Inside: *Bioterrorism Watch*

State Health Watch

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In This Issue

Seems like old times: State budget shortfalls worse than the early '90s

New figures indicate the states are facing a budget crisis that is significantly worse than the recession of the early 1990s.

In mid-December, the National Governors Association (NGA) and National Association of State Budget Officers (NASBO) released data indicating that a combination of a dramatic fall in revenues, soaring health care costs, and increased homeland security costs in the wake of Sept. 11 have produced an overall state budget shortfall of $40 billion, with the possibility of it increasing to $50 billion as unemployment continues to grow.

Raymond Scheppach, NGA executive director, says 36 states faced shortfalls in December and that the overall impact already was worse than the recession of the early 1990s. He points out that the gross domestic product declined from the third quarter of 1990 through the first quarter of 1991, with unemployment increasing during that period from 5.4% to 6.8%.

But unemployment did not peak until June 1992, when it hit 7.8%. The states' budget shortfall totaled $7.7 billion in 1990, $17.6 billion in 1991 (after 28 states had cut their budgets), and $19.5 billion in 1992, when seven more states were forced

*See **Budget shortfalls** on page 2*

Washington state's waiver request stirs fears that the public is losing accountability, review

Health care officials in Washington state say their Medicaid Section 1115 waiver request will give them the necessary flexibility to preserve services for many beneficiaries who have been added over the years.

The critics have another view. They contend that proponents are illegally seeking a blank check to make whatever cuts they want to make without public review and accountability. State officials make the case for their waiver request by asserting first that Washington has been a national leader in providing health care to children, vulnerable adults, and the working poor.

"In a time of lower health care costs and more state funding," according to Olympia-based Department of Social and Health Services (DSHS) literature, "the state was able to expand coverage.

"But now health costs are continuing to increase significantly, and the demand for coverage and services continues to grow. At the same time, state funding sources are not able to keep pace.

"The Medicaid program gives states like Washington few options with its all-or-nothing approach. This makes it difficult to manage Medicaid

*See **State's waiver request** on page 7*

Budget shortfalls

Continued from page 1

to cut their budgets.

"In terms of the three key measures — the number of budget cuts, the dollar amount of the shortfall, and the percentage of state revenues — this budget shortfall is more serious than it was during the recession of the early '90s," Mr. Scheppach says.

"If the shortfall goes as high as $50 billion, it will be 10% of state revenues, which is an unprecedented level," he explains.

Figures indicate that Medicaid costs are a major concern because they represent a high percentage of state expenditures, but could also be the source of a solution if the federal government would accept state requests for an increase in the federal share of Medicaid costs.

Medicaid spending a strain

According to NASBO's Fiscal Survey of States, growth in Medicaid expenditures continues to strain state budgets across the nation.

The Congressional Budget Office (CBO) says Medicaid is projected to grow at an average annual rate of 8.3% from 2002 through 2010. This follows an 11% growth in 2001, 9% growth in 2000, and 6.7% growth in 1999, the year that Medicaid costs began to shoot up. The CBO says factors affecting program growth include the cost and use of medical services, especially prescription drugs. States also have seen sharp increases in enrollment of children as a result of successful outreach programs for Medicaid and the Children's Health Insurance Program.

An October 2001 report from Washington, DC-based Kaiser Commission on Medicaid and the Uninsured indicates that the downturn in the economy coupled with the resurgence in Medicaid spending growth puts competing pressures on states. And those competing pressures are only likely to get worse as unemployment continues to grow in the months ahead, making still more people eligible for Medicaid.

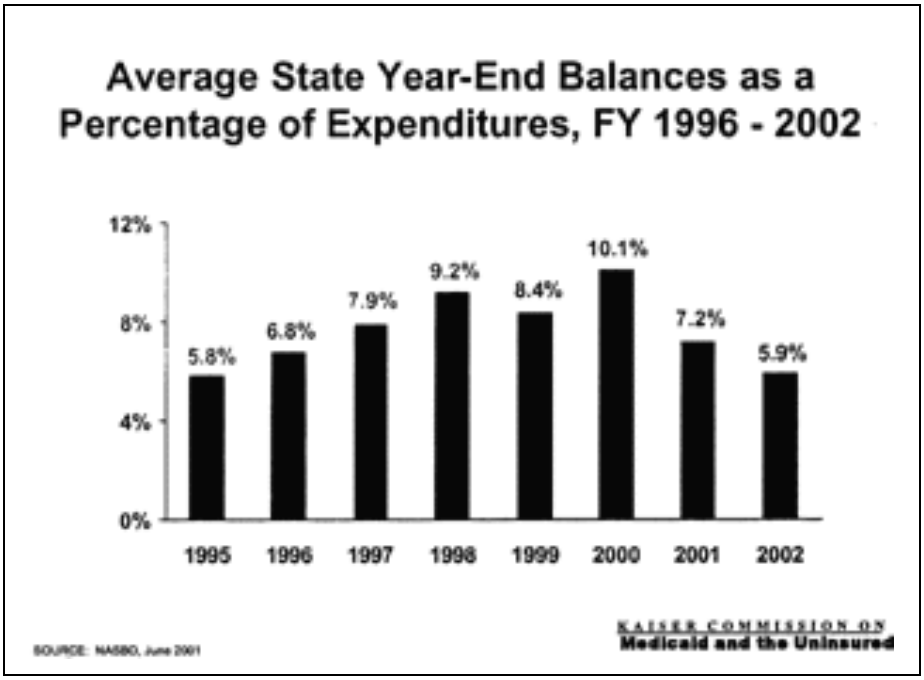
Jocelyn Guyer, a senior policy analyst with Kaiser who wrote the Medicaid report, tells *State Health Watch* that a number of factors were responsible for holding down costs before 1999. First, health care inflation had subsided throughout the industry, in both the private and public sectors. Second, as a result of welfare reform, the number of people enrolled in Medicaid declined and the rate of enrollment growth slowed.

