delivery system for approximately 1.4 million of the nation's 2 million American Indians and Alaska Natives. Its annual appropriation is approximately $2.2 billion.

Substance Abuse and Mental Health Services Administration (SAMHSA)
SAMHSA's mission is to improve the quality and availability of prevention, treatment, and rehabilitation services in order to reduce illness, death, disability, and cost to society resulting from substance abuse and mental illness.

Useful Readings in Health Policy and Public Policy

1. *Agendas, Alternatives and Public Policies, 2nd edition. J.Kingdon. New York. HarperCollins. 1995.* A-well known framework that explains why some issues get on the public agenda and get action, while others do not.
2. *And the Band Played On: Politics, People and the AIDS Virus. R. Shilts. New York. St. Martin's Press. 1987.* A journalistic account of the politics of AIDS during the early years of the epidemic.
3. *Continuous Improvement as an Ideal in Health Care. D. Berwick. New England Journal of Medicine. 320: 53-6. 1989.* Seminal article advocating the use of "total quality management" in health care as opposed to traditional quality assurance.
4. *Free for All? J.P. Newhouse. Cambridge, MA. Harvard University Press. 1993.* The compendium of the RAND Health Insurance Experiment, history's largest planned health policy experiment, which demonstrated the impact of co-payments and cost sharing on use of medical services.
5. *The Future of Public Health. Institute of Medicine. Washington, D.C. National Academy Press. 1988.* Critically important statement on the role of public health in the overall system.
6. *The Great White Lie. W. Bogdanich. New York. Simon and Schuster. 1991.* Compelling, well-analyzed stories exposing the dimension of problems in American hospitals.
7. *Healthy People (1990, 2000, 2010—forthcoming). U.S. Public Health Service. Washington, D.C. Government Printing Office. 1979, 1989, 1999.* A series of reports setting out public health objectives for the ensuing decade.
8. *Is Prevention Better than Cure? L.B. Russell. Washington, D.C. Brookings Institution. 1986.* One of the first attempts to answer the key question in health promotion and disease prevention: Is prevention better (more cost-effective and cost-beneficial) than traditional medical care?
9. *National Health Expenditures in 1997: More Slow Growth. Katherine Levit and others. Health Affairs. 17: 99-109. 1998.* Presentation of the most recent national health expenditure data and an analysis of trends.
10. *The Painful Prescription: Rationing Hospital Care. H. Aaron & W. Schwartz. Washington, D.C. The Brookings Institution. 1984.* A comparison of the British system for allocation of limited healthcare resources with the American system.
11. *The Law and the Public's Health, 3rd edition. K. Wing. Ann Arbor. Health Administration Press. 1990.* Good overview of legal issues from various vantage points.

12. *The Social Transformation of American Medicine. P. Starr. New York. Basic Books. 1982.* A sociological history of American medical care that foretold the managed care and corporate healthcare revolutions of the 1990s.
13. *The System: The American Way of Politics at the Breaking Point. H. Johnson & D. Broder. Boston. Little Brown. 1996.* What happened to the Clinton health security plan.
14. *The Tragedy of the Commons. G. Hardin. Science. 163: 1243-8. 1968.* The essential parable of the dilemma of private versus public good.
15. *Who Shall Live? Health, Economics, and Social Choice. V. Fuchs. New York. Basic Books. 1975.* The first book to raise the issue of limiting the financing and delivery of medical care and the moral and social dilemmas that would attend.

Glossary

Adverse selection: Insurance term. Adverse selection occurs when people buy more insurance when they know they are at a higher risk of an event (for example, poor health) occurring.

Capitation: A method of financial reimbursement—prominent with HMOs—in which a provider is paid a certain amount per patient for a predetermined set of services. Capitation payments are often described in terms of amounts "per member per month" or "pmpm."

COBRA: Acronym for the Consolidated Omnibus Budget Reconciliation Act of 1985 that included a provision requiring employers to permit workers to hold onto their health insurance plans for up to 18 months after termination provided that the employee pay up to 105% of the average cost of the premium.

Coinsurance, co-payments, and deductibles: Major forms of cost sharing by healthcare consumers. Coinsurance obligates the beneficiary to pay a fixed percent of medical bills. Co-payments are flat, patient pays the per-visit fees. Deductibles obligate the beneficiary to pay the first part of any medical bill up to a certain level.

Community rating: A system of insurance pricing where everyone in a certain area is charged the same rate, regardless of health history or personal characteristics, contrasted with "experience rating" where persons or groups are charged different rates depending on health history or demographic characteristics, such as age.

Cost shifting: Shifting the costs of taking care of some patients or services to another group. For example, hospitals have historically shifted the costs of providing graduate medical education to various payers who are not in a position to recognize or refuse to pay.

Defensive medicine: The practice of ordering additional and unnecessary procedures or tests to avoid potential malpractice lawsuits.

Disproportionate Share Hospital Spending (DSH): Federal funding to assist healthcare providers (primarily hospitals) that care for very large numbers of Medicare or Medicaid clients.

ERISA: The Employee Retirement Income Security Act of 1974, a federal law that has been interpreted to prohibit states from regulating employers who self-insure their employee medical benefits.

Fee for service: The predominant form of financial reimbursement prior to the emergence of managed care, whereby providers are paid a fee for every service performed.

Graduate Medical Education (GME): The system for training new physicians, funded substantially through Medicare and Medicaid payments to teaching hospitals for direct and indirect costs.

