State Health Watch
Vol. 10 No. 2 — The Newsletter on State Health Care Reform — February 2003

In This Issue

States take a stand on smallpox: Do no harm, go slow, stay small

Organizations of state and local governments have told federal officials that they fully support President Bush's smallpox vaccination plan but have several key issues that must be resolved, not the least of which is how to pay for all they are being asked to do.

In testimony on Dec. 19 to the Institute of Medicine (IOM) Committee on Smallpox Vaccination Program Implementation, National Association of County and City Health Officials executive director Patrick Libbey said that, especially as the vaccination program moves into its second phase **(see related story, p. 4)** in which up to 10 million first responders will be vaccinated, "this program has serious and far-reaching implications for local public health practice. Our message, based on the classic admonition, 'First, do no harm,' is straightforward. It is, 'Slow down and stay small.'"

While respecting the sense of urgency conveyed by the president, Mr. Libbey said, "We also believe that in light of the president's statement, there is no imminent risk of a smallpox outbreak; we owe it to our communities to proceed carefully and take the time to evaluate our

*See **Smallpox** on page 2*

Keeping PACE with long-term care costs means a savings for participating states

In Tennessee and Texas, Programs of All-Inclusive Care for the Elderly (PACE) is showing cost savings of 15% to 17%, Shawn Bloom, executive director, recently told a National Conference of State Legislatures session on controlling long-term care costs.

Fiscal Fitness: How States Cope

"PACE is the only truly integrated Medicare and Medicaid managed care model for the elderly in the country today," he said.

The PACE model is centered around the belief that it's better for the well-being of seniors with chronic care needs and their families to be served in the community whenever possible. PACE serves individuals ages 55 and older who have been certified by their state to need nursing home care, are able to live safely in the community at the time of enrollment, and live in a PACE service area. Although all PACE participants must be certified as needing nursing home care, only about 7% of them nationally actually live in a nursing home. If a PACE enrollee needs nursing home

*See **Fiscal Fitness** on page 7*

State Health Watch
The Newsletter on State Health Care Reform

On-line access / Index

Back issues of *State Health Watch* may be searched on-line for a fee at **www.newslettersonline.com/ahc/shw**. Issues may be searched by keyword and date of publication.

State Health Watch (ISSN# 1074-4754) is published monthly by American Health Consultants®, 3525 Piedmont Road, Building Six, Suite 400, Atlanta, GA 30305. Telephone: (404) 262-7436. Application to mail at periodicals postage rates is pending at Atlanta, GA 30304. POSTMASTER: Send address changes to State Health Watch, P.O. Box 740059, Atlanta, GA 30374.

Subscriber Information
Customer Service: (800) 688-2421 or fax (800) 284-3291. Hours of operation: 8:30 a.m. - 6 p.m. Monday-Thursday; 8:30 a.m. - 4:30 p.m. Friday EST. E-mail: customer service@ahcpub.com. World Wide Web: www.ahcpub.com.

Subscription rates: $349 per year. Two to nine additional copies, $279 per year; 10 to 20 copies, $209 per year; for more than 20, call (800) 688-2421. Back issues, when available, are $58 each.

Government subscription rates: $297 per year. Two to nine additional copies, $238 per year; 10 to 20 copies, $178 per year; for more than 20, call (800) 688-2421. (GST registration number R128870672.)

Vice President/Group Publisher: Brenda Mooney, (404) 262-5403, brenda.mooney@ahcpub.com.

Editorial Group Head: Lee Landenberger, (404) 262-5483, lee.landenberger@ahcpub.com.

Editor: John Hope, (717) 238-5990, jghope@worldnet.att.net.

Senior Production Editor: Ann Duncan.

THOMSON
AMERICAN HEALTH CONSULTANTS

Smallpox

Continued from page 1

vaccination activities as we go. We must also understand and document clearly the consequences of the necessary diversion of resources from other critical public health work to smallpox vaccination."