A third factor was that states learned to use creative financing techniques to get additional federal funds without having to provide Medicaid services. Such spending arrangements held real growth down in states but made real federal spending increase rapidly, she points out.

"But we're now in a period of rapid health care inflation, and Medicaid enrollment is going back up, partly in response to the good work states have done in fixing enrollment problems," Ms. Guyer says.

A chart from the Kaiser Foundation report **(see box, below left)** shows that state budget reserves grew from 5.8% of expenditures in fiscal year 1995 to 10.1% in fiscal year 2000. But in the second half of calendar year 2000, the slowing economy was felt in reductions of state revenue collections.

As a result, according to the Kaiser report, many states had to raid year-end balances to cope with budget pressures, leaving them in the current fiscal year with balances at a level only half of what they had just two years earlier.



Revenue drop = bleak outlook

And as NGA and NASBO have said, the outlook for 2002 is even bleaker because of a significant drop in state revenue growth.

Of particular concern to states is that future Medicaid spending growth is projected to outstrip relatively weak revenue growth, causing Medicaid to consume a larger share of state budgets over time. As a bar graph from the report shows **(see top box, p. 3)**, Medicaid rose rapidly as a

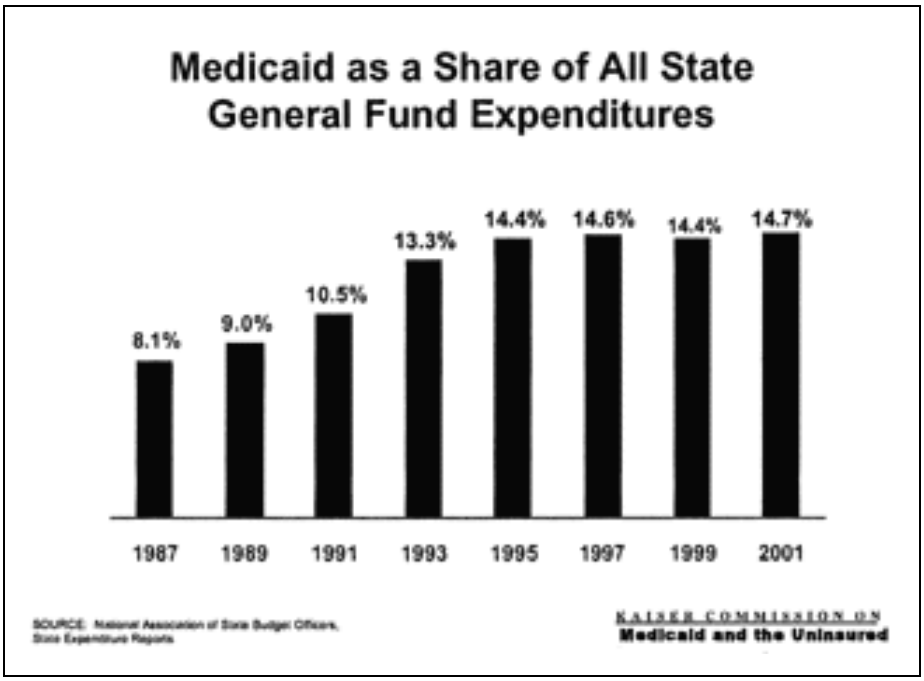
share of state budgets between 1987 and 1995, but then remained relatively level in the mid-1990s. But as of the summer of 2001, states were projecting that their revenues would grow by only 2.4% during fiscal year 2002, even as Medicaid spending was expected to increase 8.7%. **(See graph, below in bottom box.)**

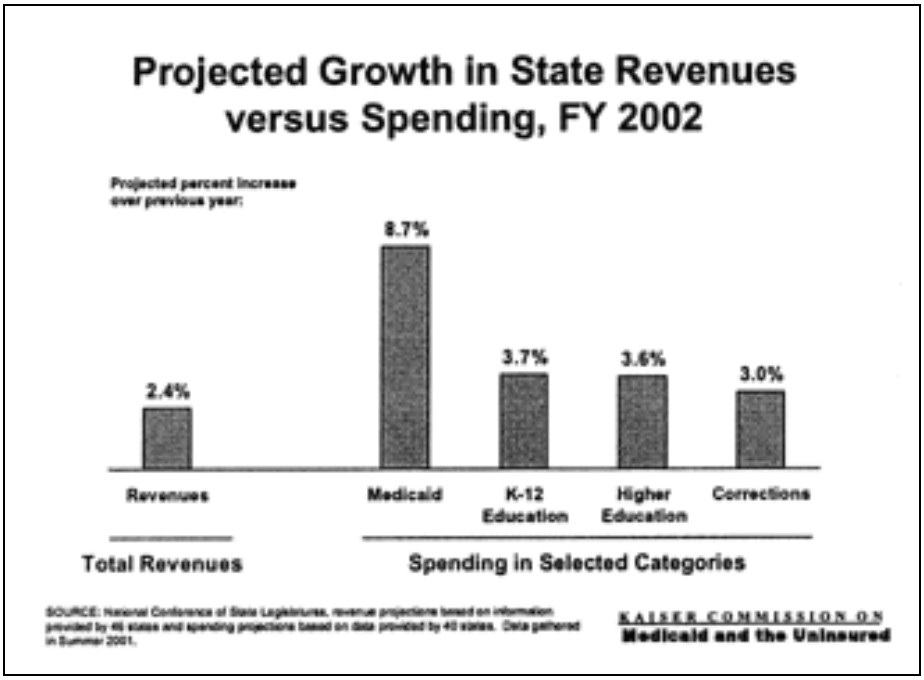
These projections seem to make it certain that Medicaid will once again grow as a share of state spending.

