# A Case of Neglect

## Why Health Care Is Getting Worse, Even Though Medicine Is Getting Better

BY KATHERINE BARRETT & RICHARD GREENE AND MICHELE MARIANI

MEDICINE IN THE UNITED STATES is enjoying a surge of innovation and creativity that promises continuing improvements in everyday life for millions of people—but it is being thwarted by federal and state health care systems incapable of delivering those improvements fairly and consistently to much of the American public. To be blunt, Americans are living with first-rate medicine and a third-rate health care system. And the problem is getting worse instead of better.

Those are some of the conclusions of *Governing*'s year-long study of health care in all 50 states, and of the relationship between state health programs and federal regulations. Scores of reports and hundreds of interviews went into this effort. In every one of the areas we investigated—public health, mental health, long-term care, the care of children and prescription drugs—we found essentially the same story: Dramatic and continual improvements in the efficacy of treatment, coupled with declining access to that treatment, even for those most obviously in need. We also looked into the underlying problem of health insurance, where an unwieldy system has left nearly 44 million citizens without coverage and imposed crippling costs on state and local governments.

The ironies of the gap between the achievements of medicine and the quality of health care are palpable. State and local public health systems all but eradicated such traditional scourges as measles and tuberculosis, only to see them return when inoculations and funding fell off. The 1990s brought a remarkable extension of health coverage to low-income mothers and children, saving thousands of lives, but state budget austerities are curtailing such programs now. Psychotropic drugs have made it possible for the vast majority of mental patients to live on their own in non-institutional settings—often holding a steady job and raising a family on their own. But many remain vulnerable because the community system intended to help them was never fully developed.

The arrival of breakthrough drugs, including such familiar ones as Prozac and Lipitor, has made pharmaceutical costs a critical element of the entire healthcare conundrum. In the long term, arguments can be made that these drugs will save society money as a greater portion of the population becomes productive or can avoid the dangers of more invasive procedures. But today, they're breaking the bank in some states.

Clearly, there is a health care crisis in America, but it is in no way a medical problem. It is a fiscal problem. And at the root of most of it is Medicaid, the state-federal program that James Fossett, of the Rockefeller Institute, likes to call the "900-pound gorilla of health care." He may be understating the poundage. Medicaid is involved in virtually all the important categories of health care. It is the second-largest item in overall state budgets. When Medicaid runs short of money, the conduit between top-notch treatment and low- and moderate-income citizens breaks down.

In the past two years, all 50 states have reduced or frozen Medicaid provider payments or undertaken other cost-cutting measures in an effort to keep their Medicaid costs under control. The result has been noticeable—following a 12.8 percent increase in costs in 2002, the rate of growth fell to 9.3 percent in 2003. But even 9.3 percent is unsustainable, and there's no guarantee that the number won't climb once again.

"This is a program that was 8 percent of state budgets 20 years ago, and by 2005 it could approach 25 percent," says Vernon Smith, former Medicaid director in Michigan. "It's reached the point where it threatens states' ability to finance other services like education or public health or corrections."

Some of the perceived savings of direct health care cutbacks are illusory. When any of the 44 million uninsured Americans become seriously ill, they aren't—thank goodness—left to die on the streets. They move to a public or private hospital. Some of this is subsidized by hospitals shifting costs to patients who are insured, resulting in higher private insurance premiums. But in the end, most of these bills are taken care of through the same tax dollars that pay for Medicaid. One way or another, taxpayers

TOM WHITE ILLUSTRATION

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are forcibly hooked to a fiscal intravenous tube that transfers their money to other people's health care—but makes high-quality care extremely difficult to obtain.

### Thinly Veiled Conflicts

State health care rests on three pillars: quality, access, and control of costs. It is on the quality side, at the higher levels of the system, where the truly good news exists. But breakthroughs in quality have not been accompanied by cost controls, and as a result, access has not only failed to improve but has declined.

In the view of some critics, states are currently in retreat on each of the critical dimensions. "After a long period of intensive analysis," writes Henry Simmons, of the National Coalition on Health Care, "we have concluded that our health care system has three serious and interrelated problems—rising costs, decreasing coverage and very serious and pervasive quality problems. We have further concluded that systemic problems of this magnitude cannot be solved by a 'patchwork' strategy."

It's only fair to point out the relentless tension state legislatures, governors and health departments must deal with in trying to provide adequate treatment. They are continually influenced by external factors that make managing any health care situation a nightmare. In all the major areas—whether it's coverage for the mentally ill, the aged or young people—advocates for the various groups are in thinly veiled conflict with one another for access to a limited pool of cash.

Within public health alone, advocates for virtually every existent communicable disease scramble for the same pot of money. Meanwhile, corporate lobbies—representing nursing homes, pharmacists, doctors, drug companies, large corporations and small businesses—all argue publicly on behalf of the greater good while maneuvering to support rules of coverage that will benefit their members financially. Perhaps it should come as no surprise that state Medicaid directors typically leave their jobs after only 18 months.

But states do have resources as they face this epidemic of problems on the health care front. In fact, a number of them are managing to come up with successful solutions in the face of daunting problems.

Some of these ideas are straightforward, but difficult to achieve. Although the benefits of preventive care are hard to measure, a focus on prevention will certainly lead to long-term cost savings. Another thrust for states is to make sure that people are cared for at the most appropriate level. If an elderly person can get by with visits from a home health aide, that person doesn't need to be in a more expensive nursing home.

Most difficult of all, states are choosing to impose limits on benefits rather than limiting the number of people covered. The use of preferred-drug lists, which constrains the medications covered by Medicaid without prior authorization, is just one example. Patients aren't happy, and it makes life trickier for doctors and pharmacists. But the reality is that states are simply following the model of managed-care organizations that work for large private-sector corporations—they've had such restrictions in place for years.

For all the discouraging news about this whole subject, one underlying point is crucial to keep in mind. Health care is in trouble these days because medicine has gotten so good. The elderly and disabled, who represent the most expensive group of Medicaid recipients, are not complaining about the fact that new medications and technologies permit them to live longer and healthier lives. Nobody worried about the supply of chicken-pox vaccine 20 years ago because it hadn't been introduced. The overriding issue in health everywhere these days is how to create a system that provides the benefits of 21st-century medicine in a way that meets the test of a fair and equitable society.

"There's more to pay for and what we pay for is more expensive," says Diane Rowland, executive director of the Kaiser Commission on Medicaid and the Uninsured—the Fort Knox of publicly available information about health care. "We now have technology and we now have drugs and medical equipment that we think a decent and humane society should provide access to. And yet that access depends on the financial means to be able to obtain it. All of us in the field of experts believe we should contain health care costs. But none of us want to contain health care costs when it comes to the services needed by our family and friends."

### Readers' Guide

In this year's report of the Government Performance Project, unlike in the past, no attempt has been made to issue grades to individual states. Rather, the GPP provides detailed reports—white papers, of a sort—for six crucial problem areas that nationally recognized experts cite as the most significant in state-funded health care.

Each report is accompanied by two lists: states that have led the way with efforts others might want to emulate—"success stories"—and states that have problems others should avoid—"trouble spots." Inclusion on the first list doesn't mean a state is a model in all areas, and a mention on the second doesn't mean a state is riddled with problems. And given the speed with which this field is changing, neither may necessarily hold true in a year from now. "This is a moving target," says John McDonough, executive director of Health Care for All in Boston and a former legislator in Massachusetts. "It's changing as we speak. And it's not going to stop changing." G

## DIGGING DEEPER

An online version of this special report, with additional material for each of the 50 states, can be found at http://governing.com/gpp/2004/intro.htm. For more details on the data used in graphics, as well as links to an array of health care resources, go to http://governing.com/gpp/2004/source.htm

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# Costs of Complacency

*Diagnosis*

**Public health programs entered the century short of supporters and cash. The new emphasis on fighting bioterrorism is starving traditional functions even more.**

THE PUBLIC HEALTH MOVEMENT has become a victim of its own success. Each of its well-documented victories, in battles against diseases ranging from childhood maladies such as measles and mumps to scourges such as polio, tuberculosis and smallpox, has reduced the nation's sense of urgency. Since the 1970s, public health agency budgets have been in steady decline. "When TB was no longer ravaging communities, the government said it didn't need to fund the system anymore," says Mary Selecky, Washington State's health secretary and president of the Association of State and Territorial Health Officials. "But you don't stop funding a fire department if there are no fires."

With cash in short supply, many public health offices have been asked to focus on problems with a political constituency, particularly those that tend to resonate among the middle class. Breast cancer prevention and treatment, for example, has continued to receive generous funding—and deservedly so. Meanwhile, however, public education about other equally deadly diseases has gone begging, as has money to support the public health workforce, facilities and technology.

Shelley Hearne, executive director of the Trust for America's Health, a nonprofit research organization, says this "disease du jour" funding pattern is a disservice to public health as a whole. "We keep dipping from the same pie," she says, "rather than making sure the pie has enough resources in the first place."

Now, bioterrorism has become the disease of the decade. The largest share of federal funding is dedicated to that cause and other needs are being ignored. "The real tragedy here is that the things that kill people every day—heart disease, lung disease—are still not getting the kind of attention they need," says Georges Benjamin, executive director of the American Public Health Association. "We're funding preparedness and cutting everything else."

The stories are the same almost everywhere. The portion of Oklahoma's public health budget derived from state general funds has been reduced 24 percent in the past two years; Indiana's state funds have declined 17 percent in the past three. In Massachusetts, lawmakers have cut the state appropriation by 28 percent in the last three fiscal years.

Underfunding public health is nearly always a short-sighted and ultimately expensive business. Vaccines save untold lives. Thousands of

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## Paying for Preparedness

Public health emergency preparedness grants (from the Centers for Disease Control and Prevention) and hospital preparedness grants (from the Health Resources and Services Administration), FY 2003

| STATE | CDC | HRSA | TOTAL |
|---|---|---|---|
| Alabama | $14,056,645 | $7,762,315 | $21,818,960 |
| Alaska | $6,284,107 | $1,958,803 | $8,242,910 |
| Arizona | $15,755,035 | $9,030,450 | $24,785,485 |
| Arkansas | $10,461,043 | $5,077,591 | $15,538,634 |
| California | $55,589,662 | $38,773,726 | $94,363,388 |
| Colorado | $13,979,790 | $7,704,930 | $21,684,720 |
| Connecticut | $11,960,524 | $6,197,207 | $18,157,731 |
| Delaware | $6,614,378 | $2,205,406 | $8,819,784 |
| Florida | $38,181,999 | $25,775,967 | $63,957,966 |
| Georgia | $22,034,847 | $13,719,390 | $35,754,237 |
| Hawaii | $7,486,672 | $2,856,721 | $10,343,393 |
| Idaho | $7,676,282 | $2,998,297 | $10,674,579 |
| Illinois | $24,923,148 | $15,875,995 | $40,799,143 |
| Indiana | $17,416,386 | $10,270,929 | $27,687,315 |
| Iowa | $10,941,890 | $5,436,624 | $16,378,514 |
| Kansas | $10,476,095 | $5,088,830 | $15,564,925 |
| Kentucky | $13,245,815 | $7,156,894 | $20,402,709 |
| Louisiana | $14,059,595 | $7,764,518 | $21,824,113 |
| Maine | $7,603,092 | $2,943,648 | $10,546,740 |
| Maryland | $15,915,365 | $9,150,163 | $25,065,528 |
| Massachusetts | $17,972,524 | $10,686,180 | $28,658,704 |
| Michigan | $25,278,581 | $16,141,386 | $41,419,967 |
| Minnesota | $15,101,600 | $8,542,551 | $23,644,151 |
| Mississippi | $10,795,501 | $5,327,321 | $16,122,822 |
| Missouri | $16,424,504 | $9,530,322 | $25,954,826 |
| Montana | $6,834,837 | $2,370,015 | $9,204,852 |
| Nebraska | $8,485,811 | $3,602,747 | $12,088,558 |
| Nevada | $9,251,219 | $4,174,253 | $13,425,472 |
| New Hampshire | $7,552,202 | $2,905,650 | $10,457,852 |
| New Jersey | $22,248,528 | $13,878,940 | $36,127,468 |
| New Mexico | $8,710,551 | $3,770,553 | $12,481,104 |
| New York | $27,794,404 | $18,019,873 | $45,814,277 |
| North Carolina | $21,630,396 | $13,417,400 | $35,047,796 |
| North Dakota | $6,290,025 | $1,963,221 | $8,253,246 |
| Ohio | $28,082,405 | $18,234,914 | $46,317,319 |
| Oklahoma | $12,031,404 | $6,250,131 | $18,281,535 |
| Oregon | $12,039,235 | $6,255,978 | $18,295,213 |
| Pennsylvania | $29,933,326 | $19,616,940 | $49,550,266 |
| Rhode Island | $7,147,493 | $2,603,466 | $9,750,959 |
| South Carolina | $13,232,255 | $7,146,769 | $20,379,024 |
| South Dakota | $6,536,811 | $2,147,489 | $8,684,300 |
| Tennessee | $16,651,663 | $9,699,934 | $26,351,597 |
| Texas | $48,310,184 | $33,338,368 | $81,648,552 |
| Utah | $9,618,011 | $4,448,125 | $14,066,136 |
| Vermont | $6,242,254 | $1,927,552 | $8,169,806 |
| Virginia | $19,584,849 | $11,890,053 | $31,474,902 |
| Washington | $17,146,134 | $10,069,141 | $27,215,275 |
| West Virginia | $8,649,835 | $3,725,218 | $12,375,053 |
| Wisconsin | $15,955,629 | $9,180,227 | $25,135,856 |
| Wyoming | $6,000,636 | $1,747,144 | $7,747,780 |

Source: U.S. Department of Health and Human Services

women can learn about proper prenatal care for less money than it takes to treat one extremely ill newborn child.

One need look no further than the current flu outbreak for a potent example. Despite repeated warnings, most states have no plan in effect for dealing with it. When the disease hits, their response is ad hoc.

### Case History

"Nothing can be more important to a state," Franklin Roosevelt said in 1934, "than its public health." By the time FDR uttered these words, state public health departments were already a major force in American life. Massachusetts formed the first one in 1869; by the turn of the 20th century, 40 states had health departments, most of them designed to control and prevent infectious diseases.

These state agencies—and by the 1920s, their local city and county counterparts—improved sanitation and purified drinking water to stop the spread of cholera and typhus. They inoculated millions against smallpox—eradicating that disease from the United States entirely—encouraged the use of antibiotics to fight TB and administered the polio vaccine after its introduction in the 1950s. Once those activities were underway, the departments expanded the scope of their work to include fighting chronic diseases and more general prevention and education activities.

But "when public health does its job well, it's invisible," says Bud Nicola, medical officer at the Centers for Disease Control and Prevention. "It's hard to raise money for something when there's no visible problem." So, despite the admirable record of accomplishment, state public health budgets declined and the system steadily eroded. In 1988, a groundbreaking report by the Institute of Medicine condemned public health in America as a system "in disarray."

That study set out three core functions that public health systems should perform: assessment, policy development and assurance. "That gave us a common base,"

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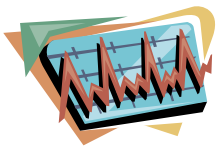
recalls Joan Brewster, director of public health systems and development in Washington State. "Health departments shifted their perspective to being part of a system with a broader framework." Officials from across the country came together in 1994 to elaborate on the IOM report and declared 10 essential services of public health *(see box below)*. But funds to implement the agenda continued to be inadequate.

Then came the terrorist acts of September 11, 2001, followed closely by the anthrax scare, which turned bioterrorism preparedness into the overwhelming focus of many public health departments. Federal grant programs for this purpose expanded dramatically: States received $1.1 billion in 2002 and $1.5 billion in 2003 to enhance their capacity for dealing with public terror-related emergencies. State health agencies have used much of the grant funding for planning and orchestrating mock emergency exercises. Those plans have highlighted weaknesses in communication—particularly among the diverse roster of first responders at the local level.

Meanwhile, the impact of the terrorist attacks was amplified by the emergence of new diseases that captured public attention and became daily news stories: SARS, West Nile virus and monkey pox. "Now," says George Hardy, of the Association of State and Territorial Health Officials, "the public knows public health exists."

In 1999, 29 states had public health labs that met criteria for biosafety level 3. (Level 4 is the highest and indicates the facility can process the world's most dangerous matter; no state agencies currently operate at level 4.) By 2002, 43 states had built or enhanced their laboratories to BSL 3. The new labs don't come cheap: Virginia's new 195,000-square-foot lab, opened last June, carried a price tag of $63 million. Missouri expects its new lab will cost the state $30 million. Iowa will be spending $29 million to replace its current lab, built in 1917 as a tuberculosis sanitarium.

There is no question that these investments will improve the quality of services in the states that are making them. Unfortunately, however, the physical plant is only a small part of the public health package. More important in the long run are the funds and trained personnel needed to operate the facilities on a continuing basis.



## Complications

Although public health departments have been accustomed to living on a frugal diet for decades, the more draconian budget cuts of the past few years have made it difficult for them to function. California was forced to reduce its newborn screening program dramatically and cut its media campaign to reduce teen pregnancies. Massachusetts cut its teen pregnancy program 82 percent in this year's budget, in addition to making drastic reductions to its environmental health, hepatitis and breast cancer programs. In the face of the lowest immunization rates for two-year-olds anywhere in the country, Colorado zeroed out its state general fund appropriation to support childhood vaccinations. Currently, Colorado public health agencies receive less than 5 percent of their funding from the state itself. "Not having funding does translate to difficulty in promoting immunizations," says Ned Calonge, the state's chief medical officer, in a model of understatement.

Even the huge influx of cash from state settlements with tobacco companies, a large part of which was to be used for public health campaigns, has been diverted to other areas as a result of hard-hit budgets. Florida's anti-smoking program had cut the rate of tobacco use 35 percent among high school students and 50 percent among middle schoolers over five years. Nevertheless, the state reduced its anti-tobacco budget from $39 million to $1 million in the past year.

In Massachusetts, where adult smoking rates fell from 22.6 percent in 1993 to 18.3 percent in 2001, lawmakers slashed the anti-tobacco program from $48 million to $2.5 million over the course of two years.

Geoffrey Wilkinson, executive director of the Massachusetts Public Health Association, believes the anti-smoking initiatives worked with an increase in the cigarette tax to reduce tobacco use, and criticizes the dismantling of what he considered a successful program. He notes the resulting cutbacks local health departments have made in their efforts to stop shop owners from selling tobacco to minors. A study by the Massachusetts Association of Health Boards found that as local programs have shut down or been scaled back, the availability of tobacco products to teenagers has tripled. "A big advertising budget was not going to survive when they were looking to preserve direct services," Wilkinson says, "but there is no way to defend logically the kinds of public health cuts that have been made in the state."

### The Brain Drain

In many states, one of the biggest obstacles to a functional public health department is the inadequacy of the workforce. About 500,000 people work in public health today. Some estimates are that the workforce needs between 10,000 and 30,000 more employees just to meet current needs.

"Since 1996," says Leah Devlin, North Carolina's state health officer, "we have lost 15 percent of our public health nurs-

## 10 Essential Public Health Services

1. Monitor health status to identify community problems.
2. Diagnose and investigate health problems and health hazards in the community.
3. Inform, educate and empower people about health issues.
4. Mobilize community partnerships and action to identify and solve health problems.
5. Develop policies and plans that support individual and community health efforts.
6. Enforce laws and regulations that protect health and ensure safety.
7. Link people to needed personal health services and assure the provision of health care when otherwise unavailable.
8. Assure a competent public health and personal health care workforce.
9. Evaluate effectiveness, accessibility, and quality of personal and population-based health services.
10. Research for new insights and innovative solutions to health problems.

ing workforce. That's as a direct result of funding." Many other states report public health layoffs and hiring freezes in recent years.

Early retirement packages have caused similar pain. Missouri lost 125 of its 2,000 health department employees this year and was allowed to fill 65 percent of the positions; 16 percent of the Illinois health department staff took the golden handshake last year. "People walked out the door with years of experience, and we had nothing to show for it," says state public health director Eric Whitaker.

The scenario darkens further. At least 25 percent of current public health employees are estimated to be eligible for retirement within the next five years, and the pipeline of workers to take their spots is depressingly dry. Most states report that they're expecting significant numbers of employees to leave in the near future—Alaska, Maine and Tennessee are prime examples—and they have no idea where they'll find replacements.

Young people are increasingly reluctant to enter the field. Low salaries are an obvious reason. That's theoretically fixable; information technology had the same problem a few years ago but addressed it with revised job descriptions and pay scales. But the current austerity in state budgets won't allow the same offers to health workers. "People who go into public health have a lot of dedication and are willing to receive less reimbursement in the long run," says Indiana Health Commissioner Greg Wilson, "but when there are large salary discrepancies, they can't afford to make that kind of sacrifice. We're beginning to approach that gap."

States were hesitant to use their new federal bioterrorism money to hire new public health workers. They feared that funding might dry up and leave them stuck with employees and no money to pay them. Instead, they made improvements in areas where funds could be used on one-time expenditures, such as building laboratories and buying communications systems. President George W. Bush has proposed additional future funding, easing those fears a bit.

### The State-Local Connection

A good deal of the public health problem is local. States can't effectively manage efforts over a large geographic area without cooperation from localities. But a number of states lack essential pieces of local public health infrastructure. "The number one public health issue here is that we don't have a statewide public health system," says Saskia Bopp, executive director of the Maine Public Health Association. "There is no formal structure in place."

Even though states acknowledge the importance of having well-performing local health departments, some are cutting their funding. Massachusetts cut local aid by 7 percent across the board over the past two years, while Colorado and others cut the per capita funding that local departments receive. Minnesota consolidated its local public health grant program from eight programs to one. While the move was made to reduce administrative costs, the state health commissioner admits it resulted in cuts to program dollars as well.

Most localities are reluctant to pony up the cash themselves. Despite Louisiana's successful media campaign to inform residents about West Nile virus, the state health officer complains that efforts to persuade local parishes to run mosquito abatement programs have been a challenge. "There's been a resistance to raise taxes for that," says David Hood, secretary of health and hospitals. "We're hoping to overcome that mentality."

### Influencing Lifestyle

Even as health officials face these obstacles, many are becoming convinced that they must confront a relatively new role in coming years: addressing the chronic diseases that are preventable by lifestyle changes. Chronic diseases cause 70 percent of American deaths, and cases of diabetes—one of the deadliest chronic killers—have nearly doubled in the last decade.

But persuading people to change the behaviors that lead to chronic illness, primarily poor nutrition, lack of activity and tobacco use, takes more time for state health departments than other responsibilities. "How do you modify people's behavior," asks Les Beitsch, Oklahoma's former health commissioner, "without becoming the behavior police?"

The federal government has stepped in to help bankroll some chronic disease initiatives, particularly those that fight obesity. The federal Department of Health and Human Services recently announced a new program, Steps to a HealthierUS, designed to address diabetes, asthma and obesity—and their causes. That effort is just a drop in the bucket.