Mr. Libbey told the IOM that as local public health agencies proceeded with planning for the initial program phase of vaccinating 500,000 volunteer medical and public health response team members, they encountered questions about the presence or absence of liability protection for entities engaged in vaccination and availability of compensation for vaccinated people who lose work time or incur medical care costs as a consequence of their vaccination.

"Local health agencies also need consistent guidance in several areas," he said. "They need accurate, uniform guidelines for clinical practice. They need guidance for communicating with potential vaccinees. They need guidance for communicating with their communities, particularly in explaining the program as the president has established it and in explaining the particular course of action that their state has adopted. It is appropriate and expected that state plans for initial vaccinations will vary, but it is essential that local public health officials be able to explain why the types and numbers of people who will be asked to volunteer for vaccination vary markedly among the states."

Mr. Libbey called on federal officials to take the time necessary to evaluate the initial round of vaccinations before proceeding to vaccinate larger numbers of additional people. That evaluation, he said, should include monitoring side effects, identifying unexpected logistical barriers to vaccination, consulting more thoroughly with the next larger group of people to be vaccinated, and putting quality assurance measures in place.

He pointed out that while the logistics for vaccinating the first 500,000 people nationwide (those on volunteer smallpox response teams) can be mastered by state and local governments, those same plans and logistics will not work when the objective expands by a factor of 20 to cover up to 10 million first responders. "The broader program cannot be successful unless we take the time not only to apply the lessons learned in the first phase of the program, but also to tackle significantly greater logistical problems. We have only begun to identify the potential issues. These include: Who will provide vaccinations and how will they be indemnified? How do we get vaccine to a larger group of vaccinators and assure its proper storage, handling, and administration? How do we train vaccinators? How do we ensure that emergency and routine first responders can be vaccinated without disrupting essential community services?"

Mr. Libbey said it also is essential to look at the costs of the program since states and localities already have diverted significant resources to smallpox vaccination and there is no endpoint in sight. "We are greatly concerned about two effects of such diversion," he testified. "First, staff hired through the state and local grants for bioterrorism preparedness cannot also pursue the other important preparedness activities that are now under way. We already see these activities slowing or halting in many locations. A disproportionate amount of resources may be spent on smallpox vaccination for an indefinite time, at the expense of

other bioterrorism and emergency preparedness programs. Second, the magnitude of a program to vaccinate 10 million [people], and possibly also other members of the general public, will drain general public health resources at an alarming rate for an unknown period of time."

American Public Health Association executive director Georges Benjamin, who had been Maryland's health secretary and also once led the Association of State and Territorial Health Officials, tells *State Health Watch* that while all states had submitted their initial plans by early December as required by the federal government, work remained to be done on how to handle the Phase 2 vaccination of 10 million first responders.

"Liability is one of the issues that needs to be more clearly defined," Mr. Benjamin says "We need to look at workers' compensation because it's going to be hard to get people to participate if workers' compensation won't cover them if they have problems. Congress is going to have to look at federal liability coverage. Some states are self-funded for workers' compensation. If a problem develops and a lot of people get sick, it could be costly to those states. The relative risk is small initially. It will be more of a problem as we move to larger groups to vaccinate."

Mr. Benjamin also points to access to care as an issue needing to be addressed. "As we expand the number of people to be vaccinated," he says, "we can't forget the citizens who are the most vulnerable such as the poor, the homeless, mentally ill, shut-ins, and those who are institutionalized. We have to think very carefully about how to obtain informed consent from such individuals and be sure they are adequately informed. We haven't yet seen educational materials, but they need to be in multiple languages and at an appropriate reading level. Health educators need to be well informed so they can share the message. States have had lots of experience with wide-scale campaigns, but we need to remember that this type of vaccination is different."

Because there are many health care workers who don't have health insurance coverage or are underinsured, Mr. Benjamin tells *State Health Watch*, an issue might develop over how to deal with the uninsured in any wide-ranging vaccination effort. "States need to work with insurers and managed care organizations about coverage for people who have an adverse reaction to the vaccination."