According to Ms. Guyer, an October survey of 20 state Medicaid directors and budget officials conducted for the Kaiser Commission found that more than half reported that in response to deteriorating fiscal conditions, they had been directed by their governors to prepare proposals to reduce current year (FY 2002) Medicaid spending below the level authorized by the legislature.

The pressure to reduce Medicaid spending could get worse because a significant number of states had made a decision to underfund their Medicaid programs in their FY 2002 budgets.

One wild card in the equation is the growing number of unemployed and their impact on the Medicaid program. Kaiser reports that the Urban Institute, also in Washington, DC, has used state-level unemployment and Medicaid enrollment data to estimate the impact rising unemployment rates might have on Medicaid enrollment absent any changes in state policy. And the picture does not bring comfort.





Swelling Medicaid rolls

The CBO has estimated that with a 4.5% unemployment rate, Medicaid enrollment would reach 44.7 million in 2002. However, with the unemployment rate rising from 4.5% to 5.5%, the Urban Institute projects that Medicaid enrollment will grow by another 1.6 billion, a 3.6% increase in enrollment. If unemployment went to 6.5% (still below the 7.8% peak in the 1990s' recession), 3.2 million people would be added to Medicaid.

As higher levels of unemployment push Medicaid enrollment up, that increased enrollment means higher Medicaid spending. Thus, if the unemployment rate goes to 6.5% and an additional 3.2 million people are eligible for Medicaid, total state Medicaid spending would rise by $2.3 billion, an increase of 2.6% above spending already projected for 2002.

Unemployment also has an impact on the number of uninsured. An analysis conducted for Kaiser by Jonathan Gruber at the Massachusetts Institute of Technology in Cambridge shows that rising unemployment likely would lead to a substantial increase in the number

of people uninsured. According to Gruber's statistical model, every percentage point increase in the unemployment rate leads to an increase of some 860,000 uninsured.

Looking at that another way, for every 100 people who lose their jobs, the number of people uninsured grows by 85.

The model shows that as unemployment climbs, the number of people with employer-sponsored insurance falls, and the number of people with public coverage such as Medicaid rises, although not enough to fully cushion the impact of falling employer coverage.

If enrollment in public programs is not allowed to expand because, for example, of state budgetary problems, the effect of growing unemployment on the uninsured would be even greater.

Learning from the '90s

In the recession of the 1990s, state actions fell generally into two categories, which may be instructive in terms of what states are likely to do now.

First, states worked hard to maximize federal funds coming in. It was during this period that states saw the first efforts at creative financing through payments to disproportionate share hospitals. Increased use of these arrangements enabled states to transform federal Medicaid matching funds into state general revenue dollars that were then used to shore up state spending on Medicaid or, in some cases, the entire state general fund budget.

The second state response was to make limited cutbacks on eligibility and services. Since much of Medicaid serves elderly and disabled people, as well as families with high medical costs, the Kaiser Commission report says it is likely that the effect of the changes was quite profound for the beneficiaries who lost coverage.

While there were cutbacks in eligibility and services, there also were expansions of Medicaid eligibility during the last recession.

This time around, much of the state effort through the NGA initially is being directed at bringing in more federal funds for Medicaid as part of the economic stimulus package. NGA says that only the federal government can assist the states because of states' balanced budget requirements.

According to Mr. Scheppach, a temporary increase in the federal share of Medicaid costs would have several major advantages over other fixes. The most important benefit is that all $5.5 billion being sought would be spent during the current fiscal year, without need for any additional state legislation, and would help states cover three million to four million individuals, including 1 million children who are expected to become Medicaid-eligible.

Cutting is self-defeating

Kaiser says that if states respond to the worsening financial situation by cutting Medicaid in the months ahead, it could make it more difficult for newly unemployed workers and their families might have more difficulty in securing public coverage and could also reduce coverage for those currently enrolled in Medicaid.

Guyer's report for Kaiser says that in recent years states have tried to slow the rate of growth in Medicaid expenditures without reducing eligibility for their programs and without cutting benefits directly. But continuing budget pressures may lead some states to look into such options. **(See the cover story on the Washington state waiver request.)**

States have broad flexibility under federal law to establish the parameters of their Medicaid programs. They are required to extend eligibility to some mandatory groups, and face some minimum federal requirements with respect to benefits and cost-sharing. But they still have broad flexibility to determine the extent to which they will cover a number of optional populations and a significant degree of discretion to determine the amount, duration, and scope of benefits they will provide to enrollees.

Guyer says the challenge for states in the coming months will be to identify effective strategies for curbing Medicaid expenditures without compromising the care of Medicaid beneficiaries. States are likely, she says, to consider a broad array of strategies, including drawing on their reserve funds, making new efforts to control prescription drug costs, using tobacco settlement funds to support Medicaid spending, working with the federal government to increase its investment in Medicaid, taking steps to strengthen state revenue streams, and identifying strategies to contain costs.