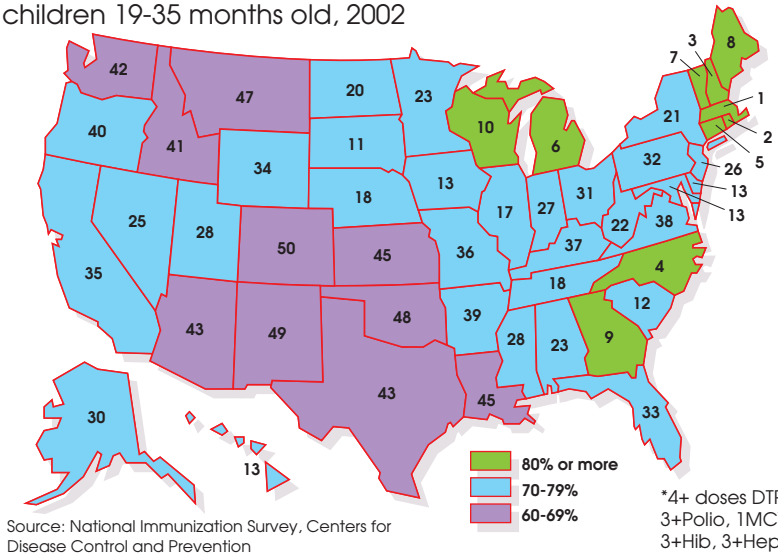
## Remedies

### Developing Data

With little hope for more funding in the near future, states need to spend every dol-

## A Shot in the Arm

States ranked by estimated vaccination coverage* for children 19-35 months old, 2002

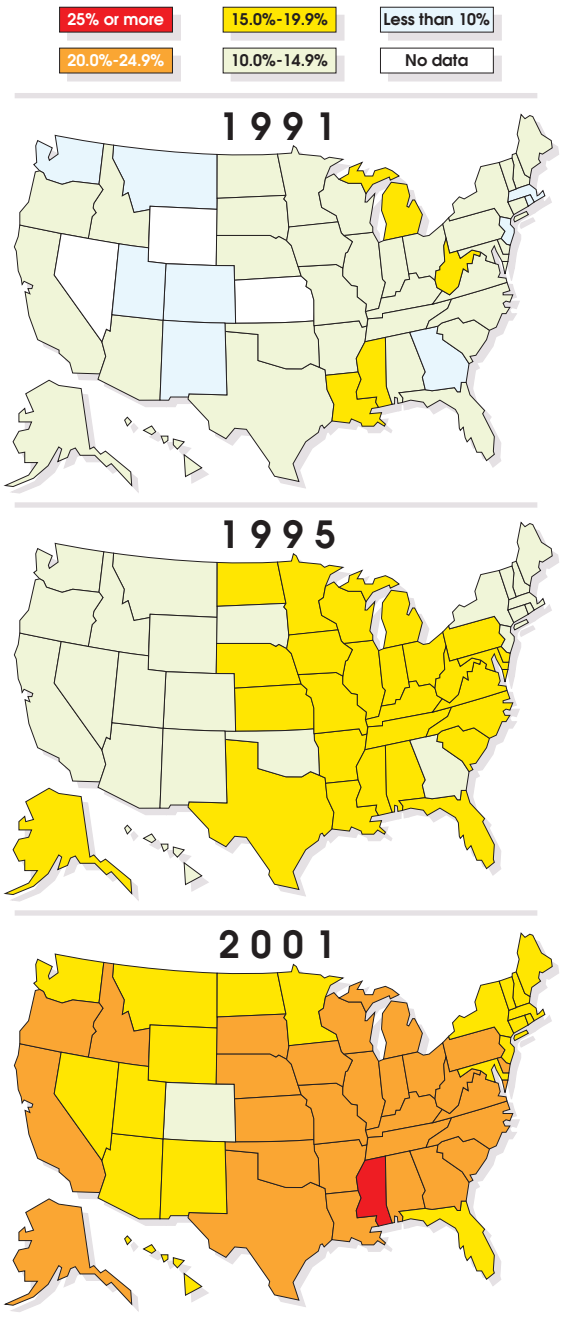



Source: National Immunization Survey, Centers for Disease Control and Prevention

*4+ doses DTP, 3+Polio, 1MCV, 3+Hib, 3+HepB

## Girth of a Nation

Prevalence of obesity among adult population, select years




Source: Centers for Disease Control and Prevention

lar they have as wisely as possible. Unfortunately, the data needed to make these judgments are in short supply. Many health departments produce reams of numbers and figures, but not the right ones. They need results-oriented information that shows, with little room for debate, the real cost benefits of public health efforts. With public health, as with any other program, people want to know how much it's going to cost and what they're going to get. And in public health, the outcomes can be expressed in very dramatic terms—lives saved or quality of life improved.

Terry Dwelle decided North Dakota needed to take a new direction in data management after being appointed as the state's health officer. The problem: the state lacked appropriate data to develop a health strategy.

Dwelle brought together 150 organizations and agencies to put together health objectives for the state; their 545 pieces were then boiled down into a strategic health plan organized around 10 main topics, such as nutrition, school health and tobacco. Now, the health agency is partnering with the University of North Dakota to develop a legislative strategy to match the health plan. Part of that strategy will include the presentation of useful data. "Health departments have been guilty of archiving data," Dwelle says. "That bothers me. If we collect it and don't use it, we're not going to collect it."

Efforts to move forward with measurement systems vary enormously. Some states, such as Washington, have struck out on their own, developing detailed strategic plans and performance reports. Others are benchmarking against Healthy People 2010, a set of objectives set by the U.S. Department of Health and Human Services, while another handful are working together through the Turning Point Initiative, funded by the Robert Wood Johnson Foundation.

More than a dozen states are participating in the National Public Health Performance Standards Program, developed by the CDC and other public health partners. The assessment tool sets optimum, not minimum, standards for state and local health agencies based on the 10 essential services outlined nearly a decade ago. Health departments and their stakeholders usually convene for one- to two-day retreats to run through the dozens of standards included in the assessment. Oklahoma used the assessment to set a baseline for its public health programs; it's now writing performance measures based in part on the information gathered during that process.

Unfortunately, developing the measures costs money and even legislatures hungry for useful information tend to be loath to spend enough to get the data. "From a legislative point of view," says Pat Nolan, Rhode Island's health director, "getting services done is more important than evaluating them."

### The Local Network

A state's public health services are only as good as its local delivery system, and that's where Nebraska has made marked improvements. Three years ago, the state had only 16 local health departments, which provided services to 22 of its 93 counties. Using part of a $50 million appropriation from the state's tobacco settlement, and a Turning Point grant, the state built 14 new local departments and restructured two others in a remarkably short time.

Ninety percent of Nebraska's counties are now receiving public health services through the state appropriation; the rest are independently funded. The state awards each department, depending on its size, between $160,000 and $850,000 a year to develop annual plans, deliver the 10 essential services and enforce previously ignored public health laws.

In other states, where local health departments have operated autonomously for years, state health agencies are demanding more coordinated control. Michigan and Wisconsin are among the ones that have moved to set formal accreditation standards. In Wisconsin, employees of the state health department conduct site visits to certify each local health department as meeting the standards of level 1, 2 or 3. Level 1 certification indicates an ability to provide basic services; levels 2 and 3 assume the capacity to attain additional goals and objectives. The process is an incentive for localities to perform at a higher standard; a portion of

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their state funding depends on their certification level. The incentive seems to be working: 85 percent of the local departments are certified at level 2 or 3.

### Finding Workers

Just about every state has begun examining the workforce issue, but they've yet to find a good answer. Some, such as Connecticut and Ohio, have convened task forces to look at options. Pennsylvania has concentrated on identifying the most immediate needs and developing depth in those areas before launching broader recruitment initiatives. Wyoming helps fund a Health Resources Network, whose primary focus is the recruitment and retention of health professionals.

On a national level, three groups—the CDC, the Council of State and Territorial Epidemiologists and the Association of Schools of Public Health—have partnered to promote a fellowship program, funded by CDC, to provide on-the-job training for recent graduates in state epidemiology departments. They placed 10 fellows in two-year positions last year; this year, they're shooting for 30. "Over the next 10 years, we could start meeting the demands of the states," says Patrick McConnon, CSTE's executive director.

More important, however, is the creation of new schools of public health to train the skilled professionals who will be needed. Right now, 33 such schools in 23 states are accredited nationwide—although there are many more public health programs within other institutions. Many state health officials consider this effort essential to meeting their future workforce needs. Arkansas, for example, set aside 5 percent of its tobacco settlement funds to create its college of public health, which opened in January 2002 and is on track to receive full accreditation this spring. Fay Boozman, the state's health officer, says the college has been instrumental in providing training in high-need areas, including epidemiology.

### Boosting Technology

In the end, though, the most significant counter-balance to the lack of funds and staffing in public health will be technology. Departments around the country point to Louisiana's "Fight the Bite" media campaign as one good example of the way that technology can be used.

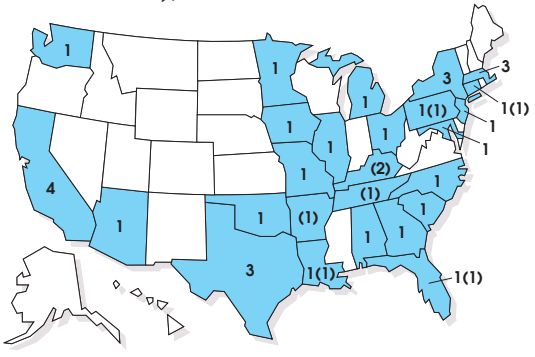
With its vast areas of swamp land, the state is prone to mosquito-borne West Nile virus. One early indicator that a region is at risk is the number of dead birds that have succumbed to the disease there. Louisiana officials worked with NASA and Oxford University in England to produce sophisticated climate data based on satellite pictures, tabulate numbers and locations of dead birds, and create "risk maps." These can be used to caution parishes that they are particularly vulnerable to the disease. This initiative was followed by a multimedia campaign in which the state's governor provided citizens with information about how to avoid West Nile, including the simple recommendation that they eliminate pockets of standing water that breed mosquitoes.

Technology is a key to advances in training for time-strapped employees. Tennessee's health department has installed satellite and video conferencing technology in its regional offices and some local health departments, enabling staff there to tune into CDC broadcasts and training classes based in Nashville.

Missouri has made the most of technology by posting on its Web site county-by-county health data, searchable by dozens of criteria. Legislators and citizens have found the database helpful in separating perceived community health problems and statistical realities, says Ron Cates, chief operating officer for the state's Department of Health and Senior Services. "We're trying to get people to look at what the real issue—not the perceived one—is," he says.

## Training Grounds

Number of accredited schools of public health (and those working toward accreditation), 2003




Source: Association of Schools of Public Health

At the national level, a Health Alert Network spearheaded by CDC helps state health agencies communicate with local health offices, hospitals and physicians via e-mail and blast faxes during times of emergency. Minnesota's network had just been completed when 9-11 occurred. "We'd intended to test it," says Health Commissioner Diane Manderbach, "but the reality is that we used it."

Kansas, which experienced at least one case each of West Nile virus, monkey pox and hantavirus, as well as a suspected case of SARS during 2003, used its Health Alert Network to handle outbreak management and response. In Wisconsin, which experienced the most significant monkey pox outbreak with 18 confirmed cases, the state's former health officer attributes a quick response to the increased sophistication in bioterrorism resources. "I don't think there's any question that we're better prepared," says Kenneth Baldwin. But there's still a long way to go.

## Prognosis

Public health indicators move slowly. It can take years, even with an infusion of resources, to move disease incidence rates up and down. This is both good news and bad news. The good news for legislatures is that they have been able to cut public health dollars dramatically in the past couple of years without too many dire results showing up in the charts. The bad news is the data will catch up with them eventually.

As a harbinger of what could eventually happen, states might consider what occurred when they defunded some immunization programs in the late 1980s. They had all but declared victory over measles by then. But there was a national outbreak of the disease in the early 1990s.

How much additional funding does the public health system need? Nobody really knows for sure. The Public Health Foun-

# States That Stand Out

## SUCCESS STORIES

### Arizona, California and Virginia

The challenges of bioterrorism and tracking communicable diseases have underscored the need for enhanced capacity in state public health labs. These states have spent tens of millions of dollars to open new, state-of-the-art labs, enabling them to better handle public health emergencies.

### Arkansas

With the nation short on public health workers, the state set aside 5 percent of its tobacco settlement monies to run a new college of public health at the University of Arkansas. Department of Health officials teach at the college, and state employees get a 70 percent tuition break.

### Missouri

Missouri posts community data profiles available on state, district and county levels for more than 25 subject areas, including chronic disease, unintentional injury and hospitalizations. The tables generate links to additional information, such as intervention strategies, resources and reports. Viewers can also access a "leading problems" profile for each community.

### Nebraska

Nebraska is a model in how to develop a local public health system. The state responded to the serious deficiencies in local public health—just 22 of its 93 counties were being adequately served—by creating 14 new departments and restructuring two others. Nearly every resident in the state can now receive services from a local public health department.

### North Dakota and Washington

Both states have written detailed plans for improving their public health. In North Dakota, 545 objectives were condensed into 10 broad health topics to comprise the strategic health plan, and the health department is partnering with the University of North Dakota to develop a corresponding legislative strategy. Since 1994, Washington biannually has published a state Public Health Improvement Plan that sets out standards, recommendations and strategies in seven key areas of public health.

### Wisconsin

Several states accredit local health departments. In Wisconsin, the state has gone further by dangling the carrot of extra funding for departments that can meet higher-than-average standards. As a result, 85 percent of the local health departments have now achieved high-level certification.

## TROUBLE SPOTS

### Colorado

The state's ability to promote childhood immunization has been stymied by severe budget cuts; no general fund money now supports vaccination programs. Colorado continues to receive federal funding for these programs, but this may not be enough to lift the state out of last place when it comes to childhood immunization.

### Hawaii

In 2000, the University of Hawaii's school of public health lost its accreditation. The university's medical school absorbed pieces of public health programs, while state and university officials worked to rebuild a separate public health school. Those efforts stalled last June when the university ended its search for management for the school, and the state health department is proceeding under the assumption that an independent school may never reopen.

### Massachusetts

Massachusetts not only gutted its anti-tobacco programs, it did so after posting some of the country's best successes at preventing young people from smoking. The state's anti-tobacco budget has been slashed from $48 million to $2.5 million, eliminating an effective television advertising campaign and scaling back local efforts to make tobacco less available to minors.

dation, a nonprofit organization that works to build public health infrastructure, estimates the system needs an immediate infusion of $10 billion. But that figure isn't agreed upon in the public health community, and some think the figure is somewhat higher.

It's unclear for now as to what the real benefit of the bioterrorism efforts will be. Experts can pontificate, but until the dreadful day when they're tested, no one will be able to assert categorically how successful these efforts have been. It appears that quick responses to anthrax, West Nile virus and SARS have been moderately successful—but none of those have been the kind of society-wide threats that polio and TB once were—or that a deliberate effort to spread smallpox in the population could be.

What is beyond dispute is that the emphasis on preventing such terrors has created a new vulnerability when it comes to containing the spread of chronic diseases. Ed Thompson, CDC's deputy director for public health services, says the successful public health department of the future will have to be able to strike a balance, acknowledging the importance of "both chronic and acute public health problems and the ability to respond to both." At the moment, that balance is a long way from being achieved.

# Promise Unfulfilled

*Diagnosis*

**Changes in mental health care over the past four decades have failed to live up to their promise, creating a fragmented and disorganized system that is scarcely more effective than the one it replaced.**

THE NUMBER OF MENTALLY ILL PATIENTS in state hospitals has dropped by 600,000 since its peak in the mid-1950s, facilitated by more effective psychotropic medications and advances in therapy. Not many years ago, mental illness was considered a lifelong affliction. Now, in millions of cases, that is no longer true.

But the care provided to mentally ill citizens has failed to keep pace with the medical advances. When President Kennedy signed the Community Mental Health Centers Act in 1963, it signaled the prospect of a new regional mental health network, one that would supplant custodial isolation with community concern and capability. Small pieces of that network have come into being. But for the most part, the vision remains unfulfilled.

Millions of people suffering from mental illnesses have struggled—and failed—to maneuver through a web of inadequate emergency, inpatient and community care. "In many communities," a presidential commission reported last year, "access to quality care is poor, resulting in wasted resources and lost opportunities for recovery."

Many of the approximately 50,000 people still residing in institutions are stuck in a bottleneck: They want to leave the hospital but have nowhere to go because community care facilities are overburdened, and their continued confinement takes up scarce inpatient beds needed by others in crisis. What's more, people with private insurance often tap out their mental health benefits quickly and are left to be caught by the public mental health safety net.

While there have been some successful government-administered mental health programs, innovation in one county or state is unlikely to be reproduced across the border, particularly in tough budget times. "The problem with these projects," says Paul Appelbaum, chair of psychiatry at the University of Massachusetts Medical School, "is that they are islands of excellence in a sea of chaos."

In many cases, states and local governments can't prove their programs work. Contracts with mental health providers tend to emphasize outputs, and outcome measures are few and far between. That means there's little concrete data to prove that money is being spent efficiently and effectively.



JIM STARR ICONS (5)

# ART

TOM WHITE ILLUSTRATION

## Case History

Institutional care for the mentally ill has traditionally been a state responsibility. States built the first so-called insane asylums in America in the mid 1800s, when they housed thousands of residents afflicted with a wide range of mental illnesses then scarcely comprehended, from depression to schizophrenia.

Early on, the size of the institutionalized population was kept in check by the reluctance of families to admit that anyone in their household had a problem. In extreme cases, they denied that a troubled relative even existed. A child with severe schizophrenia was likely to be kept in the house, away from the eyes of neighbors or schoolmates. But as people grew accustomed to the idea that they could call upon help from the outside, the number of asylums—eventually called state hospitals—began to grow.

For decades, the entire enterprise existed at the periphery of public consciousness. Patients entered state hospitals, where they were fed, drugged and treated in one building, and kept under lock and key for years, if not for life. The policy of warehousing the mentally ill continued unabated until 1963, when Congress passed the Community Mental Health Centers Act. This bill encouraged deinstitutionalization and a move to providing services for troubled patients in small-scale facilities within their community. States were to be divided into regional areas, each with a center that would receive federal and state support to offer mental health treatment.

States enthusiastically embraced the concept, and by 2000 had closed 115 of 350 hospitals and dramatically reduced bed capacity in most of the others. They sold some of the buildings and converted others into correctional facilities. And thousands of former hospital patients made a successful transition to the community, living closer to their families in adult group homes and sometimes even their own apartments, with much-improved psychotropic medications to keep their illnesses in check.

But many others fell through the cracks. The regional funding model for mental health care was scaled back in the 1980s to a federal block grant, which currently supports only about 2 percent of total state mental health budgets. As states moved away from institutionalization, many ceded responsibility for direct care of the mentally ill to county governments. Initially, most states retained their role as direct funders of mental health services, but an increasing portion of that support now comes from Medicaid and state housing, corrections and education agencies. Mental health care is so widely dispersed that most states can't even pinpoint how much they spend on the services.

Today about 50,000 mentally ill people reside in state and county hospitals, and millions more navigate their way through the complex system for treatment each year, occasionally using acute care beds to get them over the roughest times but otherwise remaining largely unsupervised. These patients are "in the community" in the sense that they are not residents of large, segregated institutions, but they are not being treated in the community the way the 1963 law envisioned. Estimates are that about one-fifth of the adults in America suffer from mental illness each year, and only about half of those seek treatment. An estimated one-third of homeless adults have serious mental illnesses.

### Going to Court

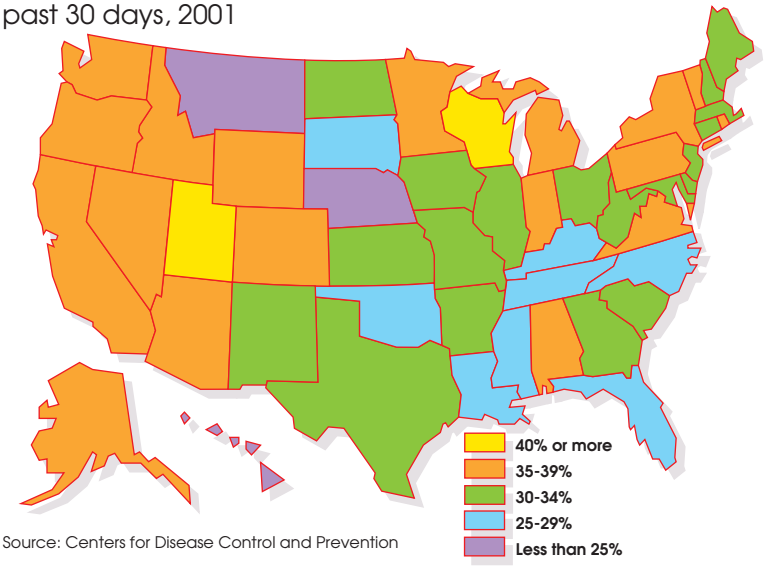
Given the history of care under the 1963 law, it is perhaps not surprising that mental health programs have been frequent targets for class-action suits charging that patients were housed or released inappropriately or neglected altogether. For some states, lawsuits have lingered on for decades. Last December, Alabama finally completed the terms of a consent decree stemming from the Wyatt case, a 1970 class-action suit brought by mentally ill residents who were involuntarily committed to state hospitals.

Maine has struggled since 1990 to comply with a consent decree that mandated improved care for patients during and after hospitalization. A court master now oversees the state's community-based system, and last October, a judge imposed a receiver to run the state hospital because of noncompliance. Maine has until March to show sufficient progress to the court, or a receiver will be imposed for the rest of the system as well.

One suit, *Olmstead v. L.C.*, has forced the states to move further in the direction of deinstitutionalization. The thrust of the U.S. Supreme Court ruling in that 1999 case was that anyone willing and able to live in the community must have that option, regardless of physical or mental disability. But while *Olmstead* could gen-

## States of Mind

Percentage of residents reporting poor mental health in the past 30 days, 2001

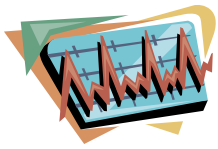



Source: Centers for Disease Control and Prevention

erate a significant expansion in some types of community services, the move from hospitals to a community setting is expensive if it is to be successful. While there is federal grant money available to implement *Olmstead*, most states remain in the planning phase.

"The problem is the transition," says Sue Walther, of the Pennsylvania Mental Health Association. "We only have 33 slots funded to move people from state hospitals to the community." In recent years, nearly 2,400 patients have been institutionalized in Pennsylvania.

It's not clear how much time the states will be given to comply with the ruling or what will happen if they don't. In a 2002 survey by the National Association of State Mental Health Program Directors, a handful of states, including Arkansas and North Dakota, indicated they had no plans to transition people to community-based services as a result of *Olmstead*. The Supreme Court left a loophole: States could get around immediate implementation if it would require "a fundamental alteration" in their programming.



## Complications

Task forces, committees and blue-ribbon commissions to consider reform of state mental health systems abounded during the prosperous years of the late 1990s. They produced plausible, well-intentioned recommendations. In Oregon, for example, Governor John Kitzhaber appointed a mental health alignment workgroup to consider what an ideal mental health system might be like; it ultimately found the existing system was funding little more than half of those responsibilities and issued recommendations for the rest.

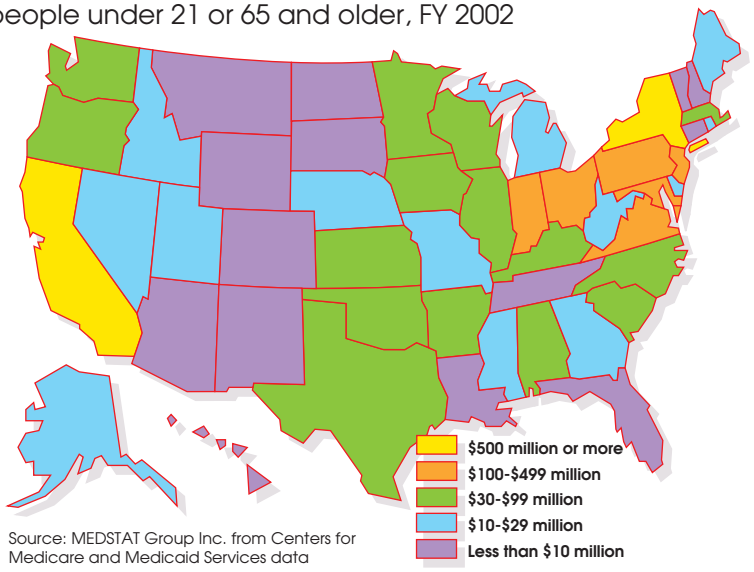
But the road to hell is paved with unfunded recommendations. Budgetary constraints have left all too many blue-ribbon reports with mildew on the pages. Oregon's grand plans were "a lifetime away from where we are now, with fiscal constraints," says Bob Nikkel, administrator of the Office of Mental Health and Addiction Services. "Now, we're scrambling to keep even 50 percent of what we need." Current Governor Ted Kulongoski has created a new task force to focus on reforming mental health given today's fiscal realities.