Gross Domestic Product (GDP): The value of all goods and services produced by assets owned by a particular country in a particular year.

Health Insurance Portability and Accountability Act (HIPAA): Also known as Kennedy-Kassebaum after the two principal Senate sponsors, this 1996 federal law imposed standards on all health insurance and benefit plans to ensure portability from one job to the next and continuity of coverage.

Managed Care (MCO): Refers to any of several organizations in which measures are taken to provide care for a group of patients within a budget. Key examples are health maintenance organizations (HMOs), preferred provider organizations (PPOs), and point-of-service plans (POS). Over time, the distinctions among these forms have blurred.

Medicare: The federal health program, created in 1965, to finance health care for people over the age of 65 and some disabled persons. Part A, funded largely through a payroll tax, funds primarily hospital care. Part B, funded through general federal revenues and recipient cost sharing, pays for physician, home health, and other kinds of care.

Medicaid: The federal/state program that finances health services for some populations of low-income families, disabled, and elderly persons. The federal government pays between 50% and 77%, depending on a state's per capita income, and states administer the programs and pay the balance. Medicaid is the principal payer for nursing home and other long-term care services in the United States.

Medigap policies: Supplemental insurance policies sold by private companies to Medicare recipients to cover things not covered by Medicare.

Modified community rating: A version of community rating that allows some variation in premiums, within prescribed limits, for things like age and location.

Morbidity: The extent of illness, injury, or disability in a defined population. It is usually expressed in general or specific rates of incidence or prevalence.

Portability: The ability of an insured person to maintain health insurance coverage when moving from one job to another. The Health Insurance Portability and Accountability Act of 1996 was designed to provide portability protection to workers, though without assurances that the extended coverage would be affordable.

Prospective payment system: The program used by the federal government to pay hospitals a lump sum for each inpatient episode of care according to the patient's principal diagnosis or "diagnosis related group" (DRG).

Public health: A branch of health services that is focused on the health of populations as opposed to medical care focussed on individual patients.

Safety net providers: Hospitals, clinics, community health centers, and other healthcare providers that care for any and all individuals regardless of their ability to pay. Financial support often comes from federal, state, county, or local governments. These providers also tend to care for high proportions of Medicaid patients. Nationally, 33% of safety net hospitals are public, 57% are private not-for-profit, and 10% are investor-owned.

Self-insurance: The practice by many large employers (with more than 50 workers) of assuming the financial risk for employee health benefit programs.

Single payer: A health care system financed exclusively or overwhelmingly by government, federal, and/or state, and generally associated with the systems in Canada and Great Britain. Coverage is universal, and spending is controlled by centralized budgeting. Such a structure eliminates the administrative costs associated with private, decentralized insurance coverage.

Title XXI/The State Children's Health Insurance Program (SCHIP): Approved in 1997, this federal program provides more than $24 billion in funding to states to expand health insurance coverage for uninsured children, primarily in families with incomes less than 200% of the federal poverty line.

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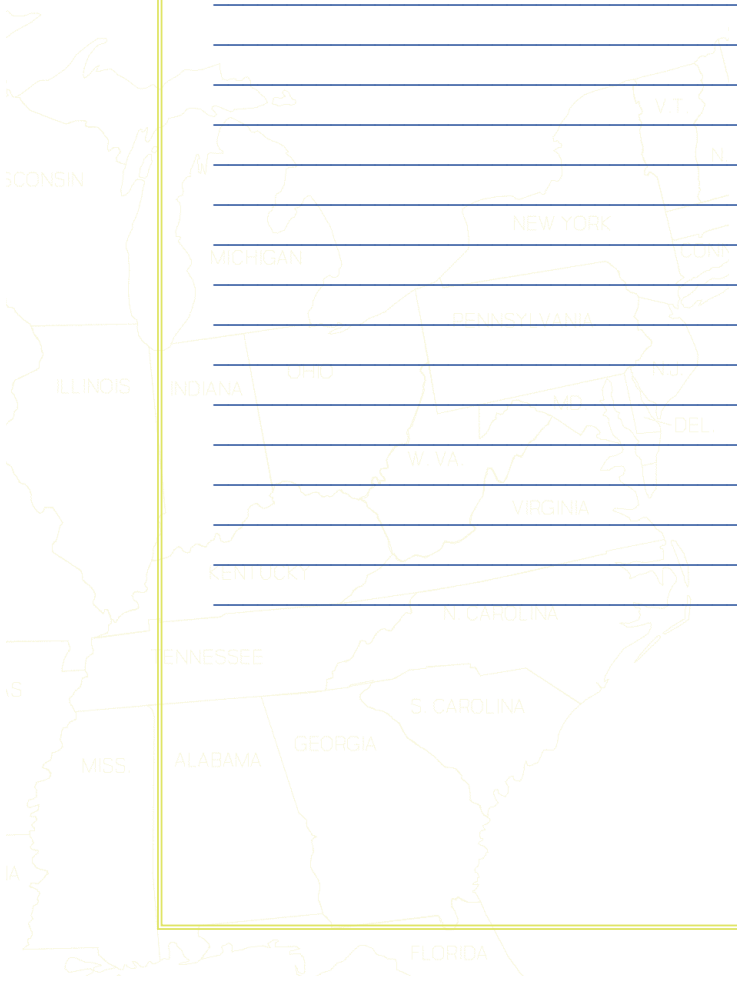

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