Reducing Medicaid spending could be counterproductive in terms of the nation's economic recovery since health care represents nearly 14% of the nation's economy and any drop in coverage would mean reduced spending in the health sector, contributing to the ongoing economic tightening and partially offsetting economic stimulus activities.

"Maintaining coverage as we face this economic downturn is important not only for workers and their families, but also for reviving our ailing economy," Kaiser says. "Policy-makers need to consider the impact of the recession on states and their ability to support Medicaid whose costs are likely to increase in an economic downturn."

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Data overload: Answers are here — now find them

With Medicaid managed care programs expanding significantly over the last several years, most states receive huge amounts of data they have requested from the managed care organizations. Sometimes, it's just too much.

State officials often don't know how to use the data to better manage their programs.

It need not be that way, according to Princeton, NJ-based Mathematica Policy Research's James Verdier, who conducted a survey of state agencies using data from the Center for Health Care Strategies.

As of June 2000, Mr. Verdier says, 42 state Medicaid agencies had implemented capitation contracting with at least one managed care organization (MCO) and were collecting large quantities of data in their Medicaid managed care programs.

Encounter data used included:

- MCOs;
- HEDIS (Health Plan Employer Data and Information Set) and other utilization and quality measures;
- CAHPS (Consumer Assessment of Health Plans) and other enrollee studies;
- External Quality Review Organization reports and focused clinical studies;
- reports on managed care organization enrollment and disenrollment;
- complaints and grievance records;
- reports on managed care organization financial performance;
- state budget tracking reports.

"Data are costly for MCOs to collect and report . . . and most states have limited resources to analyze the data and put them to effective use," Mr. Verdier says. "This puts a premium on using data strategically."

Mr. Verdier tells *State Health Watch* that his data survey came as a result of comments at a Center for Health Care Strategies purchasing institute that revealed state agency problems and frustrations with data collection and use. The agencies, he says, complained they were getting "tons of data from various places but were not able to use them to understand what was happening and to provide feedback effectively." And the managed care organizations were complaining that they have to submit a lot of data but nothing is done with them.

Work with what's available

"Our suggestion is that states do the things that they can do most easily with the data that are readily available," Verdier says.

> "We've developed a pretty complete set of encounter data. We're using it to answer questions such as how access has changed. We see it as a very rich data set that we can cut in different ways so it gives us a lot of flexibility."
>
> Alice Burton
> *Director of Planning and Development Administration*
> *Maryland Medicaid Program*
> *Baltimore*

They should use "things such as enrollment and disenrollment trends; complaints and grievances; beneficiary surveys and financial reports, although they can be expensive; and key utilization measures such as hospital days, hospital admissions, emergency room visits, and drug data."

There are two approaches states are taking to be able to make more effective use of data: building up internal staff capabilities or relying on actuaries and other consultants.

States need to develop ways to use data to support their managed care strategies, which generally focus on some combination of four goals — improving MCO performance, demonstrating value to program funders, building provider support, and building consumer support and understanding.

Encounter data have potential

Although encounter data reported by MCOs represent potentially the richest source of data for Medicaid managed care, only a small number of states have been able to tap its potential, Mr. Verdier says.

Encounter data can be used to set MCO capitated rates and to monitor the volume and cost of Medicaid services down to the level of individual providers and beneficiaries. The data can be aggregated to show trends over time, comparisons among MCOs and providers, and patterns of care and beneficiary access, he says.

"To fulfill this promise, however, the data must be reasonably complete and accurate, states must have sufficient analytic resources, and there must be clearly defined uses and audiences for the data. If any of these ingredients is missing, encounter data tend to accumulate largely unused, MCOs increasingly question the utility of collecting and reporting them, and their promise remains unfulfilled," Mr. Verdier adds.

HEDIS and CAHPS are the most fully developed tools available to states to measure MCO performance, Mr. Verdier says. They permit standardized comparisons among MCOs and can show trends over time. Even

though research and state experience suggest that consumers generally make only limited use of these measures in choosing among MCOs, they have become a valuable purchasing tool for Medicaid agencies and a significant stimulus for MCOs to improve their performance.

Because HEDIS and CAHPS are especially useful for public comparisons, Mr. Verdier says, states can use the measures to influence perceptions of key stakeholders including legislators, health care providers, advocacy groups, and the news media.

If states conclude that HEDIS and CAHPS are most useful as tools to monitor MCOs and for public accountability, rather than as direct aids to consumer choice, they can focus their publication and distribution efforts accordingly. Summary comparisons among MCOs can highlight dimensions likely to be of most interest to key stakeholders. Reports on plan performance could be made available at enrollment offices, on the Internet, and on request, rather than being mailed to every enrollee.

Looking for patterns and trends

Both states and MCOs track data on enrollee complaints and grievances for internal management purposes, looking for patterns and trends, and ensuring appropriate follow-up. Difficulties with standardization and interpretation limit usefulness of these reports for external reporting and comparisons among MCOs.

Enrollment and disenrollment trends are timely and easy to collect, but can be difficult to interpret unless the specific reasons for disenrollment are accurately obtained and recorded. Since disenrollment rates for reasons other than loss of Medicaid eligibility usually are very low, only major differences among MCOs or major changes in trends are likely to be significant. Verdier says it is important to be able to identify such differences and changes when they occur and to follow-up quickly to learn the underlying causes.