Meanwhile, however, Oregon's budget problems led this year to a temporary halt in all non-Medicaid outpatient care and almost all non-Medicaid crisis services. About 1,000 behavioral health workers lost their jobs statewide. Most of the services have been restored with funds from a new tax surcharge, but voters have a chance to roll back the surcharge early this month, which would slice the programs once again.

Mental health directors throughout the country are facing similar pressures. According to the National Mental Health Association, at least 29 states cut their mental health expenditures in 2002, with 35 doing so in 2003. Among the worst hit has been South Carolina, which lost $34.5 million to cuts in 2001 and 2002, and another $28 million in 2003. In Georgia,

## Committed to Care

Medicaid spending for inpatient mental health care for people under 21 or 65 and older, FY 2002




Source: MEDSTAT Group Inc. from Centers for Medicare and Medicaid Services data

the Department of Mental Health cut 2.5 percent from its current year budget and will have to cut 5 percent next year. "We don't have a lot of fat to cut because we haven't had much revenue growth," says program chief Cherry Finn. "But we're expected to step up with our share of the budget cuts."

Some states are bucking the trend. Nevada Governor Kenny Guinn made headlines last year when he pushed a nearly $900 million tax increase through the legislature. Guinn used a substantial chunk of the money—almost $90 million—to bolster the Mental Health Department, increasing the department's budget by 31 percent in 2004. Nebraska funneled $12 million of its tobacco settlement funds in 2001 and 2002 to expand mental health and substance-abuse programs.

There's a lot to spend those dollars on, as care for the mentally ill grows more sophisticated but also more expensive. Psychotropic drugs, which were introduced with Thorazine in the 1950s, are now the fastest growing line item in state mental health hospital budgets. The price of antidepressants, including Prozac and Paxil, rose 7.5 percent between 2000 and 2001, while the cost of drugs that fight psychotic illnesses such as schizophrenia jumped more than 16 percent during the same time.

This is an instance in which the dual goals of quality care and cost control are at odds. There's little question that many of the medications have improved the lives of the mentally ill, and newer drugs have fewer side effects and are more effective than earlier generations. As a result, people are far more willing to continue taking them. The more willing they are to persevere in treatment, the more the cost rises.

### Medicaid Enters the Picture

Even if states were able to come up with additional money for mental health treatment, the involvement of Medicaid would remain a serious complicating factor. The Medicaid program is currently footing the bill for more than 50 percent of mental health expenditures nationwide, and in many cases, reductions in state dollars cause reductions in Medicaid matching funds. In South Carolina, the state cuts have resulted in a loss of at least $5 million in federal payments.

Medicaid doesn't cover treatment costs for people between 21 and 64 years old if they are living in mental institutions, but it does cover much of the expense if they are under community care. This has left some states with a two-tiered approach, under which more mental health services are available to Medicaid recipients than to the non-eligible population. As the number of mentally ill receiving treatment in the community grows, so does Medicaid's portion of the payer pie—and its control over the programs.

Richard Frank, professor of health economics at Harvard Medical School, says the dynamic between Medicaid and state mental health agencies is one of the major issues facing the entire mental health field today. "Now that the state mental health authority isn't the biggest show in town anymore," he asks, "who has stewardship for the care of the mentally ill?"

In many states, it's hard to find an answer. Medicaid foots the bill, while housing agencies, corrections agencies and an assortment of others arrange for care. In most states, the least involved are the state mental health agencies, which often are little more than conduits of cash as opposed to planners or quality-control centers. They're responsible only for plans that address their small federal block grants, and are largely left out of other agencies' decision making.

Comprehensive planning that involves all the parties responsible for providing mental health services has the potential to reduce fragmentation, but it's rare. Instead, planning tends to take place within individual agencies, leading to uncoordinated—and sometimes contradictory—service delivery. "There is a need for broader-based planning to address those silos," says Robert Glover, executive director of the National Association of State Mental Health Program Directors.

### The Bed Shortage

Cash shortages have, among other problems, put pressure on the number of acute care beds available for patients in need of short-term inpatient stays to control a psychiatric crisis. One reason is that some governments have dealt with cash shortages by cutting back on pay for providers. As a result, physicians and hospitals are opting out of the system. Many states are watching as private hospitals turn their psychiatric inpatient wards into more profitable cardiovascular and obstetric space. Alabama alone has lost more than 400 psychiatric acute care beds in private hospitals as a result of fiscal pressures.

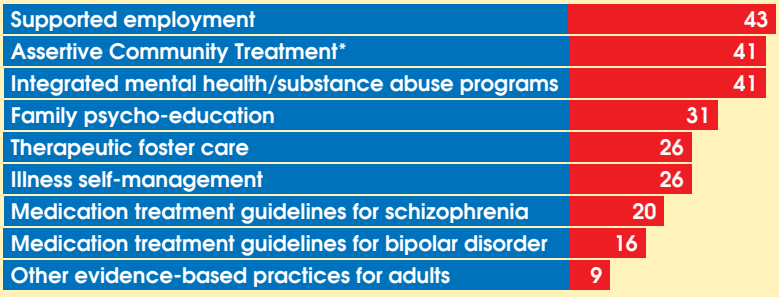
With fewer acute care beds in some states, people in need are left on long waiting lists, in emergency rooms and in jails. Sometimes the closest available bed is 100 miles away or in another state, complicating family visits and follow-up care.

These barriers to access made headlines last year in South Carolina, which operates just two emergency mental health facilities. Seventy people waited in jails because they couldn't access court-ordered treatment, until a state Supreme Court justice ordered the mental health department to find space for them.

AD

## Tried and True

Number of states implementing evidence-based practices (out of 47 reporting states), 2001




* Multi-disciplinary clinical team approach that provides intensive community services to help the mentally ill live in the community

Source: National Association of State Mental Health Program Directors Research Institute

The state has since awarded $1.7 million to 10 community mental health centers to implement programs that will keep people out of emergency rooms and to make room in the community for those who are able to leave the state psychiatric hospitals. Mental Health Director George Gintoli says he hopes the grants will cut South Carolina's waiting list in half by freeing up needed beds in the two state hospitals.

Last year, Vermont lost federal funding for its state hospital, which could amount to as much as $3 million, when a host of problems—including the failure to provide all patients with active treatment—were identified through inspections by the federal Centers for Medicare and Medicaid Services. The hospital, which once held 1,300 people, is down to 54 beds.

"Because we have focused so much on community services, we've not paid the attention we needed to the role of the state hospital," admits Susan Besio, Vermont's commissioner of developmental and mental health services. In response to the CMS report, Governor Jim Douglas increased state funding for the hospital by 21 percent to add staff and improve treatment. The hospital hopes to be recertified by CMS by July.

Insufficient community housing is an equally severe problem. Most patients released from hospitals to the community need some form of supervised living, but the supply of such housing units does not even come close to meeting the demand. Of the 50,000 people who are still living in state mental hospitals, a significant percentage would like to leave but have nowhere to go that provides an appropriate level of treatment.

In rural America, lack of access to all types of mental health treatment is particularly severe. Carlos Brandenburg, Nevada's mental health and developmental services administrator, ranks the inadequate supply of rural clinicians among his top challenges. "Twenty-three percent of the state's mental health jobs in rural areas are vacant. All of my psychiatrists," he says, "are basically tourists in rural areas."

### No Data, No Money

One problem that mental health advocates face when they try to loosen legislative purse strings: There's a numbing lack of information at the state level about which programs work well and which don't. To a large extent, mental health program data continue to be reported as outputs, detailing the number of patients treated in a given month but not the number judged to have made significant progress.

As in other areas of health care, state officials realize that if they want more money, they are going to need more proof of results. "Dollars are not flowing freely," says Pennsylvania's Sue Walther. "We are going to need to have our case in hand." And that case is often made most persuasively through the use of hard data.

Part of the problem stems from the decentralized nature of mental health programs. Even within a single state, different counties work off different technology platforms, and contractors use varying methods of reporting data. That combination makes it arduous to tease out usable information.

In a few states, decentralization has resulted in even more serious problems. Georgia moved in 1993 from statewide administration to regional boards, each of these contracting with community service boards to provide the actual mental health care. Patient advocates commended the move, until the regional boards proved unable to fulfill their responsibilities of planning and overseeing services. Two of the community service boards are under investigation for Medicaid fraud, and the state turned to consultants to fix a projected $6.5 million deficit in a third. Similar problems have occurred in Michigan's locally administered system, leading to state Senate hearings and plans for a governor's task force to look into major reforms.

## Remedies

### Parity Laws

One popular attempt to improve mental health treatment involves "parity laws"—mandates at both the state and federal levels requiring that private insurance companies provide equal coverage for physical and mental illness. Without such laws, people with mental illness frequently run up against caps on treatment, both in the number of visits allowed and the costs the insurer will cover.

States have a substantial interest in the establishment of parity in private as well as public treatment. In the absence of parity, people max out their private insurance benefits and move to the public system sooner, adding to the government's bill.

So far, 39 states have enacted some form of parity legislation. Indiana phased in its parity law, first covering state employees as a pilot and then expanding to the general population; South Carolina is taking the same approach. Vermont's parity law, widely considered the most comprehensive nationwide, covers both mental illness and substance abuse treatment. Now five years old, it seems to be working: A study found that employers didn't drop coverage as a result of the law,

access to outpatient mental health services improved, consumer spending on mental health treatment declined and health plan spending—in this case, Blue Cross—rose only 4.4 percent.

Still, insurance companies tend to fight against parity laws, contending that they drive up health care costs. Partially as a result, advocates in some states have fought—and lost—on this issue multiple times. Says Sue Walther, a veteran of two go-rounds in Pennsylvania, "If you offer parity in a time when the system is struggling to meet needs, you free up dollars for public care. But that's not the argument that wins the day. I don't see it happening anytime soon."

### Spend Now, Save Later

To their credit, a reasonable number of states are trying to take a long-term approach to mental health systems, on the premise that better care not only benefits the patients but saves money in the long run. Arizona, for example, spent $35 million to open a new 200-bed adult state hospital last year; an adjoining 16-bed inpatient adolescent facility opened in 2002. The hospital was designed to be a "rehabilitative mall," with separate areas for living, dining, therapy, shopping and other daily activities. If the theory behind this project holds true, the patients who use this facility will eventually be better able to survive on their own with minimal care, thus avoiding the public cost of more intensive long-term treatment.

Minnesota, aware of the advantages of community-based care but conscious of the obstacles, adopted the "rehab option" in 2001, under which states can use Medicaid funding for a broad range of services at the community level, including medication management and daily living skills, as an alternative to spending the money on hospitals or day treatment centers. The move added $13 million in extra federal funding to the department's budget for the 2001 biennium, although mental health director Sharon Autio says it "was not made to focus on maximizing revenue but to improve the service delivery system."

Virginia has launched a "Community Reinvestment Project," designed to shift more than $11 million from state hospitals to the state's 40 community services boards. This is a significant turnaround for the commonwealth, which has never closed one of its 15 state hospitals, even though the number of inpatients has

## The Mental Health Breakdown

State mental health agency expenditures

| STATE | TOTAL SPENDING (in thousands) FY 2001 | SPENDING PER CAPITA FY 2001 | SPENDING PER CAPITA RANK | % SPENDING ON INPATIENT SERVICES | % SPENDING ON COMMUNITY SERVICES |
|---|---|---|---|---|---|
| Ala. | $253,279 | $56.97 | 38 | 40.9% | 56.3% |
| Alaska[3,4] | $51,445 | $81.36 | 21 | 33.3% | 60.6% |
| Ariz.[1,3] | $472,342 | $89.36 | 17 | 9.8% | 87.9% |
| Ark.[4] | $75,737 | $28.25 | 49 | 30.7% | 65.0% |
| Calif.[1] | $3,147,793 | $91.61 | 14 | 18.1% | 80.9% |
| Colo. | $282,615 | $64.24 | 30 | 29.6% | 69.9% |
| Conn.[2] | $439,520 | $128.85 | 5 | 34.7% | 56.5% |
| Del.[2] | $73,506 | $92.70 | 13 | 64.5% | 33.5% |
| Fla.[4] | $578,266 | $35.41 | 46 | 43.6% | 54.7% |
| Ga. | $380,647 | $45.59 | 42 | 45.6% | 48.6% |
| Hawaii[1] | $213,644 | $175.21 | 2 | 15.8% | 71.4% |
| Idaho[1] | $60,524 | $46.01 | 41 | 36.4% | 61.8% |
| Ill. | $789,861 | $63.54 | 31 | 38.8% | 59.0% |
| Ind. | $394,001 | $64.70 | 29 | 32.7% | 66.3% |
| Iowa | $213,047 | $73.18 | 25 | 22.4% | 77.6% |
| Kan. | $161,844 | $60.31 | 35 | 35.5% | 63.0% |
| Ky. | $196,918 | $48.64 | 40 | 51.2% | 47.0% |
| La. | $200,926 | $45.18 | 43 | 57.9% | 40.2% |
| Maine | $137,508 | $107.31 | 10 | 30.1% | 65.1% |
| Md.[1] | $677,806 | $126.62 | 6 | 30.0% | 65.6% |
| Mass.[3] | $682,219 | $107.38 | 9 | 29.9% | 67.1% |
| Mich.[1,3] | $895,066 | $89.96 | 16 | 33.0% | 66.0% |
| Minn. | $517,964 | $104.60 | 11 | 29.9% | 69.5% |
| Miss. | $246,792 | $86.71 | 20 | 59.6% | 39.2% |
| Mo.[1] | $336,198 | $59.96 | 36 | 50.4% | 45.0% |
| Mont. | $111,722 | $124.04 | 7 | 23.3% | 73.3% |
| Neb. | $86,564 | $50.73 | 39 | 63.4% | 34.7% |
| Nev.[1,3] | $120,211 | $57.31 | 37 | 36.2% | 62.9% |
| N.H.[3] | $140,484 | $112.03 | 8 | 29.6% | 68.6% |
| N.J.[1] | $763,057 | $90.31 | 15 | 38.9% | 59.3% |
| N.M.[1,3,4] | $59,378 | $32.60 | 48 | 36.9% | 62.6% |
| N.Y.[1,3] | $3,331,688 | $175.97 | 1 | 29.8% | 66.3% |
| N.C. | $616,120 | $75.57 | 23 | 46.0% | 52.4% |
| N.D. | $49,854 | $78.90 | 22 | 44.9% | 53.7% |
| Ohio | $692,288 | $61.12 | 33 | 28.0% | 67.8% |
| Okla. | $136,072 | $39.49 | 44 | 29.9% | 64.3% |
| Ore. | $336,848 | $97.39 | 12 | 24.0% | 74.4% |
| Pa.[1,4] | $1,859,764 | $151.98 | 3 | 21.5% | 77.8% |
| R.I.[1,2,3] | $92,500 | $87.71 | 19 | 25.6% | 72.1% |
| S.C.[1,3] | $299,402 | $73.99 | 24 | 36.3% | 58.2% |
| S.D.[1] | $45,696 | $60.65 | 34 | 67.0% | 31.3% |
| Tenn. | $395,203 | $69.13 | 27 | 32.1% | 66.4% |
| Texas[1] | $796,974 | $37.53 | 45 | 38.4% | 58.0% |
| Utah[1,4] | $73,790 | $32.64 | 47 | 55.9% | 42.5% |
| Vt.[1,3] | $79,658 | $130.46 | 4 | 12.0% | 85.2% |
| Va.[1] | $466,573 | $65.18 | 28 | 59.5% | 34.9% |
| Wash.[1] | $525,565 | $88.13 | 18 | 31.9% | 65.8% |
| W.Va.[1] | $45,804 | $25.52 | 50 | 80.6% | 15.7% |
| Wis. | $389,417 | $72.39 | 26 | 20.9% | 78.5% |
| Wyo. | $30,097 | $61.12 | 32 | 43.4% | 53.8% |

[1] Includes funds for mental health services in jails or prisons
[2] Does not include children's mental health expenditures
[3] Includes majority of publicly supported housing for mentally ill
[4] Does not include Medicaid revenues for community programs

Source: National Association of State Mental Health Program Directors Research Institute

fallen from 8,000 to 3,600. As beds closed, the money financing them either stayed with the hospitals or left the mental health system entirely; the dollars never found their way to the community. "We are about 20 years behind in terms of the state mental health dollars that we put toward institutions versus the community," admits Mental Health Commissioner James Reinhard.

Initiatives to construct or find appropriate community-based housing for people with severe mental illness are moving forward elsewhere. In 2002, California voters approved a $2.1 billion housing bond, $190 million of which was set aside for the construction of new living space for the disabled, including people with mental illness. New York's legislature last year approved a $65 million appropriation to create 2,600 new adult beds, and another several thousand before 2010. Despite those moves, a class-action suit was brought against the state late last year alleging that it has unlawfully segregated residents of large adult homes.

### Evidence-based practices

The growing application of six initiatives known as "evidence based practices" is one of the more encouraging trends in community mental health care. The initiatives represent a consensus among treatment professionals and researchers about the strategies that have proven effective in particular situations. They are becoming established in the mental health community as a solid template for policy makers to follow, with reasonable confidence that they're not wasting money.

Among the initiatives are supported employment and housing, and assertive community treatment, in which people with severe mental illness receive intensive treatment from a team of psychiatrists and psychologists, nurses and case managers in a community setting.

Researchers at Dartmouth University have developed directions for implementing the practices, and the federal Substance Abuse and Mental Health Services Administration recently awarded nine states multi-year grants to expand their use.

States have jumped at the chance to use more consistently reliable practices. In fact, some are mandating that communities use the practices in exchange for funding. In Oregon, more than 25 percent of all mental health funds will be required to support evidence-based practices by the 2005-07 biennium; that figure will rise to 75 percent by the 2009-2011 budget.

### Gathering Information

Another positive trend: With the help of data infrastructure grants from the Center for Mental Health Services, states have begun to develop outcome measures and build technology pieces to aid in reporting. The increased use of outcome and performance measures in contracts between states, counties and contractors should also improve data collection and reporting.

Texas has used data to illustrate the success of its "Texas Medication Algorithm Project," which started in 1996 Many people with mental illness in Texas had begun taking improved psychotropic drugs, but, in the words of Steven Shon, of the state's Department of Mental Health and Mental Retardation, "we kept hearing patients and family members saying their medications were changing all the time, which was more a reflection of the doctor than their illness."

In 1996, Shon and researchers at Texas Southwestern Medical School designed TMAP to standardize treatment for major depressive disorder, bi-polar disorder and schizophrenia. Physicians are asked not only to follow specified treatment patterns but also to standardize their patient charts, so that other doctors can better understand why certain treatment approaches are chosen. In addition, patients receive detailed information about the drugs, allowing them to better understand their treatment. Evaluations have found superior clinical outcomes for all three disorders under TMAP, and at least 12 other states have begun to apply the program to their own systems.

## Prognosis

Perhaps the most important document in mental health care in recent years was the final report of the President's New Freedom Commission, issued last July. The report sets six overarching goals for the public mental health system, with dozens of examples of system failures and accomplishments. The goals:

- Americans understand that mental health is essential to overall health.
- Mental health care is consumer- and family-driven.
- Disparities in mental health services are eliminated.
- Early mental health screening, assessment and referral to services are common practice.
- Excellent mental health care is delivered and research is accelerated.
- Technology is used to access mental health care and information.

Mental health activists have lauded the report. "The theme of fragmentation is going to resonate in this tight budget climate," says Chris Koyanagi, of the Bazelon Center for Mental Health Law. "The current system is expensive and inefficient." Bill Emmet, of the Campaign for Mental Health Reform, feels much the same way. "We don't want to see it land with a thud," he says. "We want it to make some waves."

One thing the report didn't include: a formula to achieve the goals. That's up to states and counties to create, and several states have appointed task forces to develop specific reforms based on the report's recommendations. Nevada's group has already met several times and is working toward a January 2005 deadline to provide its report to the governor and legislature.

However, implementing the recommendations in any tangible way will require overcoming considerable inertia. "We don't need to reinvent anything here," says Paul Appelbaum, of the University of Massachusetts. But maintaining the status quo is always easier, and finding time and energy to work new programs or partnerships into the fold—even if they're cost-free—is tough when employees are already taking on extra tasks because layoffs have left departments short-staffed.

There's widespread hope that the commission's report will spur changes, but the budget shortfalls continue to cast a dark cloud over what could be. Koyanagi acknowledges that getting the system moving takes more than will. It takes an infusion of resources, and she doubts the New Freedom Commission's recommendations will go far without more federal funds.

# States That Stand Out

## SUCCESS STORIES

### Alabama

Alabama is closing six of its 14 state hospitals but is working hard to move patients to community-based care. To ease fears that rural areas could be bereft of mental health resources, four new regional treatment areas will retain a team of specializing physicians, nurses, psychiatrists and dentists. The state is also adding 40 beds for acute, short-term inpatient stays, split between two state psychiatric hospitals.

### Arizona

Worried that providers will leave its mental health care system, as is happening in numerous other states, Arizona has chosen to combat the problem by making its reimbursement system more competitive. In 2001, the state adjusted provider reimbursement rates upwards for the first time in 10 years.

### Nevada

The state's mental health department budget was increased this year by 31 percent. It needed to be raised: Nevada has just six state hospital beds for every 100,000 residents, far below the national average of 33. The new money is bankrolling a new state hospital with 150 additional adult beds and mobile mental health teams.

### Oregon and Texas

These states are leaders in implementing "evidence-based practices," requiring rigorous documentation on treatment results as a condition for increased funding. By the 2009-2011 budget, 75 percent of Oregon's mental health funds will go toward programs that can point to evidence-based achievement, while Texas is phasing in a policy of designating 100 percent of its funding to support the practices.

### Texas

Eight years ago, Texas introduced its "Medication Algorithm Program" to add consistency to psychotropic prescriptions by ascertaining more precisely the real benefits of various combinations of drugs. TMAP has not only led to improved patient outcomes but has become the model for other states developing prescription formulas.

### Vermont

Vermont's comprehensive parity law covers both mental illness and substance abuse treatment. A study found promising results: Employers didn't drop coverage as a result of the law, access to outpatient mental health services improved, consumer spending on mental health treatment declined and health plan spending rose only slightly.

## TROUBLE SPOTS

### Georgia

Georgia's mental health system has been plagued by confusion and corruption. Two of the state's 25 community service boards, which deliver mental health services on a regional basis, are under investigation for Medicaid fraud, and the state hired a consultant to fix a projected $6.5 million deficit in a third. Oversight of the boards has reverted back to the state from regional governing boards, and Governor Sonny Perdue has ordered audits of every community service board.

### Maine

Last October, a judge accused the state of failing to comply with a 13-year mandate to improve state mental health care and imposed receivership on the major state hospital. The state has until March to make progress, or a receiver will also be imposed on the community-based portions of the system.

### Michigan

The state closed 11 state hospitals between 1991 and 1999, and the community-based system has never managed to pick up the load. Problems in Wayne County's mental health board have grabbed the biggest headlines, but several other regional boards are unable to balance their books. A special commission on mental health care is just now getting underway.

### New York

The state's adult homes suffer from widespread and long-standing problems. They are licensed by the state Department of Health, not the state Office of Mental Health, and negative reports by the Commission on Quality of Care for the Mentally Disabled were ignored through the 1990s. A class action suit was brought against the state last year, alleging that residents of large adult homes were being unlawfully segregated from the community.

### South Carolina

Last year, 70 people were confined to jail because they couldn't access court-ordered treatment. The mental health director blamed staff and bed shortages for a backup in the state's forensic unit. Finally, a state Supreme Court justice ordered the mental health department to find space for them.

### Vermont

The state hospital lost its federal funding last year when inspections revealed numerous systemic problems. Vermont's mental health commissioner agreed too little attention had been paid to the hospital, and the hospital's budget has been increased to add staff and improve treatment.

# The Ticking Bomb

## *Diagnosis*

**Long-term care threatens to bankrupt Medicaid and the states that pay for it. The best hope for a cure lies in cutting down on the need for institutional care.**

WITH THE POPULATION AGING, states are struggling to balance the relentless need for nursing home care, increased demands for home and community-based services and a way to fund it all. Further compounding the problem is another Medicaid population in need of expensive long-term care services: younger disabled adults unable to live independently without assistance.

The cost for long-term care for the elderly and disabled who qualify for Medicaid is enormous. Traditionally, the bulk of those services is provided by nursing homes, and increasingly, the greater proportion of people in those nursing homes are Medicaid patients. In the past few years, the federal-state Medicaid partnership has been the primary payment source for over 60 percent of all nursing home patients. The state share of that tab was $21 billion in 2002.

As the demand for non-institutional care grows, many state Medicaid programs have expanded home and community-based care. All totaled, the Medicaid program spent $16.4 billion in 2002 for home and community-based care; states paid about $8 billion of that bill.

That translates into a heavy load for each state. On average, long-term care eats up 35 percent of state Medicaid budgets. Among those above the average is North Dakota, where long-term care accounts for 60 percent of the state's Medicaid budget. Four other states that are also well above the average are Connecticut, Kansas, South Dakota and Wisconsin, where long-term care is more than 50 percent of Medicaid costs.

As fiscally challenging as long-term care expenditures are now, the pressure on states will intensify. The aging of the population is inexorable. One hundred years ago, only one in four Americans lived past 65. Today, three in four do, thanks in part to advances in medical science. Medical advances have also helped many younger people injured in accidents or afflicted with devastating illnesses recover, even though many of them remain physically disabled and unable to live independently or without assistance in basic personal care.

Given the fiscal and demographic pressures, it's not surprising that Mike Lewis, chief financial officer of the Alabama Medicaid Agency, wonders "how the system will sustain itself."



JIM STARR ICONS (5)

# ART

TOM WHITE ILLUSTRATION

## Case history

Before the 1970s, the elderly or disabled generally had one alternative to living with family, and that was to take up residence in a nursing home. A societal shift began about 30 years ago with a move to de-institutionalize the developmentally disabled. This was accompanied by an active independent-living movement on the part of people with physical disabilities and a similar push from advocates for the elderly to seek alternatives to nursing homes. "All three groups struggled against the cultural beliefs of the time, which were that if you had a disability, you were broken and somebody needed to fix you and that needed to be a health care worker," says Lee Bezanson, of Boston College.

The movement toward de-institutionalization got a big boost from a 1999 Supreme Court decision, *Olmstead v. L.C.* The court ruled that, based on the Americans with Disabilities Act, unjustified institutionalization is a form of discrimination. As long as an individual wanted transfer to the community and was judged to be qualified for community living, the state should work to move him to a less restrictive setting.

The court acknowledged that this might not be immediately possible if the move required "a fundamental alteration" of a state's programs—a sizable limitation that is being tested in courts around the country. Nonetheless, the ruling has been "a catalyst decision," says Sara Rosenbaum, chair of the Department of Health Policy at George Washington University Medical Center. "The law didn't simply prohibit certain conduct," she says. "It imposed an affirmative requirement among states to start redirecting their public expenditures to get community integration to happen at a reasonable pace."

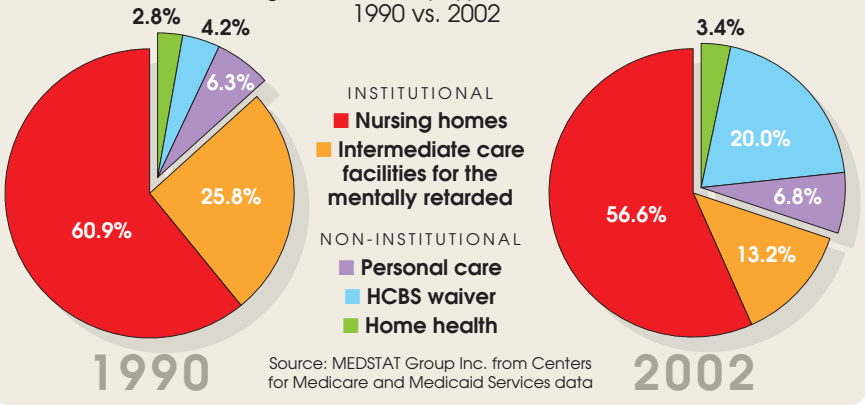
The federal government is pushing this prescription. Its Centers for Medicare and Medicaid Services, known as CMS, set up a resource network for states to share their experiences with alternative forms of services and by 2000 began awarding "real systems change grants." These provide seed money for states to experiment with fundamental alterations in the delivery of services. In 2001, President George W. Bush issued an executive order requiring federal agencies to "promote community living for persons with disabilities," and two years later the administration launched a five-year program called "Money Follows the Person." It enables an individual in an institution to take the money provided for his or her care in that setting and use it to live in the community instead.

As the demand for alternative-care options emerged, Medicaid began issuing waivers that permit the states to use federal matching funds to finance home or community-based care for patients who would otherwise qualify for nursing-home care. While the cost of that care cannot exceed that of care in a nursing home, Medicaid waivers provide substantial freedom for states to design their own systems.

In addition to those eligible for nursing home care, however, there are elderly and disabled people who qualify for Medicaid and require ongoing assistance , but require a lower level of assistance than a nursing home provides. All states offer home health services, largely medical in nature, but they are often very limited. About 30 states provide some level of personal care, which is not medical but includes help with basic personal activities: dressing, bathing, eating, using the bathroom, shopping or managing medicines. There also are state-financed services that can help prevent the need for more expensive institutional care.

### The Shift Toward Home

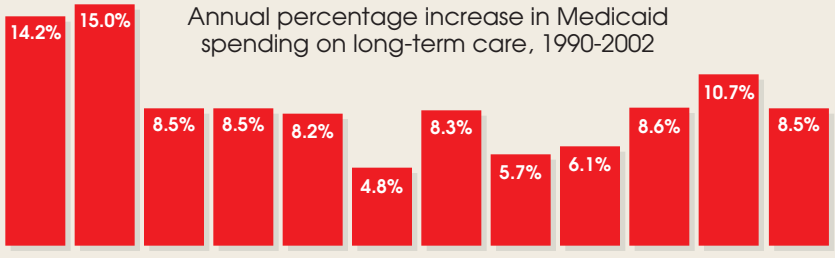
Percentage of total Medicaid spending on long-term care by type of service, 1990 vs. 2002



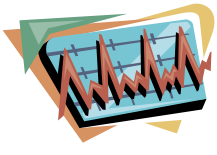

Source: MEDSTAT Group Inc. from Centers for Medicare and Medicaid Services data

### Budget Roller Coaster

Annual percentage increase in Medicaid spending on long-term care, 1990-2002




Source: MEDSTAT Group Inc. from Centers for Medicare and Medicaid Services data



## Complications

Logic suggests that keeping Medicaid patients out of institutions and in their

communities would drive down program costs. In Arkansas, for example, the cost of caring for a person through home and community-based services available through the state's Elder Choices waiver program—homemaker services, a personal emergency response system, adult day care and a respite program for family caregivers—is a third as much as placing that person in a nursing home. In Vermont, it costs $25,000 a year to provide care to someone at home and $50,000 in a nursing home.

But the long-term care fiscal ledger is more complicated than that. Individuals who use non-institutional care are often a different patient base than those who enter nursing homes. An analysis by the University of Michigan found that 45 percent of state Medicaid patients receiving waiver-funded home-care services were at the lower end of the spectrum in terms of the acuity of their personal and health needs, whereas only 8 percent of nursing home residents were at that same level.

When Michigan expanded its Medicaid waiver for home care, the state went from paying for 2,000 days a year of home care to 3 million days a year. "But we didn't see a 3 million-day decline in nursing home use. It was flat," says Paul Reinhart, Michigan's Medicaid director. When the state put a lid on home-care enrollment, demand for nursing home placement did not, as one would expect, increase. "It's decoupled," Reinhart says. "Nursing home utilization doesn't decline unless there is some forceful front-end mechanism that really constrains enrollment in nursing homes."

### Funny Figures

To control long-term care spending, states need to tamp down their nursing home bill, but lowering those costs isn't as simple as, say, capping nursing home enrollment for Medicaid patients. To start with, nursing home finances are similar to those of an airline. It costs a lot to fly a Boeing 747 from New York to Los Angeles, but the costs are about the same whether the plane is full of bicoastal fliers or has only three people on board. The airline still needs fuel, pilots, flight attendants and, of course, the 747. The same applies to nursing homes. Cutting down on the population of any individual home doesn't save much money. The facility still has to spend a set amount of money—on utilities, on the mortgage, on the medical infrastructure—to keep operating, whether the

## The Long-Term Care Tab

Long-term care expenditures, and institutional vs. non-institutional care as percentage of spending, FY2002

| STATE | TOTAL LTC SPENDING FY 2002 | % CHANGE 2001-02 | INSTITUTIONAL CARE AS % TOTAL SPENDING | HOME CARE AS % TOTAL SPENDING |
|---|---|---|---|---|
| Alabama | $978,581,437 | 5.5% | 77.0% | 23.0% |
| Alaska | $198,817,419 | 27.1 | 43.9% | 56.1% |
| Arizona* | $22,341,354 | 48.4 | 84.0% | 16.0% |
| Arkansas | $704,103,233 | 8.8 | 74.7% | 25.3% |
| California | $5,293,058,462 | –1.6 | 64.4% | 35.6% |
| Colorado | $845,928,300 | 10.1 | 48.6% | 51.4% |
| Connecticut | $1,894,697,686 | 2.9 | 65.4% | 34.6% |
| Delaware | $213,273,008 | 9.1 | 73.0% | 27.0% |
| Florida | $2,941,546,297 | 11.1 | 74.3% | 25.7% |
| Georgia | $1,269,886,217 | 15.5 | 74.5% | 25.5% |
| Hawaii | $242,841,956 | 15.5 | 73.3% | 26.7% |
| Idaho | $277,166,785 | 7.5 | 64.0% | 36.0% |
| Illinois | $2,732,511,976 | 5.8 | 81.8% | 18.2% |
| Indiana | $1,447,190,635 | 10.7 | 83.7% | 16.3% |
| Iowa | $1,128,372,617 | 49.4 | 80.9% | 19.1% |
| Kansas | $954,446,858 | 7.6 | 61.0% | 39.0% |
| Kentucky | $996,229,926 | 6.5 | 71.6% | 28.4% |
| Louisiana | $1,871,062,823 | 11.6 | 90.2% | 9.8% |
| Maine | $438,813,760 | 6.8 | 56.2% | 43.8% |
| Maryland | $1,146,893,390 | 8.1 | 71.2% | 28.8% |
| Massachusetts | $2,496,135,688 | 3.5 | 64.8% | 35.2% |
| Michigan | $2,389,481,098 | 0.2 | 75.7% | 24.3% |
| Minnesota | $2,156,106,529 | 12.5 | 51.1% | 48.9% |
| Mississippi | $717,479,703 | 11.1 | 87.4% | 12.6% |
| Missouri | $1,954,434,032 | 16.5 | 72.9% | 27.1% |
| Montana | $247,938,432 | 15.1 | 62.7% | 37.3% |
| Nebraska | $630,758,950 | 9.0 | 69.6% | 30.4% |
| Nevada | $187,693,295 | 15.7 | 73.4% | 26.6% |
| New Hampshire | $465,133,927 | 29.8 | 65.4% | 34.6% |
| New Jersey | $3,442,406,247 | 7.8 | 80.1% | 19.9% |
| New Mexico | $491,324,098 | 19.7 | 38.2% | 61.8% |
| New York | $14,445,209,022 | 6.7 | 62.8% | 37.2% |
| North Carolina | $2,154,225,906 | 5.7 | 60.6% | 39.4% |
| North Dakota | $284,396,238 | 13.4 | 80.6% | 19.4% |
| Ohio | $4,109,314,347 | 12.8 | 83.5% | 16.5% |
| Oklahoma | $881,771,565 | 8.7 | 63.8% | 36.2% |
| Oregon** | $768,706,305 | –28.2 | 27.1% | 72.9% |
| Pennsylvania | $5,541,859,959 | 8.3 | 81.2% | 18.8% |
| Rhode Island | $453,786,912 | 6.3 | 59.3% | 40.7% |
| South Carolina | $864,374,865 | 9.6 | 65.4% | 34.6% |
| South Dakota | $259,654,434 | 9.8 | 73.2% | 26.8% |
| Tennessee | $1,418,262,915 | 18.0 | 84.4% | 15.6% |
| Texas | $3,665,310,642 | 11.5 | 70.4% | 29.6% |
| Utah | $258,915,418 | 7.6 | 58.2% | 41.8% |
| Vermont | $212,155,946 | 11.3 | 44.2% | 55.8% |
| Virginia | $1,250,230,746 | 23.8 | 73.1% | 26.9% |
| Washington | $1,592,849,651 | 11.6 | 52.7% | 47.3% |
| West Virginia | $577,800,830 | 8.8 | 62.1% | 37.9% |
| Wisconsin | $2,193,324,965 | 21.0 | 70.4% | 29.6% |
| Wyoming | $133,927,383 | 18.7 | 49.2% | 50.8% |

*Arizona has a statewide managed care system. These figures reflect only the very small fee-for-service population.

**Drop in spending is due to significant one-time costs in 2001.

Source: MEDSTAT Group Inc. from Centers for Medicare and Medicaid Services data

# The Promise of Coverage

INSURANCE FOR LONG-TERM HEALTH CARE has yet to make it into the mainstream of financial planning. Most Americans carry health insurance that covers them, whatever their age may be, in case of a heart attack or the onset of diabetes—but not if they come down with Alzheimer's or suffer the aftereffects of disabling events that often occur with the onset of old age.

Medicare does not provide long-term care for the chronically debilitated, but Medicaid does. And that can be a problem. There is concern that, in an effort to make sure they have access to care, some elderly citizens are artificially impoverishing themselves to qualify for Medicaid. While it is illegal for someone to give away money for the purpose of making himself eligible for Medicaid, there are huge loopholes, and there are attorneys and financial planners who specialize in what is sometimes called "Medicaid estate planning." The effect of this, asserts Stephen A. Moses, president of the Center for Long-term Care Financing, "is that people with very substantial income and assets qualify routinely for Medicaid."

How routine and how substantial a problem this is for Medicaid is uncertain. But several states are trying to fight the problem and help plan for the financial burdens of long-term care by encouraging citizens—middle-aged and older—to invest in an alternative: long-term care insurance. Right now, under 10 percent of the elderly, and a smaller portion of middle-aged adults, have purchased private health insurance to cover their long-term care.

That said, the number of people buying long-term care insurance is increasing, and the policies themselves are much improved. More policies are now comprehensive and have a better balance of institutional and home-based coverage. States are also coming up with assistance. In 2002, about half the states offered some form of tax incentive for people who buy long-term care insurance. And some states, such as Minnesota and North Carolina, include long-term care insurance benefits for their own employees. "They get quality coverage for their constituency, and they serve as a role model for other employers," says Mark Meiners, associate director of the University of Maryland Center on Aging.

Four states have been particularly aggressive in pushing long-term care insurance. California, Connecticut, Indiana and New York started programs in the early 1990s that offered double protection for those who buy the insurance. Someone who purchases, say, $100,000 of insurance is able to shield $100,000 in personal assets. That means that after the $100,000 in insurance is used up, the shielded assets are not counted against eligibility requirements for Medicaid. Congress barred other states from instituting similar programs in 1993 but grandfathered these four in. The Bush administration has indicated an interest in revisiting this approach.

home is full of patients or nearly empty.

As a result, simple reductions in nursing home populations don't substantially lower a nursing home's costs—or the price states have to pay for Medicaid patients living in the facility. For instance, when the number of patients in Kansas nursing homes dropped by 13 percent between 1996 and 2001, the per-person bill for Medicaid patients doubled. And in Idaho, when the nursing facility population declined by 7 percent during the same time period, the bill for the state's patients increased by 39 percent.

It's only when many beds in a nursing home are closed—or the facility is shut down altogether—that Medicaid can realize savings on its nursing home bills. But almost any state action to control nursing home costs—whether it's by limiting the number of beds that can be built or operated or other means—runs smack into powerful state-level nursing home lobbyists. They have proven themselves adept at pressuring legislatures to increase rates and keep up the count of nursing home beds. They've also been effective in fighting attempts to siphon off long-term care resources for other service options. One convincing argument for legislators, many of whom have a nursing home in their district: Nursing homes are good for local economies and provide jobs.

"The business interests in the nursing home sector are very powerful," says Barbara Edwards, Medicaid director in Ohio, where 83.5 percent of the state's Medicaid budget goes to institutional care. Nursing home reimbursement is set by statute, and the facilities are guaranteed rate adjustments. "Change is inevitable," she says, "but it will be a slow change becasue so much revenue is tied up in bricks and mortar."

In Louisiana last winter, the state's executive branch proposed diverting some nursing home residents into home and community programs—a potential blow to an industry in which 7,000 beds in the state are currently empty. The reason behind the proposal was simple. "The demand for nursing home care is declining. And yet we have this vast institutional network that we continue to support," says David Hood, secretary of the Louisiana Department of Health and Hospitals. Nonetheless, the proposal went nowhere, and the lobbyists' role in fighting it off was clear.

## Remedies

### Limiting Supply

Gaining control over the supply of nursing home beds is clearly one key to taming the cost of long-term care. States can use certificate-of-need programs to restrict the building or purchase of new medical facilities or equipment, nursing homes included. But many states have abandoned the certificate-of-need approach, and that limits their ability to cap nursing home supply. A case in point is Utah. After it eliminated certificates of need in the 1980s, a number of new nursing homes opened and occupancy rates slipped to 84 percent by the mid-1980s. In 1989, when the state placed a moratorium on accepting new nursing home providers for Medicaid, the old providers kept adding beds. Occupancy is now at 75 percent. "We are hugely overbedded," says John Williams, the state's long-term care director.

Oregon and Vermont, on the other hand, have both been quite effective at controlling the growth of nursing homes through certificates of need. Oregon has used more than the blunt hammer of regulation. The state initially sweetened the pot with incentives for nursing home operators to develop alternative services, such as assisted-living facilities. These are apartment-like complexes that provide living quarters in individual apartments but also make available basic non-nursing services—personal care, meals, transportation and the like. This less expensive form of long-term care did get overbuilt, however, and there is now a moratorium on new construction. The state's success in shifting people away from nursing home care has resulted in low occupancy levels as well.

A critical element in developing Oregon's approach was the work legislators did on the state's Nurse Practice Act. In many states, such laws restrict the performance of a variety of patient-care tasks to nurses. Oregon embraced the concept of teaching and transferring skills to other individuals who could then perform them at lower cost. The newly trained personnel also helped address another issue, the shortage of nurses, particularly in the field of long-term care.

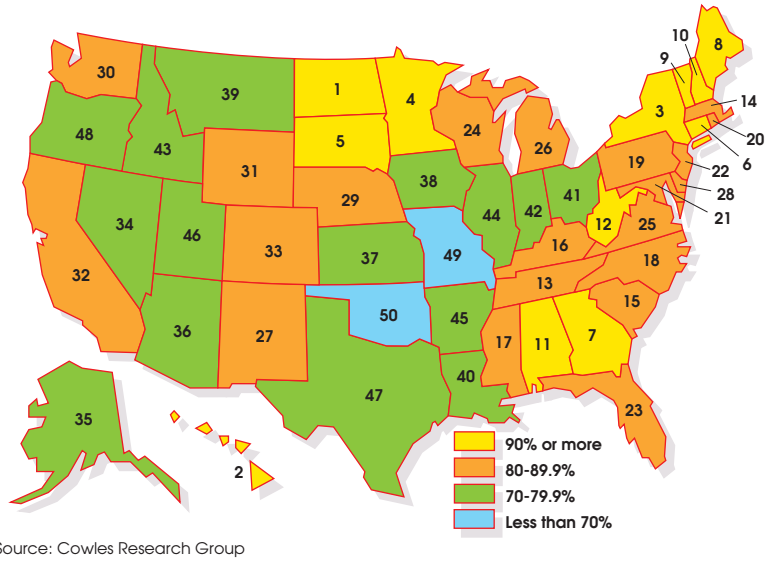
The changes dovetailed well with Oregon's overall attitude toward long-term care, which is to build a home and community services infrastructure for people who can afford to pay their own way as well as for those dependent on Medicaid.

Thanks to its tough line on limiting nursing home beds, Oregon was able to divert spending on nursing facilities to home and community care. Today, the state devotes a significantly higher proportion of its long-term care budget to home and community programs than any other state. In so doing, its overall long-term care costs are well below the national average: $604 per capita compared with the U.S. average of $996 per capita.

Vermont is on a similar course. As the state began to realize savings from limiting nursing home beds, it put the unspent money in a trust fund. That fund was then used to provide seed money to develop community programs. "We made smart investments," says Patrick Flood, commis-

## Rooms to Spare

States ranked by nursing home occupancy rates, 2002




Source: Cowles Research Group

sioner of aging. "The more you build the system, the more people can go to it, and the fewer people go to nursing homes." According to a 2002 AARP report, the percentage of long-term care dollars that Vermont spent in nursing homes dropped from 55.4 percent in 1996 to 44.1 percent in 2001. But it's still using nursing homes efficiently. The occupancy rate is 90.6 percent, compared to the U.S. average of 82.5 percent.

### Leveling Care

Several states have been able to hold down long-term care costs by making sure that the nursing home option is reserved only for those whose needs cannot be met safely in less restrictive—and less expensive—ways. This is only possible, of course, if a wide range of alternatives is available. But the approach starts with, in effect, a system of triage.

Maine, for instance, created a uniform assessment system in 1995 that is carried out by an independent agency. The agency oversees admissions for both private- and public-pay nursing home stays.

Arizona has a particularly unusual system, one that has helped that state achieve an enviable record: Its nursing-home population is 1.1 percent of residents who are 65 or older—well below the U.S. average of 3.7 percent.

To accomplish this, the state starts with individual screening to see if an applicant for care qualifies for long-term services. Those who do are then assigned to a managed care organization that receives a preset payment for every individual under its care—a blended rate corresponding to nursing home costs and home-based costs that is generally similar for every individual for whom it provides care. The MCO—five of the seven that cater to the elderly and disabled long-term community are county run—helps its patients select the setting that's right for them, but there is a clear incentive to keep people in their homes as long as those services can be offered at less cost than a nursing home.

What's to stop managed care officials from overutilizing low-cost options? "If the program contractors don't ensure that they have the right amount and type of services for those people living in home and community-based settings, they will experience more acute care and more emergency room utilization later on," says Alan Schafer, program manager for Arizona's long-term care system. In Arizona's model, those cost increases will be born by the managed care organization, not shifted to some other group.

Arizona isn't just trusting to fiscal pain to assure that care is appropriate. The state has established a number of quality-assurance mechanisms to make sure that people are getting good services and that they are being placed in a program that provides the proper level of care.

Another creative but simple approach to determining who gets what kind of care is the way Vermont handles its waiting list for home and community-based services. Instead of admitting people on a first-come, first-served basis, the state sets priorities: Those in the greatest need—the ones most likely to end up in a nursing home if they have to wait for services—are pushed to the front of the list.

In an effort to expand on that idea, Vermont is currently asking CMS to approve a waiver that will allow the state to divide the people who qualify for long-term care into two groups: a higher need group and a lower need group. Those with the most acute needs would have a choice: They would be entitled to either home and community-based care or nursing home care, depending on what would be the most appropriate level of care for them. After that population is taken care of, the money that remains would be spent on those in the lower-need group.

### Cash and Counseling

The approach that may have the greatest promise for national overhaul of long-term care is called "Cash and Counseling." Since 1996, it has been jointly funded by the Robert Wood Johnson Foundation and the federal government.

The idea is to give people who need long-term care—the frail elderly, the disabled—the choice of using cash to purchase the personal care, equipment, remodeling or other services that they need to keep them living at home safely. Instead of using an agency, the recipients (or a responsible family member on their behalf) are put in charge of hiring and firing employees and arranging for care by the individuals they choose.

To help people make their plans and choices, a counselor or consultant helps them establish a budget that will meet their needs. The adviser also stays in contact with each client to make sure that all is going well. A bookkeeping service is offered for people who want help in administrative and financial tasks, such as paying employment taxes.