External Quality Review Organizations (EQRO) can be helpful because states receive enhanced federal matching payments for work the EQROs do and because they can provide a wide variety of managed care quality monitoring and reporting functions for states. Some of the functions include in-depth clinical studies, medical record reviews, encounter data validation and analysis, MCO readiness reviews, and beneficiary surveys.

Many states, according to Mr. Verdier's survey, find MCO financial reports to be their most valuable monitoring tool, while other states make little use of them. The reports provide monthly or quarterly data on service utilization, revenues, and costs for each MCO, usually in standard forms prescribed by state insurance regulators or the Medicaid agency.

"The data are most useful when the Medicaid line of business is broken out separately," Verdier says. "States use financial reports primarily for internal monitoring of MCOs rather than for external reporting, although states in which MCOs have had solvency problems may find significant external interest in these reports. MCO financial reports can also be used to help set MCO capitated rates, especially when claims or encounter data are not sufficient for rate setting."

Maryland contracts with school

In Maryland, the state agency has had a long-standing contractual relationship with the Center for Health Program Management and Development at the University of Maryland-Baltimore County, according to Alice Burton, the state Medicaid agency's director of planning and development administration. She tells *State Health Watch* that the university center has been the agency's data warehouse as well as doing data analysis.

Ms. Burton says the agency has done a lot with encounter data in the past five years, using it in the rate-setting process for risk-adjusted patients. "We've developed a pretty complete set of encounter data," she says.

Rich source of information

"We're using them to answer questions such as how access has changed. We see [the information] as a very rich data set that we can cut in different ways so it gives us a lot of flexibility," Ms. Burton explains.

She says establishing the encounter data set has been very difficult, and there only have been enough data to use in the last couple of years. "We now have physician data about 90% complete, and that's enough to make good use of in our analyses. Actually using the data made it easier to step up collection of the data. When you use the data in rate-setting, there is a significant financial advantage to plans to have complete data." She says they have done better collecting outpatient data than inpatient data, and are still limited in the analyses they want to do.

While a report on the first five-years of Medicaid managed care in Maryland is being completed with help of the data, Burton says there are early indications that the state has made progress in expanding access to ambulatory care and well-child services. "We see that more people are generally getting into services, and we've made significant progress in rural areas."

Minnesota uses encounter data

In Minnesota, Medicaid director Mary Kennedy says her agency has collected six years worth of encounter data, with the last three years the most complete. "Each year they get better."

Minnesota, like Maryland, is using data for risk-adjustment, which accounts for 50% of the variation in rates paid to MCOs.

"Once we started using data in rate-setting, everyone was able to produce better data," Kennedy says. "We've tried to feed back data to the plans and to show contrasts with HEDIS and other public data."

Setting standards for collection

States wanting to make better use of data should set criteria for data collection that clearly specifies what elements are to be collected and reported, Ms. Kennedy says. They also should have an adequate and timely processing system, insist on data coming in as clean as possible, use data to provide feedback to plans, and use data in rate-setting.

Ms. Burton agrees, and adds that states should set priorities and concentrate on the high-priority areas initially. Thus, Maryland focused on data from the Centers for Medicare and Medicaid form 1500 first, and made a lot of progress in that particular area.

In summarizing recommendations to states, Verdier says:

1. Medicaid agencies should approach their data collection and analysis efforts in a deliberate, strategic manner, paying careful attention to the audiences for their data.
2. Agencies should involve MCOs in data planning and implementation efforts.
3. They should perform a "data inventory" of the encounter data they require MCOs to submit.
4. They should recognize that sound, timely information from MCOs on the financial performance of their Medicaid lines of business is critical to state program monitoring efforts and can compensate for gaps in encounter data.

[Contact Mr. Verdier at (202) 484-4520, Ms. Burton at (410) 767-5806, and Ms. Kennedy at (651) 282-9921.] ■

State's waiver request

Continued from page 1

benefits and choices. The Medicaid reform waiver will give the governor and legislature more sensible management options, and at the same time, continue to offer protection to the most vulnerable groups protected by Medicaid," DSHS states.

Roger Gantz, who heads Medicaid policy and analysis in DSHS, tells *State Health Watch* that Washington is breaking new ground in some of its waiver request provisions. He says the provisions are consistent with national policy direction in programs such as the Children's Health Insurance Program (CHIP) and congressional interest in flexibility. They also build on the Medicaid reform requests of the National Governors Association.

Flexibility sought in several ways

What Washington is looking for is the flexibility to bring in cost-sharing with beneficiaries, changes in benefit design, and enrollment caps for optional groups, while maintaining commitments to mandated groups, Mr. Gantz says. Cost-sharing could involve a point-of-service copayment as well as a shared premium. Benefit design changes are sought in terms of comparability of services and requirements under the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program.

Currently, if the state offers a service to one eligible group, it must offer that service to all eligible groups. The state wants to waive that provision so it could decide which groups would receive a given service. They also want to waive EPSDT for optional Medicaid children program coverage.

Mr. Gantz defends the proposal as giving policy-makers an opportunity to design benefits differently for different groups so that, for instance, benefits might be restricted for those with higher incomes. He says the EPSDT proposal is controversial, because if services are identified through a diagnosis or screening, the state must provide them even if they are not a covered service in the state plan. The agency will voluntarily maintain a benefit design floor in its Basic Health program and for outpatient therapy services, Mr. Gantz says.

If approved, the enrollment caps would be the first in Medicaid, he says. They want the ability to impose such caps if program expenditures exceed legislative appropriations. They also want to be able to use unspent CHIP funds to provide coverage through the Basic Health program for parents and possibly childless adults.