The program has been implemented in Arkansas, Florida and New Jersey, with a total of 6,700 individuals. Results are being closely watched.

The first set of evaluations centered on Arkansas, since it was the first to get the program up and running. Arkansas won an A for its efforts. There were no instances of fraud or abuse—one of the big fears officials have when control shifts from a bureaucracy to an individual. Since 1998, when the program started, only four people out of the 3,000 who have enrolled were shifted out of the program because of

AD

problems in the way they were handling their own services.

The differences Cash and Counseling makes are clear. When outcomes for those in a control group in the old system were compared to those in the new program, the disparities were "gigantic," according to Kevin J. Mahoney, national program director for Cash and Counseling Demonstration and Evaluation. In Arkansas, there was a 20-point difference in the levels of customer satisfaction. What's more, people who had control over their own employees had equal or fewer health problems, and there was a major reduction in unmet needs.

The program also appeared to provide a solution to the longstanding problem of worker shortages and to providing help in difficult-to-reach rural areas. Since participants were able to hire neighbors or even family members to help them, they had a much easier time finding people to work at difficult hours, such as early morning or weekends. "Access improved markedly," says Mahoney.

This approach was such a notable success in Florida that the legislature unanimously passed a bill making consumer-directed care a permanent option in state programs. In May 2002, CMS came out with model "independence-plus waivers," which provide a template for states to set up programs that are similar to Cash and Counseling. Meanwhile, the Robert Wood Johnson Foundation and its federal government partner are expanding their specific Cash and Counseling program to an additional 10 states.

## Prognosis

Regardless of the remedies states try, long-term care is going to grow more expensive. Simple demographics, coupled with advances in medical care, dictate that. The number of elderly people residing alone without living children or siblings is expected to reach 1.2 million in 2020—up from about 600,000 just a decade ago. Some of them will qualify for public programs, and the number of younger people available to pay that bill is declining as a percentage of the population.

The quality of services in nursing homes and in the community is improving—even as those improvements boost costs. And that is likely to continue, as will the pressure for states to deliver more and better services. The power of older Americans as a voting and lobbying group is well known to politicians, and their concerns are not easily ignored.

So, are the states stuck with an inexorably growing budget item for long-term care? Possibly, although state associations are working on the issue. The National Governors Association has argued for a shift in funding responsibilities to the feds for years, but the emphasis is now greater than before. The new chair of the NGA, Idaho Governor Dirk Kempthorne, has announced that making changes in the long-term care system in this country is his number one initiative.

A greater reason for guarded optimism

# States That Stand Out

## SUCCESS STORIES

### Arizona

A statewide managed care system helps patients avoid improper long-term care choices. "Nursing home eligibles" can move between different levels of care. There are no waiting lists for home care; only 1.1 percent of the 65-plus population lives in nursing facilities, among the nation's lowest rates.

### Arkansas

A pioneer in consumer-directed programs, Arkansas gives people in need of care—or their representatives—control over spending and hiring to meet their needs. Arkansas also does well promoting home and community-based alternatives. Since Elder Choices was put in place in 1992, nursing home residency has decreased by 60 percent.

### Maine

Assisted-living programs and screening protocols for nursing home care have, since 1995, restrained spending growth on long-term care to 17 percent of Medicaid budgets, compared with 53 percent nationally. Since 1995, there's been an 18 percent decline in the number of Medicaid residents in nursing homes and a 24 percent decline in the number of nursing home beds in the state.

### Oregon

The state boasts the nation's lowest percentage of elderly people in nursing facilities. Its long-term care program provides incentives to the nursing home industry to develop home-care programs and diverts savings in institutional care to community and home care. Recent budget cutbacks, however, will limit patient access to the system.

### Pennsylvania

To address the shortages of personal aides and other staff that bedevil long-term care, Pennsylvania has been a pioneer in finding out what direct-care workers themselves think are the issues in promoting better recruitment and retention. The legislature provides funding so local agencies can put creative ideas into practice.

### Vermont

The state has a very good track record for getting diverse groups involved with long-term care to work together. Patients are diverted from nursing homes, and the money saved goes into a trust fund, which is then used to develop more community and home-care programs.

## TROUBLE SPOTS

### Kentucky

Projected Medicaid deficits led to cutbacks in long-term care services last year that were among the most extreme in the country. About 1,400 people formerly eligible for long-term care are now denied these benefits, though officials say they may appeal the decision. There's a 3,000-person waiting list for the state-funded elderly home care system.

### Louisiana and Mississippi

Both states have unbalanced long-term care systems with very high percentages of funding going to institutional care. In Louisiana, the courts are now forcing the state to expand home and personal-care services.

### Ohio

State statutes guarantee nursing home rate increases. This makes it hard to apportion money to home and community-based alternatives. Although Medicaid administrators are trying to alter the equation, spending is substantially below most states.

### Tennessee

Managed care organizations, at the heart of the TennCare system, bear no responsibility once someone is deemed nursing-home eligible. The result is that patients have been denied home health care and steered to nursing homes. The state ranks low in spending on home and community services as a percentage of long-term care expenditures.

lies in state efforts to encourage citizens to take individual responsibility—expressed, for example, by bolstering families' capacity to take care of one another and by encouraging more affluent citizens to buy insurance to cover long-term care costs.

What appears to be missing from the equation is appropriate education of the American people about the horrific financial burdens that await them. Just as many self-interested Americans finally realized that they could not have a comfortable retirement based exclusively on Social Security income, states would be well advised to encourage a similar awakening regarding long-term care. Only 15 percent of Americans polled by AARP were able to make a remotely accurate guess as to the cost of long-term care; most were totally confused about whether Medicare would pay for their long-term needs. As an AARP report concludes, Americans "know less about long-term care than they think—and than they should." G

# Sudden Reversal

*Diagnosis*

**Dramatic recent improvements in health care for poor children in America are being threatened by a new wave of cost-cutting in the states. Changes are being made that not only endanger the health of young people but are likely to lead to greater costs in future years.**

CHILDREN ARE HEAVY CONSUMERS of health care, but they are the cheapest of patients. About a third of all children in America get health services through Medicaid or the State Children's Health Insurance Program (SCHIP), and that cost taxpayers an average of $1,475 for a child enrollee in 2002, compared with $12,764 for one who was elderly. The payoff from that $1,475 investment is large: Immunizations, annual visits to a pediatrician, dental care, and screening for vision, hearing and developmental problems are all long-term money savers for the health care system as a whole.

The same goes for prenatal care for pregnant women. Premature babies cost about $13.1 billion annually, according to the March of Dimes Prenatal Data Center. The average premature baby racked up $75,000 in hospital fees in 2001, compared with $1,300 for a healthy full-term infant.

That's fairly well known. What's less well known is that states made remarkable progress on children's care in the few years just before the most recent budget crunch. Between 1999 and 2002, the number of children without insurance nationwide fell from 9.6 million to 7.8 million. At the upper end of performance, Iowa, Massachusetts, Minnesota, Nebraska, New Hampshire, North Dakota, Rhode Island, South Dakota, Vermont and Wisconsin all had less than 7 percent of total children uninsured.

By 2002, nearly 70 percent of all U.S. children were getting regular doctor's visits, and 83 percent of new mothers were receiving prenatal care in their first trimester—up from 76 percent in 1990. Infant deaths dropped from 9.2 out of 1,000 in 1990 to 6.9 out of 1,000 a decade later.

In recent years, improvements occurred even as the percentage of children covered by private insurance was shrinking. "Medicaid demonstrated its strength as a counter-cyclical safety net program," says Tara Straw, of the March of Dimes. "When children were losing insurance, Medicaid filled the gaps."

Elected officials realize the emotional importance of children's health to millions of Americans. No legislator ever denounces immunization or prenatal care as a waste of tax dollars. And yet—when budgets need to be cut—medical care for children often seems to be sitting in a prominent and vulnerable place on the table.

The most obvious approach, of course, is to tighten eligibility standards for children. But although a few states have taken that route, most



JIM STARR ICONS (5)

# ART

TOM WHITE ILLUSTRATION

have chosen far more subtle methods to achieve the same outcomes. These maneuvers depend on the fact that Medicaid recipients can be difficult to reach in the first place; many have limited literacy skills, and filling out forms and complying with regulations can be a powerful barrier. Moreover, since recipients are from lower economic strata, they tend not to have easy access to transportation.

As a result, cutting back on outreach to potential recipients is a very effective means of keeping them off the rolls altogether. Reducing the number of administrative workers denies many clients the help they may need in filling out forms or complying with rules. Complicating the application process has the same effect.

## Case History

As recently as the early 1980s, children were eligible for Medicaid only if their families were on welfare. That meant that only the very poorest were covered. But over the course of the past two decades, Congress steadily expanded eligibility. By October 2002, all children under 19 in families with incomes below the poverty line were eligible for Medicaid coverage.

Seven years ago, the federal government gave states a tool to reach children at much higher income levels, as well. SCHIP, the State Children's Health Insurance Program, provides a higher federal matching rate than Medicaid, encouraging states to ease the standards for eligibility. Currently, 39 states cover children in families up to 200 percent of the poverty level, either through SCHIP or expansions of traditional Medicaid.

Some go way beyond this. Minnesota covers infants at 280 percent of poverty and all other age groups at 275 percent. New Jersey, with one of the highest per capita incomes in the country, covers children up to 350 percent of the poverty level. Vermont and Missouri offer coverage to all age groups at 300 percent. "Functionally, we have universal access," says Paul Wallace-Brodeur, director of Vermont's program.

Not only did states expand eligibility in recent years, they worked to make sure that potential recipients actually took advantage of the programs. Most states abolished the requirement for a face-to-face interview and let families simply mail in applications. Forty-four states dispensed with the asset test requirement—allowing families with low annual incomes to apply even if they owned a car or had a small bank account. Georgia and other states also eased up on documentation of income, on the basis that personal information available on databases made it unnecessary for applicants to gather this material themselves.

During the same period, the federal government declared its willingness to cover prenatal care through the SCHIP program, reasoning that the actual patient is the child, not the mother. Most states chose to decline the federal dollars rather than implicitly take a position in the abortion debate favoring the legal rights of the fetus. But six states—Illinois, Massachusetts, Michigan, Minnesota, Rhode Island and Washington—opted to accept the offer and began including pregnant women as part of their SCHIP-eligible population.

The expansion of the system continued until recently in most places. It is over now. "There was an unmistakable march forward," says Cindy Mann, a senior fellow at the Kaiser Family Foundation, "but the march forward has stopped."

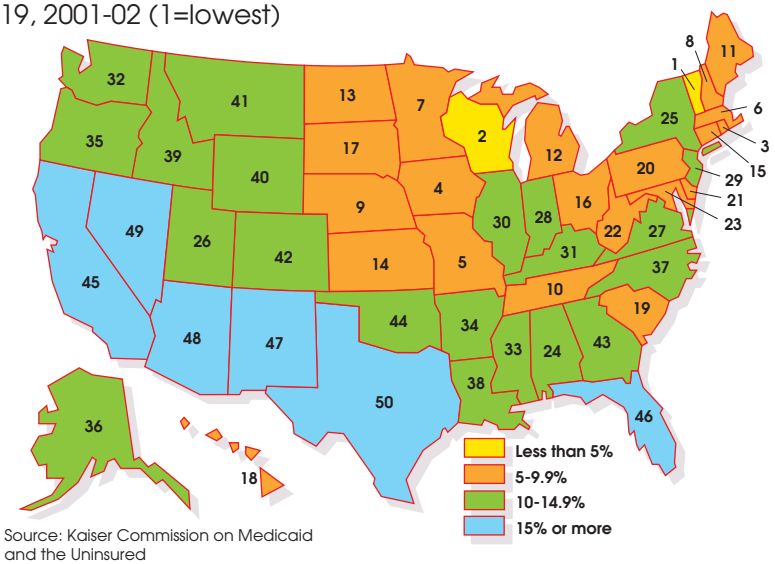
These days, with budgets impossibly tight, states are looking for cuts wherever they can find them. A few have affected children and prenatal programs directly. Last June, Alaska cut eligibility for its SCHIP program from 200 percent of poverty level to 175 percent. Other states have taken less obvious but equally effective paths toward reducing the number of children who receive coverage. "States are rolling back on the simplification processes they put in place," says Donna Cohen Ross, co-author of a July 2003 Kaiser study on Medicaid and SCHIP eligibility and enrollment practices. "It's a way of curbing enrollment and implementing a cut in your program."

One way to discourage participation is simply to ask people to renew their coverage more frequently. A study by the Urban Institute found that when it comes time to renew coverage, less than 50 percent of children covered through SCHIP stay eligible. Some are dropped from the rolls for good reasons, such as a change in family income. But a close look at eight states suggested that between 10 and 40 percent of children were "lost." One reason was that parents didn't answer renewal notices or re-submit applications.

States might conclude from this research that they should do more to educate and retain potential clients. And in the 1990s, many states did just that.

## Insecurity Blanket

States ranked by uninsured rates among children under age 19, 2001-02 (1=lowest)




Source: Kaiser Commission on Medicaid and the Uninsured

But cutting back on SCHIP outreach saves substantial amounts of money, because it keeps the size of the rolls down. In both fiscal 2003 and 2004, California eliminated more than $13 million in funding to community-based organizations for outreach and application assistance as well as another $6 million a year for school-based outreach, such as media advertising and aides to help families fill out applications. Mississippi, Nebraska and Washington have recently added more rigorous documentation requirements for reporting income, while Connecticut, Indiana, Nebraska and Washington did away with the guarantee of 12 months of uninterrupted coverage.

All told, about half a million children will have lost coverage in fiscal years 2003 and 2004.

### A More Direct Approach

If tightening up on eligibility sounds like a form of budget-cutting by stealth, many states are taking the more direct approach of actually freezing enrollment in their SCHIP programs. Alabama, Colorado, Florida, Maryland, Montana and Utah all have taken this path. The levels of income used to determine eligibility have not changed, but no new children are being admitted. In Florida, some 63,000 children who are eligible for SCHIP are now on waiting lists for coverage. Utah doesn't have a waiting list; it just sends people home and tells them to watch for a time when enrollment is open again.

The impact of such actions is immediate and dramatic, as was pointed out in a study of an enrollment freeze in the North Carolina SCHIP program, which took place between January and October 2001. About 34,000 children went on a waiting list. In interviews with University of North Carolina researchers, families who were wait-listed complained that they had been forced to delay medical or dental care, were unable to afford prescriptions, and in some cases had put off paying rent or utility bills.

Texas has made the most drastic cutbacks of all. Historically, the Lone Star State has been one of the weakest in children's health; an analysis of census data by the American Academy of Pediatrics puts the uninsured rate for children in Texas at 23 percent, compared with a U.S. average of 11.9 percent. This is in part a function of the state's percentage of

## Natal Numbers

States ranked by rate of pre-term births, low birthweight and infant mortality (1=lowest)

| STATE | % PRE-TERM BIRTHS, 2002 | RANK | % LOW BIRTH-WEIGHT, 2002 | RANK | INFANT DEATHS/ 1,000 BIRTHS, 2001 | RANK |
|---|---|---|---|---|---|---|
| Alabama | 15.8% | 49 | 9.9% | 46 | 9.4 | 47 |
| Alaska | 9.8 | 5 | 5.8 | 1 | 8.1 | 39 |
| Arizona | 12.6 | 30 | 6.8 | 14 | 6.9 | 25 |
| Arkansas | 12.7 | 35 | 8.6 | 38 | 8.3 | 41 |
| California | 10.2 | 9 | 6.4 | 9 | 5.4 | 5 |
| Colorado | 12.0 | 26 | 8.9 | 40 | 5.8 | 10 |
| Connecticut | 10.1 | 7 | 7.8 | 23 | 6.1 | 16 |
| Delaware | 13.6 | 43 | 9.9 | 46 | 10.7 | 50 |
| Florida | 13.0 | 37 | 8.4 | 36 | 7.3 | 29 |
| Georgia | 12.6 | 30 | 8.9 | 40 | 8.6 | 43 |
| Hawaii | 13.7 | 45 | 8.3 | 34 | 6.2 | 18 |
| Idaho | 10.4 | 10 | 6.1 | 4 | 6.2 | 18 |
| Illinois | 12.6 | 30 | 8.2 | 32 | 7.7 | 36 |
| Indiana | 12.5 | 29 | 7.6 | 21 | 7.5 | 34 |
| Iowa | 11.6 | 21 | 6.6 | 12* | 5.6 | 8 |
| Kansas | 11.0 | 14 | 7.0 | 16 | 7.4 | 31 |
| Kentucky | 13.6 | 43 | 8.6 | 38 | 5.9 | 13 |
| Louisiana | 15.1 | 48 | 10.4 | 49 | 9.8 | 48 |
| Maine | 10.1 | 7 | 6.3 | 5 | 6.1 | 16 |
| Maryland | 12.9 | 36 | 9.0 | 42 | 8.1 | 39 |
| Massachusetts | 10.6 | 12 | 7.5 | 19 | 5.0 | 3 |
| Michigan | 11.9 | 25 | 8.0 | 27 | 8.0 | 38 |
| Minnesota | 9.8 | 5 | 6.3 | 5 | 5.3 | 4 |
| Mississippi | 17.2 | 50 | 11.2 | 50 | 10.5 | 49 |
| Missouri | 13.0 | 37 | 8.0 | 27 | 7.4 | 31 |
| Montana | 11.3 | 15 | 6.8 | 14 | 6.7 | 22 |
| Nebraska | 11.8 | 23 | 7.2 | 17 | 6.8 | 23 |
| Nevada | 13.0 | 37 | 7.5 | 19 | 5.7 | 9 |
| New Hampshire | 9.5 | 2 | 6.3 | 5 | 3.8 | 1 |
| New Jersey | 12.0 | 26 | 8.0 | 27 | 6.5 | 21 |
| New Mexico | 12.6 | 30 | 8.0 | 27 | 6.4 | 20 |
| New York | 11.4 | 19 | 7.9 | 24 | 5.8 | 10 |
| North Carolina | 13.3 | 40 | 9.0 | 42 | 8.5 | 42 |
| North Dakota | 11.3 | 15 | 6.3 | 5 | 8.8 | 45 |
| Ohio | 12.2 | 28 | 8.3 | 34 | 7.7 | 36 |
| Oklahoma | 12.6 | 30 | 8.0 | 27 | 7.3 | 29 |
| Oregon | 9.7 | 4 | 5.8 | 1 | 5.4 | 5 |
| Pennsylvania | 11.4 | 19 | 8.2 | 32 | 7.2 | 27 |
| Rhode Island | 11.3 | 15 | 7.9 | 24 | 6.8 | 23 |
| South Carolina | 14.2 | 47 | 10.0 | 48 | 8.9 | 46 |
| South Dakota | 11.3 | 15 | 7.2 | 17 | 7.4 | 31 |
| Tennessee | 13.8 | 46 | 9.2 | 45 | 8.7 | 44 |
| Texas | 13.3 | 40 | 7.7 | 22 | 5.9 | 13 |
| Utah | 10.5 | 11 | 6.4 | 9 | 4.8 | 2 |
| Vermont | 9.0 | 1 | 6.4 | 9 | 5.5 | 7 |
| Virginia | 11.8 | 23 | 7.9 | 24 | 7.6 | 35 |
| Washington | 9.6 | 3 | 5.9 | 3 | 5.8 | 10 |
| West Virginia | 13.4 | 42 | 9.0 | 42 | 7.2 | 27 |
| Wisconsin | 10.9 | 13 | 6.6 | 12* | 7.1 | 26 |
| Wyoming | 11.7 | 22 | 8.4 | 36 | 5.9 | 13 |

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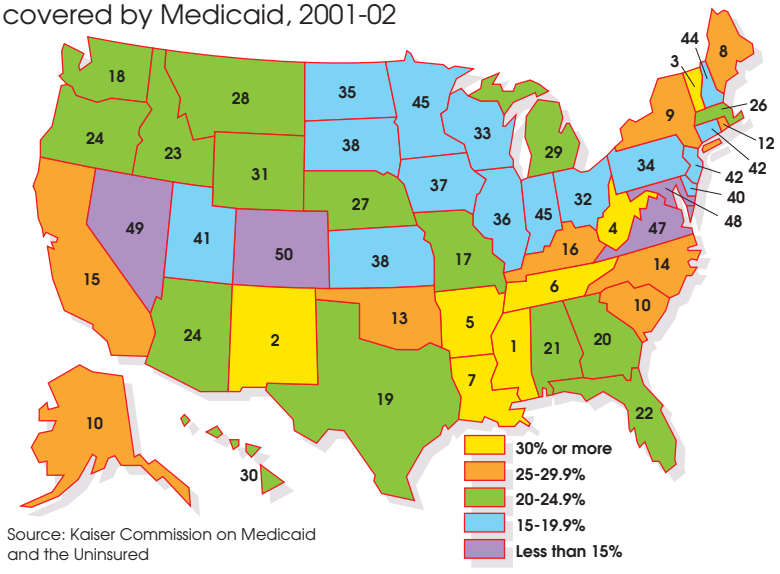
Source: National Center for Health Statistics, Centers for Disease Control and Prevention

## The Safety Net

States ranked by percentage of children age 18 and under covered by Medicaid, 2001-02




Source: Kaiser Commission on Medicaid and the Uninsured

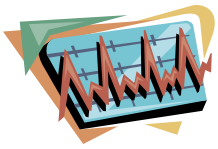
low-income Hispanic families and a business sector with no strong tradition of employee benefits.

For a while, however, there was a serious effort to overcome these obstacles. After waiting until 2000 to implement its SCHIP program, Texas received deserved accolades for a massive expansion in which 500,000 children received new coverage through SCHIP and another 335,000 were added to the Medicaid program by 2002. Enrollment was simplified, Spanish-language outreach was initiated, and documentation requirements were eased. Medicaid officials reported a significant decline in the use of emergency rooms and county indigent care programs—settings where the uninsured often access their medical care.

But with its budget in trouble, and with a statewide aversion to new taxes, Texas has retreated. It reduced eligibility levels for pregnant women on Medicaid from 185 percent of poverty to 158 percent. It imposed asset limits and added a requirement that families on SCHIP re-enroll every six months, rather than once a year. One of the changes with the most impact is a new 90-day delay in starting coverage for children after they're determined to be eligible. This delay includes newborns as well. "It is unconscionable that crucial health care be delayed for an eligible newborn as a cost-saving measure," says Straw, of the March of Dimes. In all, the package of restrictions enacted by the legislature reduced SCHIP enrollment in Texas by about 54,000 children in the last six months of 2003.

Texas also increased both premiums and co-payments for SCHIP families—an action taken by many other states as well. By April 2003, 31 states were charging premiums to SCHIP families, and 22 states were requiring co-payments. This is significant, because studies have shown a steep fall-off in the use of medical services when low-income families are charged co-payments or fees. So far, this tactic has not been applied to Medicaid, which has traditionally been protected from significant cost-sharing requirements under federal law. But this may change. Washington State has asked for permission from the federal Centers for Medicare and Medicaid Services to charge premiums to families on Medicaid as well as those on SCHIP.

All this has been occurring at a time when federal dollars available for child health are declining as well. Between 1998 and 2001, states were allotted $4.3 billion in federal dollars for SCHIP coverage annually. As a number of states got a slow start in ramping up, there was more than enough money to go around in the early years of the program. But that won't be the case from now on. In 2002, 2003 and 2004, total federal dollars were reduced to $3.1 billion annually. New Jersey and Rhode Island have reported that they may run out of federal funds this year, with Alaska, Arizona, Maryland, Minnesota, Mississippi, Nebraska and South Dakota likely to have similar problems in 2005.



## Complications

Finding the money to insure children for health care is only half the battle. The other half is ensuring that there are physicians available who are willing to take the cash that's been offered. Even in good economic times, compensation to physicians hasn't kept pace with inflation. In tough economic times, things get worse, with states actually freezing or cutting back on payments to doctors and managed care plans. Many states, including Alabama, Georgia, Mississippi and Texas, have taken this path.

In general, the move to managed care has improved access for poor children and their families, but managed care organizations are in trouble in many states and failing outright in some. In states that rely on traditional fee-for-service compensation, reimbursement rates are sometimes so low that doctors decline to take on Medicaid patients.