'Sustain coverage commitments'

"We look at this waiver request as a way that we can continue to sustain our coverage commitments," Mr. Gantz says. "The intent is not to cut people off the program, but to be more flexible in how we apply the program. It could mean that some families that right now have free health coverage could be asked to help pay. I believe that a reasonable copayment could have an impact on utilization. There wouldn't be any copayment for preventive care."

The agency has not yet put a dollar figure on any of the options to get a sense of how much would have to be done, he adds. "What we've said in the request is that we want to expand the policy options for our governor and legislature. Implementation of any particular changes would be up to them. The waiver does not say specifically what we will do; it says that there are things that we want the freedom to do."

But it's that very lack of specificity that concerns advocates for Medicaid beneficiaries.

Joan Alker, associate director of governmental affairs for Families

USA, says her group opposes any waiver request that asks that a state be given approval in advance to make any cuts that it wants to when the need arises. "It would be very bad policy for the Centers for Medicare & Medicaid Services to grant the Washington waiver," she tells *State Health Watch*. "There would be no accountability for federal tax dollars being spent or for Congress' intent for the Medicaid program. The state is just trying to avoid public scrutiny of what they're doing. States already have a lot of flexibility without a waiver like this."

Can CMS legally approve request?

The National Health Law Program's Washington, DC, managing attorney, Steve Hitov, tells *State Health Watch* that Department of Health and Human Services Secretary Tommy Thompson doesn't have legal authority to approve such a waiver.

"The secretary is charged with determining whether a waiver is likely to further the objectives of the act. He can't do that if he doesn't know what the state is going to do. Suppose the state imposed an enrollment cap so that only one disabled person in the whole state is eligible. That wouldn't further the purposes of the act. It may seem silly, but there's nothing in the waiver request that would stop them from doing that," he says.

Mr. Hitov also says that Thompson has no authority to waive prohibitions against cost-sharing. "He might think cost-sharing is the best idea in the world, but he has no authority to approve it. Many states are requesting things from the National Governors Association wish list for Medicaid reform. Since much of that wish list is based on cost-sharing, the secretary's authority is more circumscribed than the states seem to think. It's probably the wrong road for states to head down."

He points out that expansion of Medicaid coverage to optional populations in Washington and other states generally came about because a political constituency demanded them. If those constituencies still exist, cutting their benefits could be difficult and thus there needs to be a well-aired political debate on any such proposal. "But the Washington waiver request is a perfect example of a document that no rational human being could read and know what is planned. That's not a debate."

Janet Varon, the executive director of Northwest Health Law Advocates, tells *State Health Watch* that her organization's concern is the state is asking the federal government to "waive quite a few federal provisions without specifying how they will be implemented. [It} wants an opportunity to decide later. There are no specifics on the populations affected, on when changes will be applied, whether changes will affect just one population or be spread across many. There's no indication of demonstration or control groups, although this is supposed to be a demonstration program and nothing on how it will be evaluated. We don't think state officials have demonstrated that they will affect as few people as possible. There's nothing that guarantees that. It could result in a crumbling of the health care infrastructure."

Always questions of trust

Ms. Varon says the reason the Medicaid act has protections built into it is to prevent the kinds of problems that the waiver request could cause. While DSHS has done good things in the past with its expansion efforts, she says, there always are questions of trust with any governmental agency. "There's no guarantee going forward that the people and processes involved will be what we've had. It's undefined in the request how they will decide what to implement."

A better approach, Varon says, would be to focus on ways to control significant cost drivers such as prescription drugs, and to do a waiver just on use of unspent CHIP funds, without all the other changes being requested. Even with that proposal, she says, it's not clear if the result would be an expansion of coverage in the Basic Health program.

Wanted: Flexibility

Doug Porter, who recently moved north from California's MediCal program to become Washington's Medicaid director, tells *State Health Watch* that what Washington wants to do is use the flexibility some other states have gotten to preserve the commitments the state already has made.

"For example, if we don't get the right to impose enrollment caps, the alternative might be that we have to terminate everyone in a particular category. It's true that most other waiver requests specify what will be done and when. We're listing options we want to be able to pursue if needed," he explains.

Mr. Porter says he understands the anxiety felt by critics of the proposal because of the lack of specificity. "But I'd ask people to look at our request in light of some from other states. There are many states that are just now asking to cover things that we've covered for some time.

"We're not seeking to reduce coverage. But without the waiver, we'll be forced to scale way back the benefit package for everyone and take many people off the rolls." **(A Louisiana Medicaid program involving waivers for children is in search of itself. See article, p. 9.)**

[Contact Mr. Gantz at (360) 725-1880, Mr. Porter at (360) 902-7806, Mr. Alker at (202) 628-3030, Mr. Hitov at (202) 289-7661, and Ms. Varon at (206) 325-6464.] ■

Advocates now are feeling more positive toward Louisiana's Children's Choice program for disabled

A Medicaid waiver program designed to help disabled children in Louisiana receive care at home may be moving in the right direction, according to advocates for the disabled, after the program had a rocky start and drew fire from the advocates.

The Children's Choice program was to open at the start of 2001 but was delayed briefly because of questions from the Centers for Medicare & Medicaid Services. Designed for families caring for children with developmental disabilities living at home who have medical and other expenses, the program is to provide some community-based services and medical care for children up to age 19 who have disabilities. The state stressed at the outset that the program was designed for children with low to moderate needs and not for every child with a disability. An annual service cap of $7,500 was in the program design initially, but state officials now say they will seek legislative approval (and funds) to increase it to $15,000.