When the American Academy of Pediatrics surveyed 13,000 pediatricians about their participation in the Medicaid program in 2000, they found that low reimbursement was one of the dominant reasons for limiting participation in Medicaid. Even before the economy faltered, more than half the pediatricians surveyed said Medicaid payments did not cover overhead. Since then, the situation has gotten worse. According to Steve Berman, director of Children's Outcomes at the University of Colorado School of Medicine, only 19.1 percent of pediatricians in private practice are now accepting all Medicaid patients in Colorado—down from 41.4 percent in 2000.

Adjusted for inflation, physician reimbursement rates in California's Medi-Cal program declined 54 percent between 1985 and 2001. After more recent efforts to cut reimbursement, the state was hit by a lawsuit that was launched against California by a coalition of professional medical organizations whose members serve children.

Cutbacks in reimbursement have a significant impact on access to care. A study in 2001, published in the journal *Pediatrics*,

looked at the difficulty in obtaining treatment for a child covered through Medi-Cal, compared with one covered by private insurance. Researchers called the offices of 50 orthopedic surgeons, asking for a follow-up appointment for a 10-year-old boy with a broken arm. When researchers described the boy as having private insurance, all the offices gave him an appointment within seven days. When offices were told that he was on Medi-Cal, only one of the 50 offices offered an appointment within seven days, and 47 refused him entirely. Only 13 percent of the offices that turned him away were able to recommend another office that would accept Medi-Cal.

Children's access to private pediatricians under Medicaid varies wildly from one state to another. In Massachusetts, North Dakota, South Dakota, Vermont and Wyoming, more than 90 percent of primary care pediatricians in private offices took all Medicaid patients, according to the American Academy of Pediatrics survey. But in California and Oklahoma, this was true of only 34.5 percent and 31.8 percent, respectively, and in Tennessee, the number was 18.8 percent.

Meanwhile, there are multiple problems throughout the states with Medicaid administrative systems. Doctors complain that it is difficult to get through via online systems to confirm that children are eligible and are not clients of someone else. Referrals require heavy paperwork and in some states, including Alabama and Tennessee, unpredictable or delayed payments are a problem as well. In the American Academy of Pediatrics survey, 39.4 percent of pediatricians regarded "paperwork" as a very important reason for limiting participation in Medicaid. But this criticism also varied a good deal among the states. In Florida, Mississippi, Nevada, New Jersey and Pennsylvania, more than half the pediatricians who responded complained about a paperwork problem. In Montana, Rhode Island, Vermont and Wyoming, fewer than 20 percent did.

## Remedies

### Targeting Acccess

Cutting back on access—either by freezing enrollments or cutting reimbursement rates—is not a choice states have taken happily. But it's a choice they were willing to make as a means of bringing budgets closer to balance. Children's health is universally seen as a worthy cause, but the fact remains that SCHIP and Medicaid families are not a very strong political constituency anywhere in the country.

Still, some states are doing better than others. Despite severe budget problems, Virginia simplified its application forms in 2002, instituted a joint form for SCHIP and Medicaid, and started new outreach efforts, with Governor Mark Warner going on what he called "a road show" to community fairs and churches to encourage families to sign up their children. The result by mid-summer 2003 was an additional 50,000 children enrolled.

Illinois last year increased coverage in its SCHIP program from 150 to 185 percent of poverty, adding an additional 20,000 children. Louisiana increased eligibility levels for pregnant women to 200 percent of the poverty level, and now covers a total of 600,000 children through either Medicaid or SCHIP, nearly twice as many as it covered five years ago. "We don't have uncoordi-

## Out of the Loop

Percentage of children under age 18 with health care access problems, by select characteristics, 2001

| | NO HEALTH INSURANCE COVERAGE | UNMET MEDICAL NEED | DELAYED CARE DUE TO COST | NO USUAL PLACE OF CARE | 2 OR MORE E.R. VISITS IN PAST YEAR | UNMET DENTAL NEED | 5+ YEARS SINCE LAST DENTAL CONTACT |
|---|---|---|---|---|---|---|---|
| **ALL CHILDREN <18** | **10.4%** | **2.6%** | **4.1%** | **5.1%** | **6.8%** | **6.7%** | **14.8%** |
| FAMILY STRUCTURE | | | | | | | |
| Mother and father | 9.3 | 2.1 | 3.3 | 4.4 | 5.7 | 5.8 | 14.9 |
| Mother, no father | 11.9 | 3.9 | 6.2 | 6.4 | 10.6 | 10.2 | 15.1 |
| Father, no mother | 19.2 | 4.0 | 8.4 | 9.9 | 6.1 | 6.1 | 13.6 |
| No mother or father | 18.5 | 3.1 | 1.8 | 10.4 | 8.0 | 3.4 | 12.8 |
| POVERTY STATUS | | | | | | | |
| Poor | 18.4 | 4.8 | 6.0 | 9.8 | 10.9 | 12.8 | 19.8 |
| Near poor | 16.9 | 4.6 | 7.2 | 7.1 | 8.5 | 11.7 | 19.5 |
| Not poor | 4.4 | 1.4 | 2.8 | 2.4 | 5.6 | 4.5 | 12.3 |
| REGION | | | | | | | |
| Northeast | 5.4 | 1.7 | 3.4 | 1.1 | 6.1 | 5.6 | 11.7 |
| Midwest | 6.3 | 2.4 | 3.9 | 3.9 | 7.1 | 6.3 | 12.4 |
| South | 13.3 | 3.3 | 4.4 | 5.9 | 7.8 | 7.2 | 17.4 |
| West | 14.0 | 2.4 | 4.4 | 8.6 | 5.6 | 7.3 | 16.0 |

Source: National Center for Health Statistics, Centers for Disease Control and Prevention

nated care anymore," says Louisiana Health Secretary David Hood. "We have a program that I hope is going to change both recipient and provider behavior."

A few states have revamped their organizational and management systems to ensure better access to medical care while keeping costs under control. Rhode Island stands out in this respect. Currently, about 5 percent of Rhode Island children are uninsured. The state's "Rite Care" Program covers those below 250 percent of the poverty level and guarantees benefits to their mothers for two years after delivery. The state's immunization rates and infant mortality rates are significantly better than the national average. One of the state's major achievements has been to narrow the gap in infant mortality between high-income and low-income families. In the 1990s in Rhode Island, the infant mortality rate for children receiving public health coverage dropped 36 percent.

One of the keys to Rhode Island's success has been an organizational structure in which a "Children's Cabinet" crosses departmental boundaries. "The nature of government is to be insular and not look across many sections of government," says John Young, the state's Medicaid director. "But that's been our effort."

Rhode Island relies heavily on a managed care approach for meeting children's health care needs. Early on, it established a consumer advisory committee to deal with concerns voiced by patient advocates about managed care, and this committee has helped to establish safeguards. The state has buttressed quality in its managed care health plans through the use of performance contracting—setting up clear expectations for what the programs are expected to accomplish and rewarding those that meet the goals.

To encourage lead screening, for example, Rhode Island offers bonuses to managed care plans in which most physicians test for lead. The most recent figures show that 79 percent of Rhode Island physicians perform this test—four times higher than the rate reported nationally in a 1999 study. The state Medicaid office has received an unusual waiver from the federal government to establish "lead centers" that will not only help treat poisoning cases but prevent new cases by making modifications to housing units.

### Alternative Treatments

Massachusetts, Minnesota and Wisconsin are also making effective use of performance measurement in children's health. Wisconsin has been at it longer than anyone else, and its establishment of clear expectations for health plan performance has had obvious results. Four Wisconsin health plans that offer Medicaid service are among the top 15 performers nationwide, according to the National Committee for Quality Assurance, which rates both commercial and Medicaid plans.

"This is all consistent with the tenets of value-based purchasing," says Michael Bailit, a private health care consultant. "You reward them if they do better and penalize them if they don't do well." New York State rewards plans that have higher percentages of doctors who screen young patients for vision, dental, hearing or developmental problems by sending more patients their way. It publishes statistics on the Web that compare individual plans on a variety of measures. Utah and Wisconsin withhold some portion of a health plan's compensation if it does not meet screening standards for lead exposure, developmental problems or vision difficulties.

Arkansas, Maine and Florida also make good use of information in their primary care case management, each in different ways. Arkansas produces a "physician report card" so doctors can compare referrals, hospitalizations and emergency room use in their own practices to those of other primary care physicians. Maine has a primary care physician incentive program that measures such topics as well-child visits and immunizations and provides bonuses to doctors who can demonstrate high performance. Florida has established training programs to keep providers informed about their screening responsibilities, and has attacked the problem from the client side as well by sending letters to parents to remind them when their children are due for tests.

Why don't all the states rely more heavily on this model? Primarily for one reason: Many of them lack the ability to turn the numbers generated by managed care plans into useful data from which standards can be derived. "The Achilles heel is having the information support technology and staff to mine and use the information," says Kip Piper, a consultant and former Medicaid director in Wisconsin.

## Prognosis

The states are now at a crossroads in children's health coverage. If their revenues revive, and efforts are renewed to make sure needy children and pregnant women receive care, it's likely that the recent difficulties will be remembered as an unfortunate and painful episode—but not a calamitous one. If, however, the trend toward short-term cost cutting continues, the inefficiencies of this approach will become crystal clear. Those states that continue to diminish the number of children receiving quality health care will not only wind up with sicker kids, they'll wind up with chronically diseased budgets in the future.

Plenty of data backs up this point of view. A study published in November in *Pediatrics* noted that some $17 billion is spent in the U.S. annually on unnecessary hospitalizations. The study, which surveyed parents and doctors of children admitted to Boston Medical Center over a 14-month period, found that between 13 and 46 percent of the admissions could have been avoided with better care at home or by primary care physicians.

Many states have reported a decline in emergency room use when children are provided with their own doctors. The year after the Rite Care program started in Rhode Island, both hospital days and emergency room use decreased by one third—a result that has been found in a number of other states and studies as well.

"If you introduce a child at a young age to a primary care physician and not the emergency room, it has a long-term effect on the behavior of your population," says Newell Augur, director of legislative and public affairs for the Maine Department of Human Services. "It sets a framework for your future medical costs and savings."

# States That Stand Out

## SUCCESS STORIES

### Alabama

Although sub-par in many health indicators, Alabama has a good statewide children's dentistry program. By working closely with professional dental groups, the state has been able to target the problems that keep dentists in other states from treating Medicaid patients: rejected claims, no-shows and low payment rates. Since the official kickoff of Smile Alabama in 2000, 260 providers have been added to the program, and 50,000 more children have received dental care.

### Illinois, Louisiana and Virginia

Although none of these states has been a leader in child health in the past, all three made it a priority last year, countering the national trend to pull back. Illinois expanded participation in its KidCare program by 20,000. Virginia increased outreach and adopted new policies aimed at simplifying the enrollment process, and Louisiana increased low provider rates, boosted eligibility levels for pregnant women and continued to expand primary care case management.

### Maine, Minnesota and Wisconsin

These states stand out in using information to improve their child health programs. Managed care organizations in Minnesota and Wisconsin are offered financial incentives for improved performance. Maine approaches individual practitioners with the same techniques, an even more difficult feat.

### Massachusetts

In a poll conducted by the American Academy of Pediatrics, Bay State pediatricians complained far less than doctors in most other states about heavy paperwork, low reimbursement or unpredictable payments. The state has one of the country's highest pediatric participation rates in Medicaid, one of the lowest infant mortality rates and the highest rate of immunizations.

### Missouri, New Hampshire, New Jersey and Vermont

These four states expanded their children's coverage well beyond that of most other states—and have so far avoided the temptation to cut back on children's programs despite fiscal shortfalls. Missouri and New Jersey have cut back substantially on parents' coverage, however.

### Rhode Island

Rhode Island has the best record in the country at providing women with prenatal care. Credit goes to its Rite Care program, which has improved children's health generally. The key to this managed care effort comes in setting standards for provider performance and then following up to see that they are met. Attention to pre- and post-natal care results in lower infant mortality.

## TROUBLE SPOTS

### Alabama, Colorado, Florida, Montana and Utah

All five states have frozen enrollment in the Children's Health Insurance Program. This avoids hard decisions as to who should be included by simply closing the door on new applicants, regardless of how needy they may be. Since these states have Medicaid programs that provide eligibility only at the minimum levels, the freezes impact children from the poorest families.

### Connecticut, Indiana, Nebraska and Washington

These four pulled back on the length of time children retain their eligibility for Medicaid. They had provided 12 months of continuous coverage but have now reverted to a six-month eligibility period. This increases administrative costs and adds to the "hassle factor" for families. The states will save money when more children drop off the rolls at renewal time, but studies suggest that it may be the poorest who lose coverage.

### Nevada

While Nevada offers relatively limited benefits, maintains low eligibility levels and has the second highest rate of uninsured children in the country (19.3 percent), the state nevertheless treats its doctors with unusual generosity, reimbursing them better than most other states. "We didn't do a good job of managing our fee schedules," the state's Medicaid director admits. Nevada tried to pull back on those rates last year, but pediatric specialists and obstetricians threatened to boycott the Medicaid program, and government officials backed down.

### Texas

Far more children lack health care coverage in Texas than in any other state—about 23 percent of the population under 19. Efforts to expand coverage through SCHIP looked promising. But in the past year, the state has taken steps to cut costs, instituting waiting periods for coverage, creating an asset test for new enrollees and changing the rules for income calculation in a way that makes it more difficult to qualify.

# Bitter Pills

*Diagnosis*

**A little over a decade ago, Medicaid spent $5 billion a year on outpatient drugs. The tab is now an overwhelming $30 billion a year, with help from the new Medicare reform law an iffy proposition at best.**

WHEN ASKED TO NAME THE PRIMARY FACTORS contributing to the dizzying growth rate of state health care expenditures in 2003, 40 states fingered prescription drugs. Regardless of where drug costs rank on their list of ills, all 50 states have been actively working on plans to curtail the growth of their spending on pharmaceuticals, especially within their Medicaid programs.

The drug problem has become particularly acute in the past five years. Medicaid payments for outpatient prescription drugs rose more than 18 percent annually between 1997 and 2000, far outstripping the 7.7 percent annual growth for total Medicaid expenditures over the same period.

While nobody is actually forcing the states to pay for outpatient prescription drugs for their Medicaid recipients, all do. "That has not been considered controversial," says Richard Cauchi, a program manager for the National Conference of State Legislatures. "Drugs are considered a cost saver."

It doesn't take an M.D. to see, for instance, that it's a lot less expensive to provide daily insulin injections for a diabetic patient than it is to pay for weeks of hospitalization that can follow an acute diabetic coma. That's long been the case. The new wrinkle today is that innovative drugs have come on the market that offer alternative treatment for ailments that used to require surgery or other therapies—or that simply improve on existing medications. "It's hard to keep your arms around the problem and stay ahead," says Bob Sharpe, Medicaid director in Florida, "and that's because of new drugs, successor drugs and new uses for existing drugs."

Every pharmaceutical advance—however beneficial to the sick—costs money, and the costs of pills are rising faster than those for other goods and services. A recent study by Families USA found, for instance, that the price for the 50 medications most used by senior citizens rose at three times the inflation rate within one year. Between January 2002 and January 2003, eight of these medications increased in price more than 15 percent. Those include the popular antihistamine, Claritin, which increased 21 percent over that period, and Toprol, a beta-blocker used for various heart ailments, which went up 16 percent.

Another factor pushing up the price and use of drugs is advertising. Until the late 1990s, ads for prescription drugs had to include detailed information about their use and potential side effects. When those rules



JIM STARR ICONS (5)

# ART

TOM WHITE ILLUSTRATION

were relaxed in 1997, the pharmaceutical industry tripled its direct advertising to consumers, from $800 million to $2.7 billion in 2001. Anyone who has watched an hour of primetime television is intimately acquainted with the "purple pill," Nexium, whether or not they actually have acid reflux disease, for which the pill was developed.

Those ads have a direct effect on the Medicaid prescription drug bill. "Medicaid recipients are not immune to ads that show that with a certain drug you can run barefoot through a field of flowers," says Ray Hanley, former Medicaid director in Arkansas. "Patients want what they see on television. These drug ads drive demand for more expensive drugs than are needed."

Drug manufacturers take exception to such arguments. They claim that drug advertising is a reasonable way to educate consumers and that this can only help improve their health.

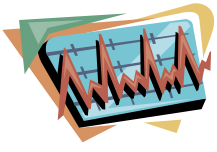
## Case History

More than half the drugs that Medicaid buys are for dual-eligibles—poor elderly or disabled people who receive much of their health care through Medicare but have their prescription drugs paid for by Medicaid. That's why, when the U.S. Congress began debating a Medicare reform bill with a prescription drug benefit at its heart, state officials thought there might be some deliverance from their prescription-cost woes.

The bill Congress finally passed and President George W. Bush signed into law in December did not fulfill those hopes. Had it simply shifted pharmaceutical costs from Medicaid to Medicare, it could have had potential savings for the states of $115 billion over the next 10 years. But a provision in the bill requires states to return 90 percent of the potential annual savings in 2006, the first year the legislation takes effect. The percentage declines over time, but the net benefit to the states will shrink to $17 billion over 10 years.

It may not even come to that much. The Medicare bill's drug coverage is inferior to what a number of state Medicaid plans offer. Some of those states will inevitably supplement the Medicare coverage with their own dollars, unmatched by the federal government. If that happens, some states may wind up spending more money on their dual-eligibles than they did before.

The Medicare bill could be problematic in a couple of other ways: It precludes Medicare from trying to obtain discounts through bulk purchases, and it rules out reimportation of drugs from Canada. While it's not certain that this will hurt states' efforts in those directions, it can't do them any good.



## Complications

Opposition to state efforts to control drug costs is vigorous, led as it is by the pharmaceutical industry and supported by many of those who do business with that industry. "You're probably dealing with more special interests and agendas in the pharmacy area than in any other health care field," says Hanley. "You've got manufacturers to deal with, pharmacists, advocacy groups and the physicians who write the prescriptions."

The Pharmaceutical Research and Manufacturers of America have been active in working to influence state policies—by going to court and by lobbying. "It's got to be that paying the lawyers and lobbyists costs less than the alternatives," says one knowledgeable observer. When a cost-control measure was being discussed in the Maine legislature, observers in the state joked that whatever the outcome of the debate, at least the hotels and restaurants in Augusta were thriving from all the expense-account lobbyists staying there.

"PhRMA has a very aggressive team of folks assisting government affairs people in each state to fight these initiatives," says Charles Duarte, the administrator of the division of health care financing and policy for Nevada. In his state, the pharmaceutical manufacturers were able to get their own bills before the legislature, successfully steering the process away from more extreme efforts to cut drug costs.

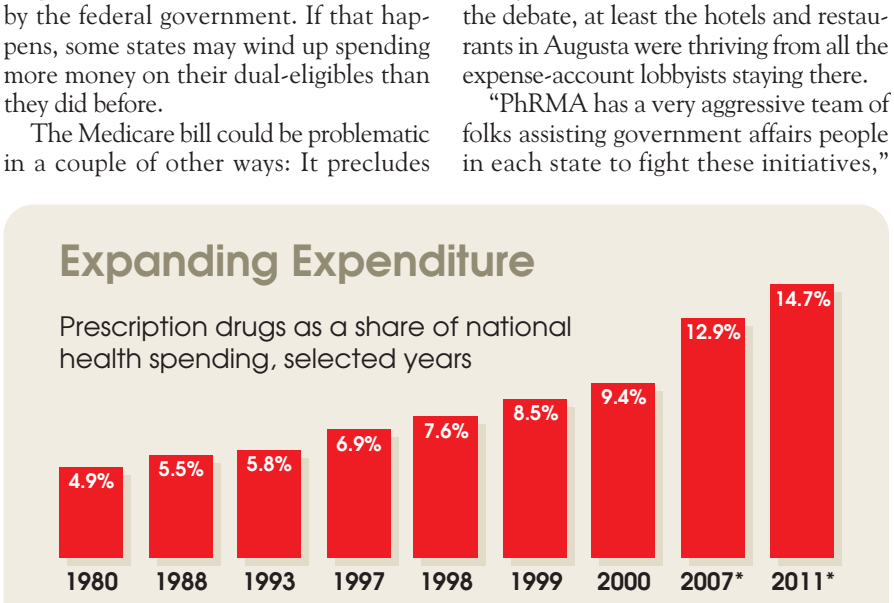
"They have an army of lobbyists," says Cheryl Rivers, executive director of the National Legislative Association on Prescription Drug Prices. "They contribute heavily to political campaigns at both the state and federal levels. And they fund front groups that purport to represent seniors."

## Remedies

### The Chosen Few

The maneuver that may well have the greatest potential for cutting the prescription bill is the preferred drug list. It may also be the most controversial.

A preferred drug list, as defined by the National Governors Association, "steers



Medicaid beneficiaries toward drugs that are therapeutically appropriate and less expensive." That is what California started to do in the early 1990s, when it became the first state to move down this path. "We basically thought the state ought to apply businesslike practices to get cheaper costs," says Stan Rosenstein, deputy director of the state's Department of Medical Care Services.

Here's how it works: An advisory group comes up with a list of approved drugs. Most of the criteria involve efficacy and safety, but cost is also taken into account. If two drugs are deemed to be equally useful for a specific treatment, the less expensive one makes it onto the list. As a result, manufacturers who want to be included often provide "supplemental rebates" to the state to get their products in the right price range. The rebates are supplemental in the sense that all drugs purchased by Medicaid programs are already discounted deeply by the manufacturers.

Of course, there are times when a drug that doesn't make it onto the list is clearly preferable for an individual patient. In those instances, states with preferred drug lists require that doctors or pharmacists call in for prior authorization from the state to utilize that medication.

The program had a rocky start in California and set off a great deal of controversy. Drug manufacturers, in particular, didn't like the idea; advocacy groups were wary. But some of that initial uneasiness has been ironed out and the program is, according to Rosenstein, "widely accepted by pretty much everybody." Taxpayers should be happy, too. The preferred drug list, along with its supplemental rebates, saves the state and federal governments $366 million a year.

Some states have allowed drug companies to get their products on preferred drug lists by coming up with alternative cost-saving programs. Pfizer, for example, cut a deal with Florida to put some of its drugs on the list in exchange for providing disease-management services for Medicaid patients with congestive heart failure, diabetes, asthma and hypertension. The state expects to save $33 million over the next couple of years from this arrangement.

As more states have followed California and Florida in developing preferred drug lists, PhRMA has fought hard, bringing a series of lawsuits based on the argument that such efforts "deny poor patients access to needed prescription drugs, forc-

## A Budget Buster

State spending on prescription drugs and Rx spending as a percentage of all Medicaid expenditures

| STATE | DRUG EXPENDITURES FY 2002 | PERCENT CHANGE 2001-02 | DRUGS AS % MEDICAID SPENDING |
|---|---|---|---|
| Alabama | $452,269,953 | 16.9 | 14.5% |
| Alaska | $70,820,710 | 20.4 | 10.1% |
| Arizona* | $3,754,074 | 45.0 | 0.1% |
| Arkansas | $273,258,152 | 13.1 | 12.1% |
| California | $3,588,682,134 | 20.2 | 15.3% |
| Colorado | $189,717,036 | 14.3 | 8.2% |
| Connecticut | $357,919,257 | 17.4 | 10.0% |
| Delaware | $97,750,161 | 20.4 | 15.4% |
| Florida | $1,719,583,398 | 16.5 | 17.3% |
| Georgia | $873,411,174 | 19.0 | 13.6% |
| Hawaii | $87,293,917 | 18.8 | 11.6% |
| Idaho | $119,177,013 | 15.7 | 14.9% |
| Illinois | $1,278,418,754 | 43.6 | 14.3% |
| Indiana | $631,637,846 | 12.5 | 14.3% |
| Iowa | $286,818,905 | 21.3 | 12.4% |
| Kansas | $210,476,558 | 10.5 | 11.4% |
| Kentucky | $652,904,065 | 10.3 | 17.1% |
| Louisiana | $715,521,536 | 22.1 | 14.5% |
| Maine | $220,156,654 | 14.8 | 15.1% |
| Maryland | $297,291,733 | 21.7 | 8.1% |
| Massachusetts | $962,188,017 | 20.5 | 11.0% |
| Michigan | $671,465,090 | 14.9 | 8.9% |
| Minnesota | $310,175,326 | 16.7 | 6.7% |
| Mississippi | $567,313,801 | 15.0 | 19.5% |
| Missouri | $790,665,732 | 17.1 | 14.8% |
| Montana | $83,587,410 | 15.2 | 14.2% |
| Nebraska | $207,796,832 | 21.6 | 15.1% |
| Nevada | $86,945,316 | 41.4 | 10.6% |
| New Hampshire | $99,682,997 | 8.7 | 9.7% |
| New Jersey | $690,055,943 | 5.2 | 8.9% |
| New Mexico | $73,877,785 | 27.4 | 4.2% |
| New York | $3,654,848,012 | 22.5 | 10.1% |
| North Carolina | $1,089,180,219 | 10.6 | 16.0% |
| North Dakota | $52,508,626 | 19.1 | 11.2% |
| Ohio | $1,334,136,463 | 21.3 | 13.6% |
| Oklahoma | $285,071,939 | 66.5 | 12.4% |
| Oregon | $279,047,125 | 22.1 | 10.8% |
| Pennsylvania | $718,204,613 | 3.7 | 5.9% |
| Rhode Island | $125,187,888 | 21.9 | 9.0% |
| South Carolina | $457,066,475 | 4.1 | 13.5% |
| South Dakota | $62,383,701 | 20.6 | 11.3% |
| Tennessee | $912,746,185 | 34.1 | 15.7% |
| Texas | $1,591,068,749 | 20.0 | 11.9% |
| Utah | $140,103,478 | 19.7 | 13.9% |
| Vermont | $114,157,870 | 9.5 | 17.2% |
| Virginia | $459,799,544 | 8.1 | 13.3% |
| Washington | $541,964,359 | 18.2 | 10.0% |
| West Virginia | $277,039,990 | 7.3 | 17.3% |
| Wisconsin | $443,594,557 | 15.5 | 11.3% |
| Wyoming | $39,130,761 | 24.2 | 14.1% |

*Arizona has a statewide managed care system. These figures reflect only the very small fee-for-service population.

Source: MEDSTAT Group Inc. from Centers for Medicare and Medicaid Services data

## Crossing the Line

PERHAPS THE MOST PUBLICIZED of current efforts to save money on drugs is the effort to import them from Canada, where they are dramatically cheaper than in the United States. Ironically, many of these drugs were manufactured in the United States in the first place. Thus, states that want to follow this path refer to it as the "reimportation" of drugs.

There doesn't appear to be any move to apply this approach to Medicaid, yet. That's because the state Medicaid programs already get hefty discounts on the drugs they purchase in the United States. But the concept has the potential to save significant sums on medications for state employees, retirees, prison inmates and others that the state covers. "There's no guarantee that Medicaid officials won't look into the possibilities here at some point in the future," says the NCSL's Richard Cauchi.

Two cities, Springfield, Massachusetts, and Montgomery, Alabama, have been conducting experiments with Canadian drug purchase plans. And about 10 states, including Illinois, Iowa, Minnesota, Vermont and West Virginia, have all considered heading down that path. But they've discovered a huge "Road Closed" sign posted by the Food and Drug Administration. Although the FDA has long ignored a steady flow of senior citizens crossing the border to buy Canadian medications, it stands firmly in the way of any broad-scale purchase of Canadian drugs.

The FDA's argument has been based on concerns about the safety of Canadian drugs relative to those in the United States. This argument has drawn fire. Representative Barney Frank of Massachusetts, for example, indicated that he was disinclined to take the safety argument seriously until he hears that "there are a large number of dead Canadians" who were killed by unsafe prescription drugs.

Illinois Governor Rod Blagojevich has been leading the pack to import cheaper prescription drugs, requesting a waiver that would permit the state to purchase Canadian drugs for its state workers and retirees. Estimated savings: more than $90 million a year. The state offered a number of measures to ensure safety of the drugs:

- No drug that was likely to spoil in transit would be imported.
- Orders for drugs would be placed with Canadian retailers that would supply only brand-name drugs in packages that were warranted as unopened from manufacturer to consumer
- Illinois laboratories would test the drugs
- Illinois pharmacists would act as gatekeepers to make sure patients didn't receive prescriptions that might create harmful interactions.

In December, the Bush administration made its objections clear. "It's absolutely illegal," Peter Pitts, an FDA associate commissioner, told *USA Today*. "There's no way importing drugs not FDA-approved can be legal in any way or form."

This was good news for drug manufacturing firms. For obvious reasons, they've long opposed reimportation of drugs. Some have even started raising their prices in Canada.

The feds, however, could loosen up. Although the new Medicare bill, signed into law in December, clearly rules out imports, it does authorize the Department of Health and Human Services to study the safety of Canadian drugs.

ing them to settle for older, less expensive and often less effective medications."

Although the drug companies have lost on all the principal points of the completed suits, there are unquestionably some powerful objections to preferred drug lists and supplemental rebates. For example, although states may argue that it is relatively simple for a doctor to get prior approval for any drug that's genuinely warranted, that may not be the case in the real world.

"If a drug is subject to prior authorization, often the pharmacist will just say, 'Sorry, it's not covered, go back and talk to your doctor and see if he can prescribe something else,' " says Sheldon Toubman, staff attorney of the New Haven Legal Assistance Association. "Or the pharmacist might call the doctor and do the same thing, but rarely." According to Toubman, what happens next depends on who's getting the prescription filled. The healthy mother of a sick kid is likely to be aggressive in actually getting the proper medications, but a disabled person, who might have had difficulties even getting to the drug store, may find revisiting a physician daunting. Or someone on psychiatric medicine may not want to be on that drug in the first place and so may not pursue an alternative.

It's not realistic to expect doctors to know whether a medication is on the preferred drug list, Toubman says. HMOs and insurance companies have their own lists of preferred drugs, which differ from one another as well as from those created by the state. And at any one time, there are literally thousands of drugs going on or off the lists.

Moreover, in some states, there's a powerful suspicion that some drugs aren't included on the preferred drug list primarily because of price, even though the states claim that price is the last, not the first, criterion.

One approach that addresses that concern is to use evidence-based analysis. This leads states to apply great rigor in compiling information about the most effective and efficient drugs to use for any individual purpose. Oregon, which doesn't require prior authorization, has been leading the way on these efforts. The state's Health Resources Commission has been charged with determining within drug classes what is the most effective medication, and it has subcontracted with the Evidence-based Practice Center at Oregon Health and Sciences University to analyze the research that's been done. The commission also accepts information from the drug manufacturers. "There's a real scientific rigor to

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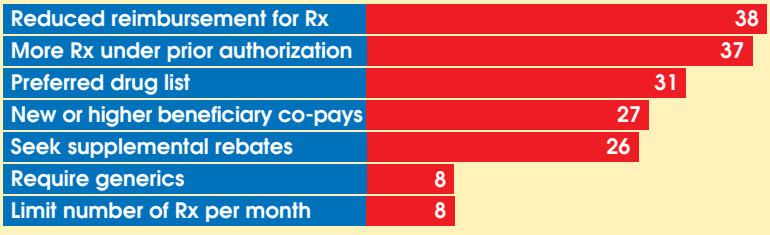
the process that is used," says Lynn Read, Medicaid director in Oregon. "And it's done in an open forum."

Washington and Idaho are among the states taking the same route, as is Missouri. How the state approaches the program is key, says Christine Rackers, Missouri's Medicaid director. Had Missouri proposed the approach strictly as a cost-savings measure, "it would have been dead on arrival," she says. "But we're just applying what the research studies show is best for this disease, given the drugs that are available. That's definitely sold much better."

Meanwhile, former Oregon Governor John Kitzhaber is part of the Evidence-based Practice Center at OHSU and is working to bring other states into the fold. By pooling resources from many states, Kitzhaber reasons, researchers will have the wherewithal to expand the number of categories of drugs they look at, and states can avoid "reinventing the wheel."

## Reining in Rx

Number of states adopting or expanding pharmacy cost-containment measures in FY2003 or 2004 budgets




Source: Kaiser Commission on Medicaid and the Uninsured survey, Sept. 2003

### Going Generic

Somewhat less contentious than the preferred list is the move to encourage doctors to prescribe generics instead of brand-name drugs. This approach has been around for more than 30 years, but it's gained steam in the past five or six. In fact, almost every state has adopted laws and regulations that encourage either the generic or therapeutic substitution of drug products. In 2003, nine states moved to toughen up the emphasis on the use of generics legislatively: Colorado, Maine, Maryland, Minnesota, Nebraska, Nevada, New Jersey, Rhode Island and Virginia.

New York's generic-drug program, like that of a number of other states, requires that physicians get prior authorization for most brand-name drugs when a therapeutically equivalent generic is available. The state anticipates savings from the mandate to be in the $20 million range for 2004.

Clearly, any plan that restricts the drugs available to Medicaid beneficiaries is going to dissatisfy some. The Medical Society of the State of New York, for example, came out against the state's mandatory generics program. A spokesman for the group, which represents 27,000 New York physicians, says that the government should not "make clinical decisions" as to what is best for the patient.

### Cheaper by the Dozens

Bulk purchasing of drugs is another increasingly popular approach. The concept is simplicity itself. States buy pharmaceuticals for a variety of groups in addition to Medicaid beneficiaries, including their own employees. Combining these purchases gives states the potential to bargain with what traditional retailers call a big pencil: They can push the pharmacies to provide far steeper discounts than would otherwise be available.

Delaware has been a leader in this area. All totaled, the drug needs of its Medicaid patients and state employees make up about one-third of the entire pharmaceuticals market in the state. When Delaware decided to negotiate with pharmacies in the state on behalf of both of those groups combined, it was able to get dramatically better prices. The savings, so far, have amounted to $3.5 million.

How did the pharmacies react? Recalls one state official, "They didn't exactly jump up and embrace it," but eventually, when they recognized that because of the state's financial stresses even more draconian options were possible, "they suggested other ways we can save money, which was a very fruitful effort."

Maine tried to take this same concept in a slightly different direction. The idea there was to use the volume purchases made by Medicaid to help make drugs more available for a portion of the state's population that needed financial help in purchasing drugs but wasn't poor enough to qualify for Medicaid. On the last day of the Clinton administration, the state was granted a demonstration waiver for its Healthy Maine prescription program that allowed up to a 25 percent discount on drugs available to families below 300 percent of the poverty level. The program went into effect in 2001, but a year later, a PhRMA lawsuit led the federal appeals court to strike it down, based on a technicality.

A similar effort called Maine Rx was held up for three years while it wended its way up through the court system, ultimately gaining a hearing before the U.S. Supreme Court. Having survived that test, the program was somewhat modified, becoming Maine Rx-Plus. This authorized the state to negotiate with pharmaceutical companies to get the best price available for its low-income non-Medicaid population, based on the state's total buying power. It was scheduled to go into effect at the beginning of January. But Maine officials delayed the program by a couple of weeks while they scrutinized the new Medicare prescription drug bill.

Another approach to bulk purchasing is to form a multistate pool. A number of states have considered putting together or joining such a group. Michigan and Vermont are the first to do it. "Clearly," says Giovannino Perri, Michigan's chief pharmacist, "the more states involved, the more pressure there would be on the pharmaceutical manufacturers to offer a good price."

The potential of multi-state plans is enormous. As a result, the drug companies haven't been friendly to these efforts. As Perri points out, "If you put all the Medicaid programs together, it's the single biggest purchaser of pharmaceuticals in the country. So, there is a large market. And I think that does pose a threat to the manufacturers."

### Mining the Data

By definition, there's a huge amount of information available about prescription drugs: Every pill used by a Medicaid recipient—or anyone else for that matter—

AD

## Price Hikes

Percentage price increase in five commonly prescribed drugs, 1998-2003

| | |
|---|---|
| Lipitor | 30.8% |
| Prilosec | 22.5% |
| Paxil | 31.7% |
| Synthroid | 63.6% |
| Zoloft | 19.6% |

Source: Families USA

tracks back to a prescription written by a doctor, which is entered into a computer database by a pharmacist. As a result, there's a gold mine of data available for analysis, and a growing number of states have realized that this effort can lead to financial savings.

Arkansas uses that data to link pharmacy claims to physician claims. With that information, the state profiles physicians on their prescription patterns and shows them how they compare with their peer group. The state also sends physicians with brand-name prescription preferences a letter to show them how much their brand-name prescriptions were costing, as opposed to generic prescriptions. Hanley points to typical differentials of $25,000 for brand-name drugs versus $6,000 if that physician had written prescriptions for generic drugs.

Arkansas also developed a physician-support program that allows the state to profile claims by diagnosis. For example, the state can pinpoint where its diabetes patients live. Diabetes consumes about one out of seven health care dollars, Hanley notes. "So, after we identified the patients, we brought in Eli Lilly, and they funded the creation of certified diabetes centers." Patients are enrolled at the education centers, which then work with them on particular diabetes issues and see whether individual targeted interventions help improve the patient's health and also help save money.

The state of Washington is moving in a similar direction. It has had point-of-sale information for decades, but outdated state technology precluded it from using the resultant data to help manage its prescription drug costs. The solution was to hire a firm to load point-of-sale information into a data warehouse that can analyze the information. "We'll be able to track, by doctor, who is prescribing in accord with the state's preferred drug list and who is not," says Doug Porter, the state's assistant secretary of medical assistance. Additionally, the state can now tell which physicians are overprescribing and then teach them how to help the state save money through better prescription practices.

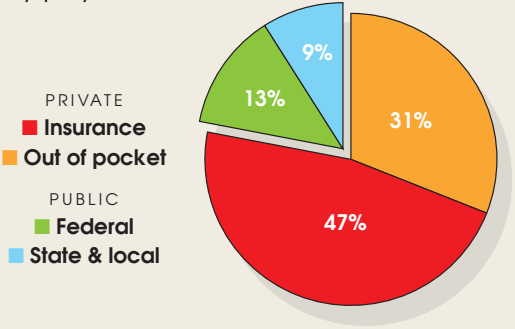
### Small Fixes

Since many medications cost about the same regardless of the dosage—a 40 milligram pill costs the same as an 80 milligram pill for certain medications—states can save money if pharmacists prescribe the bigger pill. One anti-psychotic, Giaron, for example, costs roughly $4 per pill, regardless of strength. Prescriptions for Giaron often call for patients to take a 40-milligram capsule twice a day, but one 80-milligram capsule would be just as appropriate. North Dakota is using this approach, and obviously, it works only for medications that can be safely prescribed at higher doses and won't compromise patient care.

The same logic led North Dakota to its "tablet-splitting initiative." Under this program, the state again looked at products that are priced the same across a realm of strengths. It then told pharmacists it would pay them an extra 15 cents a pill for cutting it in half, if the pill had scoring so that the pharmacist could safely do so. A 100-milligram tablet of Zoloft is $2.45, for instance, as is a 50-milligram Zoloft. When the pharmacy splits the tablets, the patient gets two 50-milligram doses for the price of one.

## Paying the Tablet Tab

$140 billion in national retail prescription drug spending by payor, 2001




Sources: Centers for Medicare and Medicaid Services

## Prognosis

"Everyone is trying everything right now with prescription drugs," says Washington State's Doug Porter. "The silver bullet has yet to emerge."

Most of these efforts are sufficiently untested that there simply aren't solid statistics to demonstrate their long-term benefits or potential side effects. Pointing to preferred-drug lists, Josh Weiner of the Research Triangle Institute, notes that the programs probably save money "but I couldn't point to an evaluation that knows that's true in the long term." He adds that the approach might also reduce access to needed drugs by certain populations. "Hard to say whether that's so or not," Weiner says. "I can't point to any study that proves it is or isn't a problem."

One truth emerges: Some combinations of the schemes to hold down drug costs are here to stay. Many, in fact, are not particularly different from those that the private sector has long been using. "Corporations restrict access to certain drugs," says Brandeis University's Michael Doonan. "They have prior authorization. They have co-payments. In fact, state employees are facing increasing co-pays."

States simply cannot afford to continue paying for rapidly escalating prescription drug costs. The dam has burst. And 50 states and their governors are trying to make repairs before education, public safety and other health care needs are swept away in the tide. "There's a point where publicly funded programs will be overwhelmed," says John Chappuis, Montana's Medicaid director. G

# States That Stand Out

## SUCCESS STORIES

### Arkansas

Arkansas has been at the forefront in using technology to profile physician prescription patterns and detail claims by diagnosis. The benefits include the capacity to identify physicians who could be prescribing drugs more cost effectively.

### California

California pioneered two effective but initially controversial protocols for its Medicaid program: preferred drug lists that limit the medications available without prior authorization and supplemental rebates that require drug companies to cut prices even lower than the mandated Medicaid rebates in order to get on the preferred lists. These practices are now used by almost all states; in California, they produce $366 million a year in drug savings.

### Delaware

The larger the purchase, the greater the leverage in obtaining discounts. Delaware has taken advantage of this shopper's fact of life by combining its pool of Medicaid patients with its state employees to create a buying entity that accounts for one-third of the entire pharmaceutical market for the state.

### Florida

The Sunshine State is attacking escalating drug prices with more programs, more quickly, than any other state. Over the past two years, Florida has reduced spending by $500 million through a preferred drug list, data management, use of counterfeit-proof prescription pads, restricting some beneficiaries to just one pharmacy and deals with manufacturers to finance value-added programs for the state.

### Idaho, Missouri, Oregon, Washington

All three northwestern states have contracted with the Oregon Health and Sciences University to use "evidence-based analysis" to help guide decisions on pharmaceutical use. Missouri also has been a frontrunner in using this scientific approach, which takes a long-term view in analyzing the efficacy of drugs. The idea is to use solid research to make sure that short-term price advantages don't eliminate drugs that may be more beneficial, and cost-effective, over time.

### Michigan and Vermont

In 2003, the Medicaid programs in these states joined together in a purchasing pool. The pool utilizes a uniform preferred drug list in its negotiations with drug manufacturers. Although other states have discussed similar arrangements, these two are the first off the drawing board.

## TROUBLE SPOTS

### California

The internal controls necessary to ensure that drug rebates from manufacturers supplying medicines for the Medicaid program are accurately calculated and collected fall short in many states, but California has one of the biggest problems of them all. A recent audit suggests that there is currently more than $1 billion in uncollected rebates, but since the state can't reconcile its records or support that figure, its chances of collecting are low.

### Kentucky

Medicaid officials have done a lot to control drug costs, but ran into one roadblock last year that illustrates how difficult cutting costs can be. The Board of Pharmacy rejected a mandatory pill-splitting initiative, arguing that it compromised pharmaceutical professionalism. The drugs, which cost the same in varying strengths, were all already scored by manufacturers, and splitting them would have enabled the state to deliver twice the medicine at the same price. The state now has a voluntary program.

### Massachusetts

Although Massachusetts was the first state to legislate a bulk purchasing program—aggregating the buying power of the state's senior pharmacy assistance enrollees, Medicare and Medicaid recipients, state workers and under- and uninsured people—legislation hasn't equaled progress. Thanks to resistance from executive branch leadership and executive agencies, implementation has been on hold thus far.

### South Carolina

Managers would love to use data to better understand prescription patterns, but they're saddled with computer systems that are decades old. Like other states with aging technology, they have plenty of data but can't effectively use it.

### Tennessee

In the past few years, growth in pharmaceutical expenses in TennCare has outstripped the high growth in most other states. The differences in managed care plans were an administrative headache for pharmacists, and doctors and the state couldn't maximize rebates. In October, the state's first preferred drug list went into effect, which should help.

# Access Denied

*Diagnosis*

**Nearly 44 million Americans lack health insurance. It's a serious and chronic problem for those who can't afford care and for both the private sector and the states, which are left picking up the tab.**

HEALTH INSURANCE, and the growing lack of access to it, is a daunting national issue, one that congressional committees, presidents and presidents' wives have wrestled with—to no avail. Meanwhile, the situation continues to deteriorate. In 1992, there were 35.4 million uninsured people in the United States; a decade later, there were 43.6 million, with the biggest jump coming in 2001-02 when the rate rose 5.8 percent in that one year alone.

States want to reduce the ranks of the uninsured within their borders, and they keep trying—with very little success. Right now a bad situation is growing markedly worse in 18 states, with a small statistical improvement in only one. The rest have stayed stable, but stable is not exactly a good place to be. "The best thing we can say we've done for the uninsured is that we haven't created more of them," says Barbara Edwards, Medicaid director in Ohio, one of the states where the rates haven't changed.

The basic problem is systemic: The United States relies on the private sector to insure its citizenry, but that arrangement is being undermined by changes in the economy. There's been a migration of workers from benefit-rich manufacturing jobs to benefit-poor service jobs, and to small businesses, many of which do not provide any coverage at all. On top of that, the economic downturn that started in 2001 tore yet more holes in the net of coverage: Many people lost their insurance when they lost their jobs. Although the economy is recovering, job growth has not been impressive, and many employers continue to rely on temporary employees, who usually do not qualify for health benefits.

"Employer-based coverage is eroding at the edges, and that erosion is contributing to the growth in our uninsured population," says Diane Rowland, executive director of the Kaiser Commission on Medicaid and the Uninsured. In 2002 alone, the number of U.S. residents insured by their employers dropped by 1.3 million to 61.3 percent of the total population.

Lack of insurance translates into unfortunate outcomes for those without it: higher mortality rates, lost productivity, increased personal bankruptcies and the need for more expensive care when early signs of illness are ignored. "You see many more people coming in through the emergency room or with poorly managed conditions or later-stage diseases," says Benjamin Chu, president of the New York City Health and Hospi-



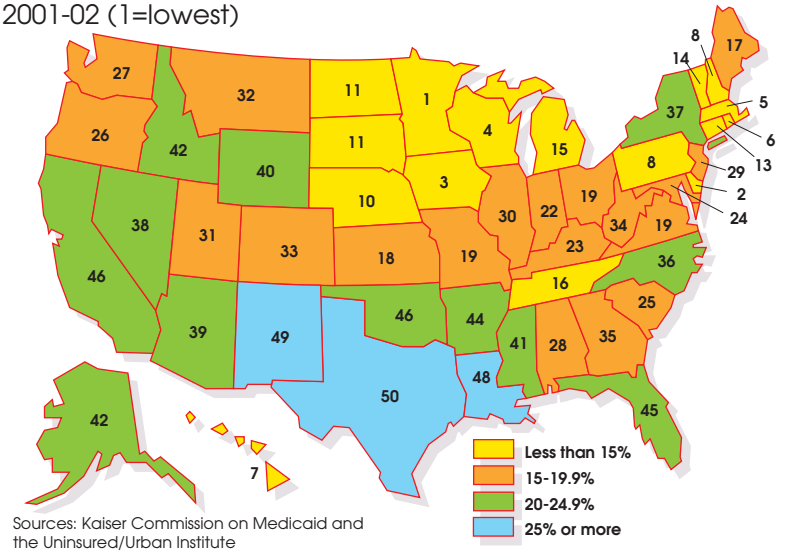
JIM STARR ICONS (5)

# ART

TOM WHITE ILLUSTRATION

## The Uninsured Landscape

States ranked by uninsured rates among adults under age 65, 2001-02 (1=lowest)




Sources: Kaiser Commission on Medicaid and the Uninsured/Urban Institute

tals Corp., the largest municipal hospital system in the country. The bottom line, Chu says, is that "the uninsured ultimately get care somewhere. They come to our system, and they contribute to a large bad-debt pool, and someone has to pay that."

Medical costs for the uninsured were about $60 billion in 2001. Of that, $35 billion was "uncompensated care," which means it was care not paid for by the patients.

Who foots the bill? State-financed public hospitals or charity hospital systems as well as nonprofits provide care to needy patients. That pressure on a hospital's balance sheet, however, translates into higher prices for paying patients, which in turn helps push up the cost of insurance premiums—making health insurance more expensive and putting a financial squeeze on the companies that provide it.