Federal approval of the waiver request for Children's Choice was delayed because of concerns expressed about provisions in the application process under which families who choose to participate in Children's Choice would be taken off the waiting list for waiver services. That was a particular sticking point for advocates for the disabled, and state officials now have said they are withdrawing that requirement.

Once the program was approved, it moved slowly in actually delivering services to individuals. With a goal of reaching 800 families, state officials said in early November 2001 that there were 219 children enrolled, with 88 of them actually receiving services such as alterations to make homes and vehicles more accessible, respite care to give parents a break, and personal care attendants.

Kay Marcel, a parent of an adult disabled child and the statewide service coordinator for Louisiana Citizens for Action Now (LaCAN), tells *State Health Watch* that advocates started going public in the fall of 2001 with their concerns about how few people actually were receiving service. "They were funded for six months from January to June 2001, and we hadn't heard of anyone who was receiving services. We wanted to know where the money was going and what happened. The department began to hear our concerns and has been responsive."

State Department of Health and Hospitals Secretary David Hood tells *State Health Watch* that his agency has been listening to the concerns expressed by the advocates and is working to improve the program. "We're going to the legislature with a request that the cap be increased, perhaps to as much as $15,000 a year instead of $7,500. We're hoping such a change will encourage more families to find the program attractive and enroll."

Adjust case management fee

Ms. Marcel says one quirk in the cap is that of the current $7,500 limit, $1,500 is mandated for case management for each client, leaving only $6,000 for direct services. "We'd like to see that case management fee individualized," she says. "Case management is a good thing, but not every child needs $1,500 worth of it. Some may need more and others less. Many parents tell us they know more about their child's needs and how to meet those needs than the case managers. There should be more flexibility in the case management fee."

Mr. Hood says the agency is hoping to become more flexible in that area as well as in eligibility, all changes he hopes will make the program more attractive to parents and persuade them to enroll.

Opposition from advocates, he says, has been one factor in the slow and low enrollment. "There has been a coordinated effort by some advocates to convince families that Children's Choice is not a program that will meet their needs," he told the *Baton Rouge Advocate*. "It certainly will help meet the needs of some families. It never was designed for all families."

His department designed Children's Choice, he says, because it has a limited amount of money to spend and has done a good job of providing services but wanted to help the lengthy waiting list move more quickly. "We thought that if we could enroll people in Children's Choice, the waiting list would move more quickly. The length of the list was not acceptable to the families or to us. We thought that those who were not served by Children's Choice still would be helped because they would be able to move ahead on the waiting list."

Mr. Hood says the department did not want a one-size-fits-all program. "We want families to use Children's Choice if it meets their needs. If a family's needs increase, we will provide the additional services. They will not lose their place on the waiting list, and we will provide the additional services as quickly as we can. We're continuing to work with the families and advocates. We believe this is a good program, and we're trying to make it work."

Ms. Marcel says advocates are "very pleased" with the attitude shown by the department in working to make changes in Children's Choice. She says she had been involved in early discussions about the program and expressed concerns then about the adequacy of a $7,500 cap. Thus, the decision to work to raise the cap is an important one for her.

There also have been communications problems, Ms. Marcel says, so that some parents may have understandings about the program that are not accurate. She says Mr. Hood has made a commitment to improve communication within his agency and between the agency and parents.

"I'm cautiously optimistic that there has been a turnaround," she says. "It's still not clear what the department will do to improve the eligibility determination process and speed it up. We know that sometimes families are missing appointments and do other things that slow the process, but we think those cases are minimal. We're going to continue to work with the department to identify problems in eligibility determination and how they can be corrected. It seems that a new wave of constructive dialogue has opened and we're going to work together to get this program going the way it should be," Ms. Marcel says.

[Contact Ms. Marcel at (337) 367-7407 and Mr. Hood at (225) 342-9500.] ■

Virginia retardation services suit settled

A federal court suit filed by advocates for people with mental retardation against the Virginia Department of Medical Assistance Services has been settled by the parties involved.

Attorney Victor Glasberg represented the six adults and two children who charged in their suit that the department violated federal Medicaid law when it denied them needed services under a waiver for lack of funding and failure to meet emergency criteria. He tells *State Health Watch* that state officials agreed with the advocates' position and have been doing everything correctly since the agreement was reached.

"We're very happy with the results to date," Mr. Glasberg says. "But the overriding problem — a lack of money — hasn't gone away."

The suit was filed in December 2000 on behalf of Virginians with mental retardation who are eligible under a Medicaid waiver to receive medically necessary services in the community. Such services include group home placement, vocational support, behavior management, respite care, and other supports for community living. Under federal Medicaid law, once people have been designated as eligible to receive waiver services, it is a violation to deny requests for additional services.

When the suit was filed, Ray Burmeister, immediate past president of The Arc of Virginia, a statewide advocacy organization for people with mental retardation and other developmental disabilities, and their families, said, "These services are critically needed. We aren't talking about extravagant spending. These services are for basics — a place to live, well-trained caregivers, respite care for families, and other simple everyday supports."

The suit (*Quibuyen v. Rossiter*) was captioned for Rubin Quibuyen, one of the adult plaintiffs, who has autism, profound mental retardation, and developmental disabilities. In court documents submitted by the Washington, DC-based Bazelon Center for Mental Health Law, Mr. Quibuyen was described as ". . . much taller and stronger than the rest of his family, is hyperactive, and while gentle, has no understanding of danger. He requires constant supervision as well as a great deal of assistance in daily living."