To defray some of the uncompensated-care costs, the federal government and the states chip in with special Medicaid payments for hospitals that serve large numbers of poor people. These are called "disproportionate share" payments simply because those hospitals serve a disproportionate share of the poor population. Hospitals also seek donations, and states and localities provide tax exemptions or credits, as well as indigent-care grants.

This patchwork of funding is a poor way to support a medical system. Medicaid's contribution through its disproportionate share program, for example, compensates hospitals but not necessarily in direct proportion to the number of uninsured they serve. "It's grossly inefficient. The distribution of these dollars across the states is very uneven," says John Holahan, director of the Urban Institute's Health Policy Center. "There are a lot of inequities and a lot of problems with it."

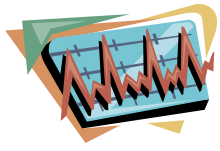
There are also administrative expenses. Lower-income individuals in particular may go off and on insurance several times during any given year. "If they fall off insurance, we send in a claim and the claim is denied," says New York Hospital System's Chu. "Then we spend a lot of time and manpower working on the denied claims. It's an administrative nightmare."

## Case History

Employer-based health care insurance was introduced in this country during World War II, when wage and price controls were in place and health insurance was a great fringe benefit that helped employers attract employees. Coverage expanded for 25 years. Then, in the 1980s, a slow contraction set in. Since foreign competitors didn't have the same obligation to their employees, U.S firms found themselves at a disadvantage in a global economy. "The general economic pressures of a world market made it more difficult for firms to continue the unabated growth of private, employer-based insurance," says Allen Koop, visiting history professor at Dartmouth University.

In the past decade, medical advances have continued pushing health costs higher, and these increased costs have made insurance increasingly unaffordable to businesses and individuals.

To lower their health care expenses, companies have begun forcing their employees to shoulder more of the load. The Kaiser Foundation's Annual Employer Health Benefit Survey for 2003 found that 65 percent of companies hiked the employee's share of the health premium in 2003, and 79 percent of large firms planned to do so in 2004. By 2003, employees reported paying 50 percent more for both individual and family coverage than they did in 2000. Some employees, particularly low-income workers and young adults, decided they couldn't afford to pay, or didn't want to, and dropped their health insurance.



## Complications

One of the biggest obstacles states face in expanding employer-based health insurance is ERISA. Passed by the U.S. Congress in 1974, the Employee Retirement Income Security Act was primarily intended to protect employees' pensions. But it also put employee benefits under the jurisdiction of the federal government and not the states. That meant a state could not mandate that all companies provide their employees with coverage, even if the political will to do so were there. "ERISA was enacted for a totally different set of purposes," says Kaiser's Rowland. "But it's become a fundamental barrier for states in dealing equitably with insurance plans and employers."

The only state exempted from ERISA's health care clauses is Hawaii, which passed its Prepaid Health Care Act a few months before ERISA was enacted and was, therefore, grandfathered in. Hawaii's law mandates that employers provide cov-

erage for any employee who works more than 20 hours a week. Not surprisingly, Hawaii's uninsured rate is among the lowest in the country. California passed a law this fall that also has mandates for employee coverage, but employers are challenging it in court, arguing that it is out of compliance with ERISA.

While employers have played the ERISA card in every state that has toyed with legislating coverage, people in general support the idea of employer mandates. A recent poll taken by Stony Brook University on Long Island found that 71 percent of respondents were in favor of the government requiring businesses to provide health insurance. Of course, that support would likely erode if businesses perceived the idea as a genuine threat and started to lobby heavily against it.

In any case, the current situation is putting pressure on small businesses and self-employed individuals to find bargain insurance plans. That demand is creating an opportunity for con artists who have flooded the market with fraudulent policies that charge very low premiums but have no intent of actually paying anything but small claims. Recently, Mila Kofman, an assistant research professor at the health policy institute at Georgetown University, looked at four health plans that were shut down by states or the federal government and found $85 million in unpaid claims for 100,000 individuals. "When you have a demand for affordable alternatives and there aren't any, you'll always have a criminal element providing the supply," she says. The U.S. General Accounting Office has been asked to do a study on this issue. The results are expected early this year.

## Remedies

### Small Business Boost

The weakest links in employer-based coverage are small and very small businesses. Among uninsured workers, 14 percent are self-employed and 49 percent come from businesses with fewer than 100 employees. Many states have tried to encourage small businesses to provide their workers with health insurance, with only limited success.

The latest—and arguably most ambitious—effort in the field is Maine's recently enacted Dirigo (the Latin for "I lead"). The plan, which begins implementation in July, is the "last best test of an employer-based system," says Trish Riley, director of the Governor's Office of Health Policy and Finance in Maine.

A key element of the multi-layered system is state-administered health plans for small businesses and the self-employed. Private insurers will provide the health coverage, with the state regulating rates. The state will also help with enrollment, eligibility determination, wellness programs and disease management. The assistance with administrative details, which will help eliminate employer hassle, is a vital element, Riley says. "They work through us. If we have to change insurers every year, it will be invisible to them."

Riley sees this as an important part of

## Tapping Into Health Benefits

Health insurance coverage, by type of provider, for adults under age 65, 2001-02

| | PRIVATE | | PUBLIC | | UNINSURED |
|---|---|---|---|---|---|
| | Employer | Individual | Medicaid | Other* | |
| Alabama | 67.8% | 4.3% | 7.0% | 3.9% | 17.1% |
| Alaska | 62.4% | 3.7% | 6.8% | 4.8% | 22.2% |
| Arizona | 61.1% | 7.1% | 6.8% | 3.7% | 21.3% |
| Arkansas | 58.8% | 6.6% | 6.5% | 5.7% | 22.5% |
| California | 59.7% | 7.0% | 8.0% | 1.8% | 23.5% |
| Colorado | 66.9% | 7.2% | 3.6% | 3.1% | 19.2% |
| Connecticut | 73.5% | 5.4% | 5.2% | 2.0% | 13.8% |
| Delaware | 74.1% | 4.8% | 6.5% | 2.9% | 11.6% |
| Florida | 60.9% | 7.3% | 5.8% | 3.2% | 22.8% |
| Georgia | 67.2% | 5.5% | 4.3% | 3.3% | 19.7% |
| Hawaii | 71.4% | 5.1% | 7.1% | 3.9% | 12.6% |
| Idaho | 63.2% | 5.5% | 6.7% | 2.4% | 22.2% |
| Illinois | 69.4% | 5.2% | 5.7% | 2.2% | 17.6% |
| Indiana | 73.1% | 5.0% | 3.7% | 2.3% | 15.9% |
| Iowa | 72.4% | 8.7% | 5.3% | 1.8% | 11.7% |
| Kansas | 69.9% | 7.5% | 4.3% | 3.2% | 15.1% |
| Kentucky | 68.3% | 4.4% | 6.2% | 4.8% | 16.4% |
| Louisiana | 57.9% | 5.8% | 6.7% | 4.1% | 25.6% |
| Maine | 66.6% | 4.7% | 10.6% | 3.0% | 15.0% |
| Maryland | 73.4% | 5.1% | 3.4% | 1.5% | 16.6% |
| Massachusetts | 71.7% | 4.9% | 9.8% | 1.4% | 12.1% |
| Michigan | 72.4% | 4.3% | 7.0% | 1.9% | 14.4% |
| Minnesota | 75.5% | 6.9% | 6.3% | 1.4% | 10.0% |
| Mississippi | 58.7% | 4.2% | 11.9% | 3.1% | 22.1% |
| Missouri | 69.5% | 6.5% | 6.3% | 2.2% | 15.4% |
| Montana | 56.7% | 12.7% | 6.7% | 5.3% | 18.6% |
| Nebraska | 68.3% | 10.9% | 4.8% | 2.8% | 13.3% |
| Nevada | 68.9% | 4.1% | 3.1% | 2.7% | 21.2% |
| New Hampshire | 78.1% | 3.5% | 2.9% | 2.4% | 13.1% |
| New Jersey | 71.8% | 3.2% | 6.1% | 1.5% | 17.4% |
| New Mexico | 55.0% | 5.1% | 7.4% | 4.3% | 28.3% |
| New York | 63.4% | 4.1% | 10.0% | 1.5% | 21.0% |
| North Carolina | 64.7% | 4.7% | 6.0% | 4.3% | 20.3% |
| North Dakota | 65.3% | 11.6% | 5.7% | 3.7% | 13.7% |
| Ohio | 72.3% | 4.5% | 5.9% | 1.9% | 15.4% |
| Oklahoma | 61.4% | 5.4% | 5.4% | 4.4% | 23.5% |
| Oregon | 63.3% | 8.2% | 9.4% | 2.2% | 16.9% |
| Pennsylvania | 72.8% | 5.5% | 6.9% | 1.6% | 13.1% |
| Rhode Island | 70.5% | 5.4% | 10.4% | 1.4% | 12.3% |
| South Carolina | 66.1% | 4.9% | 8.3% | 4.0% | 16.7% |
| South Dakota | 67.5% | 11.0% | 4.8% | 3.0% | 13.7% |
| Tennessee | 63.2% | 5.6% | 13.8% | 2.8% | 14.6% |
| Texas | 58.6% | 5.5% | 4.3% | 1.9% | 29.7% |
| Utah | 69.2% | 6.4% | 4.6% | 1.7% | 18.1% |
| Vermont | 67.1% | 6.5% | 11.1% | 1.5% | 13.9% |
| Virginia | 70.3% | 5.4% | 4.2% | 4.6% | 15.4% |
| Washington | 66.3% | 6.6% | 7.5% | 2.5% | 17.0% |
| West Virginia | 61.6% | 3.4% | 10.3% | 5.3% | 19.3% |
| Wisconsin | 73.1% | 6.8% | 6.2% | 1.9% | 12.0% |
| Wyoming | 65.0% | 5.6% | 4.5% | 3.2% | 21.7% |

*Medicare and military-related

Source: Kaiser Commission on Medicaid and the Uninsured

the program's appeal to a small business. She ran her own small enterprise for 15 years and says her problem with health insurance "wasn't just the high cost of the increases. It was the unpredictability."

The program also includes state subsidies to help with the purchase of private insurance, through employers, for those whose incomes would otherwise qualify them for public help. Those with incomes below 300 percent of the poverty level, and who don't have employer insurance, will still qualify for Maine Care, the state's Medicaid and Children's Health Insurance Program.

In an effort to control health care costs and thus keep insurance premiums affordable, the state imposed a temporary moratorium on capital expenditures for such things as new hospitals, enforced through its certificate-of-need program. When that moratorium ends in May, the state will explicitly limit the capital expenditures it is willing to finance on the public side. Meanwhile, the state has sought voluntary cooperation from the private side—both providers and insurers—to limit operating profits for a year and publicly post both prices and quality measures. A forum has been set up to monitor quality issues and act as a clearinghouse for evidence-based medicine.

This drive to erase the problem of the uninsured was a key campaign issue for Governor John Baldacci, who was elected in 2002. While the private sector, particularly hospitals, had muted enthusiasm for a number of Dirigo's elements, there's been a major effort to include diverse representation on the study commissions and task forces that are moving the program from idea to implementation.

In its first year of funding, the plan will be bolstered by $53 million in one-time state money. In the future, the state plans to use an assessment of up to 4 percent assessment on gross revenues of insurance companies. Eventually, this assessment may be reduced —"offset" by the elimination of bad debt and charity care, as well as other cost-containment activities. All payments—from employees, employers and insurers—will stream into the Dirigo Health Fund where the state hopes to use some of them to match Medicaid dollars.

### Pooled Purchasing

Several states have set up purchasing cooperatives for small businesses with the idea that these organizations could

eliminate some of the administrative hassle and improve bargaining power, thereby increasing rates of employee coverage. But states often find that their own regulations provide huge obstacles to negotiating good deals. In Florida, for example, state insurance rules prohibited the cooperatives from negotiating with insurers based on price, except for administrative costs. The latter just didn't make enough of a dent in the financial terms to persuade businesses to sign up.

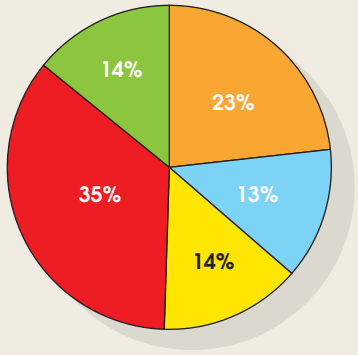
Texas also attempted to establish cooperative plans that would be marketed by the state centrally, thereby skirting the expense of insurance agents. But it turned out that agents are tied in to small businesses for a variety of financial services. Once bypassed, "they turned out to be a formidable adversary," says Linda Blumberg, senior research associate at the Urban Institute. One problem, she notes, was that alienated agents worked against the purchasing cooperatives by sending them high-risk individuals—the most expensive to cover. Eventually, the state decided it had to work with the agents, but as soon as it did, the cost savings went away, and there weren't real financial incentives for businesses to join the plans.

California probably has the most successful cooperative insurance program for small businesses. The program was started in the public sector and was subsequently privatized. Initially, the state set rules and negotiated contracts to provide businesses with two to 50 employees with up to 20 health plan choices and two levels of benefits. The actual operation of the program was left to private-sector vendors and health plans. Employers who participated loved it, but market share remained small. At its peak, only about 2 percent of small businesses that purchased insurance did it through this program.

In spite of good programs, California has seen an increase in the number of uninsured over the past two years and

## Burden on Business

Employees without insurance by business size, 2002




Sources: Kaiser Commission on Medicaid and the Uninsured/Urban Institute

# Two Grand Experiments

TENNESSEE AND OREGON both expanded coverage for the uninsured dramatically in the 1990s by remaking their Medicaid programs—and winning federal waivers to experiment with their approaches.

Tennessee moved most of its Medicaid system to managed care in one fell swoop in 1994. The idea behind TennCare was to use managed-care savings to provide enough money to expand Medicaid to cover Tennesseans whose incomes reached as high as 400 percent of poverty—a level of coverage way beyond what any other state had attempted.

Initially, TennCare appeared to be a national model as the number of uninsured Tennessee residents plummeted. But TennCare had managerial problems from its early days. A change in governors a year after the program's inception, unrealistic assumptions about cost and a very high rate of managerial turnover led to ongoing difficulties.

The major issue was the state's reliance on unstable and untried managed care organizations. At the basis of the program's philosophy was the use of capped fees, but following negotiations with the federal government in 2000, Tennessee leaders reverted to a partial fee-for-service system. Expenditures escalated by 15 percent in both 2001 and 2002 and 13 percent in 2003. A study by McKinsey & Co. in December 2003 concluded that on its current course, TennCare would eat up 91 percent of all new state tax appropriations by 2008. Even with improvement efforts and solid management, "TennCare as it is constructed today will not be financially viable," the study concluded.


Oregon took a very different tack. Rather than relying totally on controlling provider costs through managed care, it designed a plan to control costs by limiting types of care. The state set up a list of benefits in priority order—treatment for a heart attack was near the top of the list; surgery for back pain was much further down. When dollars ran short, the state would eliminate benefits from the bottom of the list, instead of cutting back on the number of people insured, which is one of the basic ways most Medicaid programs control costs when budgets are squeezed.


This bold plan provided coverage to adults age 19 to 64 who wouldn't otherwise be eligible for Medicaid. The federal government, however, was uneasy about overt rationing of health services—as opposed to the covert way of rationing through access to insurance. When Oregon needed to cut lower-priority benefits, the feds occasionally agreed but more often refused permission.

Currently, the state is awaiting approval from the Centers for Medicare and Medicaid Services to drop 30 lines of coverage, including treatment for earaches, incontinence and arthritis. "This will be a real test to see if CMS is willing to let us use that tool," says Lynn Read, Oregon's Medicaid director. If CMS denies Oregon's request, the underlying structure of the state's approach will be compromised. Meanwhile, faced with gigantic budget problems, Oregon has gotten tough about its requirement that adults who don't qualify for the traditional Medicaid program pay a modest monthly premium. If a payment is missed, the person loses coverage. As a result, enrollment of this group has dropped by about 45,000 individuals.

ranks a lowly 46th in the country on this measure.

### The Subsidy Approach

If states can't mandate universal coverage, they can help lower the rates of the uninsured by helping those in need pay the premiums for health insurance.

In Massachusetts, one innovative effort requires employers to pay into a fund that helps the recently unemployed buy their former employers' coverage through COBRA. The federal Consolidated Omnibus Budget Reconciliation Act requires many employers to offer continued health benefits to terminated employees. The former employees, however, must pay the premiums themselves—not necessarily affordable for someone who has just lost a job. Massachusetts will kick in with supplementary payments, so indi-

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viduals—even those with incomes as high as 400 percent above the poverty level—will have to pay only 25 percent of the COBRA premium.

Rhode Island and Massachusetts also are trying to promote the use of private insurance through subsidies. Rhode Island has had moderate success with Rite Share, its premium-assistance program. The program has identified about 5,300 people who have qualified for public insurance but who work for employers who offer private coverage. The state pays the employees' share of the premium so they can afford the private plan. This reduces the costs of coverage by about half. In Massachusetts, the premium-assistance program covers 10,000 to 12,000 individuals—substantially less than the 60,000 once anticipated. But the program, which provides subsidies to both employer and employee, is regarded as a qualified success and has continued a steady, if slow, growth.

### A New Tool

For several years, states have been able to use waivers to shift SCHIP dollars that were not spent on children to cover their parents. CMS is now approving a second generation of waivers that allows this money to go to childless adults as well. Money for hospitals that serve the poor—disproportionate share dollars—also can be shifted by states to expand insurance coverage for adults.

The waivers appeal to states because they provide more freedom to cut back on benefits and increase cost sharing as long as the individuals affected are not among the groups mandated to receive coverage. A few states, notably Arizona, Illinois and Maine, have taken advantage of this new opportunity with vigorous coverage expansions. But overall, the new waivers have had far less impact than was hoped, according to a December 2003 study from the Kaiser Commission on Medicaid and the Uninsured.

One of the big problems is that the new waiver program was introduced just as the economic downturn clicked in. California, which intended to add coverage for 275,000 people by the waiver's third year of operation, never implemented the program. Colorado, which was going to cover 13,000 over a four-year period, had 253 enrollees by September 2003. Faced with budget problems, it closed its enrollment, as did New Jersey. While federal officials ballyhooed coverage of 2.7 million more Americans when the waivers were designed in 2001, the actual net impact has been fewer than 202,000.

Some experts worry that the waiver contains a big risk: In a strained budget climate, states could take advantage of the permission to cut back on benefits but limit the expanded-coverage part of the equation.

Meanwhile, the new waiver-based flexibility provided by CMS can also be used to focus on premium assistance. This approach removes some of the regulations that have made these efforts administrative nightmares in the past. It's too soon to know how effective this will be, although state officials say they are optimistic.

## Prognosis

The Bush administration has provided grants to 30 states over the past several years to study the issues of the uninsured within their borders and to develop policy decisions. And that fits in with the current public mood. "When you ask the public what government should do about the problem, most people would like to see it do something," says Leonie Huddy, director of the Center for Survey Research at Stony Brook University on Long Island. "Everyone realizes that this is a major problem. But the problems rise when you get to specifics."

One specific in particular: It costs money to insure people. Innovation and experimentation can certainly help. But most states simply don't have the financial resources they need to come anywhere near a full solution to this problem.

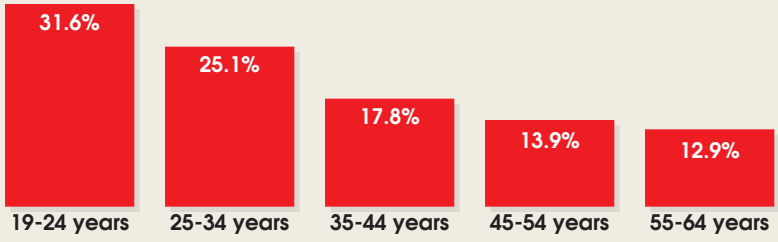
Within government circles, there is great frustration, even among wealthier states with greater resources. Mary Kennedy is the Medicaid director for Minnesota. She's worked under three governors and observed three different health-cost containment commissions attempt a variety of innovations. Today, Minnesota has one of the highest levels of public coverage in the country and the lowest rate of uninsured people. But segments of the population continue to be beyond the grasp of the state's substantial efforts. Meanwhile, escalating costs are dimming the luster of past programs that looked successful for a while, such as the state's reform of the insurance market for small businesses.

"I think it's very difficult for an individual state," she says. "People will say that individual states can be incubators of new ideas, but employers have to be competitive across all states. Even our public programs can't be dramatically different from our border states, or we wouldn't be able to afford it."

From the states' point of view, only Uncle Sam has deep-enough pockets, or the authority, to help them come anywhere near a broad-based solution. But waiting for Uncle Sam to arrive is like waiting for Godot. Everybody can talk endlessly about him, but it's not likely that he's going to show up anytime soon. G

## The Age Question

Nonelderly adults without insurance by age group, 2002




Sources: Kaiser Commission on Medicaid and the Uninsured/Urban Institute

# States That Stand Out

## SUCCESS STORIES

### Delaware and Iowa

Both states have a long-standing commitment to confronting the problem of the uninsured and have achieved the second- and third-lowest adult uninsured rates in the U.S. In Delaware, consistent attention to the problem has come through the work of the 14-year-old Delaware Health Care Commission. Iowa's strengths are in outreach and education.

### Maine

This is the state to watch this year. New legislation sets the stage for universal coverage, with a phase-in to begin in July. Maine has a three-pronged attack on the problem, focusing on quality and cost control as well as access. A key element has the state taking on the role of purchaser for small business health plans, with an eye toward eliminating hassle and lowering costs.

### Minnesota

With only 10 percent of non-elderly adults uninsured, Minnesota has the most successful insurance record of the 50 states. It has the highest rate of employer coverage, the most generous public coverage for parents, and a state-funded program for childless adults, though this was cut back some last year. A strong safety net is also in place for the people who still fall through the cracks.

### New York

Despite having a low rate of employer coverage, New York's expansive public programs, including one for childless adults, have helped the state make headway in covering low-income, non-elderly adults. In addition, a new program will make insurance more affordable for small businesses that employ low-income employees by shifting risk to the state for high-cost cases.

### Rhode Island, Vermont and Wisconsin

All three states emphasize full family coverage, providing insurance to parents at higher levels of income than most states. One bonus to this approach: When parents are insured, children also end up getting better preventive medical care.

## TROUBLE SPOTS

### California

The state's extreme budget problems are making a bad situation worse. With the rates of uninsured already higher than in 45 other states, California made several changes last year that will dramatically reduce the number of people covered by Medicaid. Proposals are also on the table to cap the number of immigrants covered. A new law to expand health care to the uninsured by mandating employer coverage was signed by former Governor Gray Davis but faces legal and political challenges.

### Louisiana and Oklahoma

These states cover parents only at the very lowest of income levels. Their bare-bones public coverage contributes to very high rates of uninsured adults. Oklahoma's situation particularly is likely to worsen because it has dropped coverage for the "medically needy"—people who qualify for Medicaid because of high health bills.

### Oregon

A long-time model for other states, Oregon's innovative health plan has fallen on hard times. With a get-tough policy that kicks people off of public insurance if they miss premium payments, the state has reduced the numbers of adults covered by about a third. It also ended its inclusion of the "medically needy," which had covered selected population groups. If last year's tax increase is repealed, the Governor says the Oregon Health Plan, which tried to expand the number of people covered by setting limits on benefits, will cease to exist in its current form.

### Tennessee

An adult uninsured rate of 14.6 percent, the lowest in the South, shows the Volunteer State did something right in TennCare. But the beleaguered program provides other states with many lessons of what not to do. The state plunged into a near-total managed care environment without a solid infrastructure of managed care organizations. A restructuring of the program led to vastly weakened cost controls. A major study recently concluded that TennCare is unsustainable in its current form.

### Texas

The state dropped into 50th place in its rate of insured adults last year. Texas has low rates of employer coverage, covers parents only at very low income levels and has no coverage for childless adults. Cutbacks in Medicaid eligibility and the elimination of the state's medically needy program in 2003 will only compound the problem.