In 1999, Rubin Quibuyen's mother and stepfather asked the Fairfax County Community Services Board to cover his placement in a group home under the Medicaid waiver because neither they nor his grandparents, with whom he stayed weekdays while the parents were at work, could continue to provide the intensive care he needed. The request was denied.

Under the agreement providing for dismissal of the lawsuit, the state will issue new regulations assuring that requests for waiver services will be evaluated under federal Medicaid standards that require services when needed to protect the health and safety of waiver recipients and avoid institutionalization. The regulations affect more than 5,000 current recipients of waiver services.

In a joint statement, the department and plaintiff's attorneys reported that although the parties disagreed on the merits of the claims made by the mentally retarded individuals who filed the suit, "they agreed that the most productive course of action was to reevaluate the needs of all the plaintiffs and to approve funding for all services necessary to protect their health and safety, while allowing plaintiffs to remain in their respective communities and avoid institutionalization. The plaintiffs applaud the willingness of the Commonwealth both to take a fresh look at the needs of these individual plaintiffs and to take new steps to assure appropriate consideration of future requests for mental retardation waiver services. The Commonwealth recognizes that the plaintiffs' efforts have provided the basis for a constructive dialogue regarding mental retardation waiver services between the department, the community service boards that serve mental retardation waiver clients, and the recipients of mental retardation waiver services."

Mr. Glasberg tells *State Health Watch* that as a result of the agreement, "the bureaucratic glitches that encumbered the process have been resolved." There had been problems, he says, with the criterion for emergency services and the use of lack of funds as a legitimate reason to deny services.

[Contact Mr. Glasberg at (703) 684-1100, Mary Giliberti of Bazelon at (202) 467-5730, and The Arc of Virginia at (800) 732-9507.] ■

Clip files / Local news from the states

This column features selected short items about state health care policy.

Panel approves TennCare rewrite, reserves comment

NASHVILLE,TN—Gov. Don Sundquist's sweeping TennCare rewrite won substantive approval from a legislative oversight committee, despite objections from medical providers and patient advocates.

The TennCare Oversight Committee voted 9-2 to endorse one key section that asks the federal government to waive seven specific Medicaid law provisions. But the committee avoided directly addressing the controversial program changes, which would divide and shrink TennCare, remove an estimated $475 million in federal funds from the state's health system, and strike at least 180,000 people from TennCare's rolls. Sundquist's plan has drawn opposition from all of the major health provider groups and advocacy organizations linked to TennCare.

—*Memphis Commercial-Appeal,* Dec. 6, 2001

Nebraska's infant mortality stats worrisome

LINCOLN, NE—Infant deaths in Nebraska increased by 10% last year because more babies died of sudden infant death syndrome, birth defects, and maternal health problems. The increase came despite recent efforts by the state to investigate Nebraska's high mortality rate. During the 1990s, about 180 babies died in the state each year — a rate higher than the national average.

"This isn't what we were hoping for," said Richard Raymond, MD, the Nebraska Health and Human Services System's chief medical officer. He leads a panel appointed in 1999 by Gov. Mike Johanns to investigate the infant mortality rate.

According to new state health statistics, 178 Nebraska babies under 1 year old died last year, compared with 162 in 1999. That put the state's rate at 7.2 deaths for every 1,000 infants born in Nebraska in 2000, compared with a rate

This issue of *State Health Watch* brings you news from these states:

of 6.8 in 1999. Last year's infant mortality rate would have been even higher if not for the high number of births last year, Mr. Raymond said.

Nebraska recorded 24,643 births, the most since 1985. The state's top medical experts have been puzzled over why infants are dying at a higher rate in Nebraska.

—*Associated Press*, Dec. 6, 2001

Agency reconsiders dropping Medicaid for 4,000 Iowans

DES MOINES, IA—A Department of Human Services panel changed its mind about dropping 4,000 Iowans from the Medicaid program after hearing pleas from Lt. Gov. Sally Pedersen.

Ms. Pedersen asked the Council on Human Services, the agency's policy-making board, for more time to find alternatives to cutting off the "medically needy." That's the term used for Iowans — many of them disabled adults and the elderly — whose limited resources keep them just above the eligibility line for medical services.

The reversal followed a discussion by board members on how to trim $18.6 million from Medicaid spending to comply with 4.3% cutbacks ordered in state government this year.

—*Des Moines Register*, Dec. 13, 2001

Barriers to kids' dental care found

RALEIGH, NC—Medicaid recipients in North Carolina find far too many barriers when seeking dental care for their children, a UNC Chapel Hill study concludes. The study, published in the January issue of the *American Journal of Public Health*, examined the attitudes of Medicaid recipients. "Low-income populations have to worry about so many things in their lives, and as this study pointed out, they have to negotiate multiple barriers in order not only to find and access care, but also receive acceptable care," said Mahyar Modifi, a dentist and one of the study's authors.

The study said finding dentists who accept Medicaid patients is just one of the hurdles recipients face. Other barriers cited by Medicaid patients who were interviewed included longer waiting-room stays, language barriers for Hispanics, demeaning behavior by front-office personnel, policies that restrict visits, and lack of transportation. Modifi said raising reimbursements should be the first of many steps to improve dental care.

—*Associated Press*, Dec. 28, 2001

On-line access / Index

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