Mr. Benjamin reiterates Mr. Libbey's recommendation that things move slowly enough to allow evaluation and learning from the early steps. "We should pause and understand what happens when the first 500,000 people are vaccinated," he says, "and then reassess going forward, including an assessment of whether the general public really is at risk. We shouldn't vaccinate the mass population unless there is a credible risk."

States likely are to vary in how they will handle their responsibilities, according to Mr. Benjamin, with some contracting out the work or adding to existing contracts.

George Hardy, Association of State and Territorial Health Officials executive director, said at the IOM's Dec. 19 hearing that there were a number of issues the agency should consider within its charge:

- **Timing and reassessment.** While most people agree with plans to vaccinate members of smallpox response teams, many question the need to move to additional phases of mass vaccination unless there is a criminal release of the smallpox virus, and certainly will see a need for evaluation before moving quickly ahead. "If there is one thing we learned from the swine flu experience in the 1970s, it is the critical need for built-in reassessment points throughout this process," he said. "Moving rapidly from Phase 1 to Phase 2 without appropriate analysis has the very real potential to cause more harm than good and violate our responsibility to do no harm."
- **Liability and compensation.** Mr. Hardy cautioned that protections under the Homeland Security legislation accrue to the vaccinator and the manufacturer, but offer essentially no protection for the people who are vaccinated or any secondary contacts of those who are vaccinated.
- **On-demand vaccination.** While endorsing the administration's strong recommendation that there is no need at this time for routine vaccination of the general public, he said there are concerns about the announced policy of making the vaccine available to members of the general public who insist upon getting it. "We urge a slow, measured approach to vaccination of the general public that is based on evaluation of the first phase of the vaccination plan."
- **Communication.** "It's critical that the public, physicians who advise the public, and other health care providers fully understand the nature, extent, and rationale for this vaccination program and the benefits and risks of vaccination," he said. **(See related story on public opinion poll, p. 5.)**
- **Resources.** Mr. Hardy told the IOM that bioterrorism money given to states earlier this year was intended to strengthen the public health infrastructure so that it would be prepared to anticipate and respond to multiple possible threats and was not intended to

be used for smallpox vaccinations. "We cannot afford to be unprepared for other possible agents because we have focused solely on smallpox. If we move to Phase 2, extensive funding will be needed for implementation at the state and local levels. At a time when 46 states are experiencing budget deficits, this cost would need to be borne by the federal government. It's important to prepare for smallpox, but not at the expense of preparedness for other health threats. We must remember there is more to public health than our preparedness responsibilities. Prevention and health promotion efforts cannot be lost in the process."

- **Work force.** He said that state governments have both short- and long-term work force development needs. "Public health can divert staff for a while as was done during the anthrax crisis, but such diversion is not without cost. The long-term consequences of diversion include a less healthy public and a less prepared work force."

While many concerns were raised, the officials stressed support for what the administration wants to accomplish. Mr. Hardy summed it up: "No program of this magnitude and controversy could expect to be easy, seamless, or without differences of opinion. I want to close by reiterating our deep conviction that the Centers for Disease Control and Prevention is doing everything possible to seek input and respond to the ideas and concerns of its state and local government partners."

[Contact Mr. Libbey at (202) 783-5550; Mr. Benjamin at (202) 777-2430; and Mr. Hardy at (202) 371-9090.] ■

President's smallpox vaccination plan covers several phases

President Bush's smallpox vaccination plan projects a phased program that starts with those most likely to come in contact with the smallpox virus first and then proceeds to people in the general population.

Initially, the smallpox vaccination was offered to approximately 500,000 military personnel located in high-threat areas, some 20,000 State Department employees working in U.S. embassies in the Middle East, and approximately 450,000 members of civilian smallpox response teams — people most likely to come in contact with a contagious smallpox patient, including people who work in hospital emergency departments (ED) and people on public health teams who would investigate suspicious cases of smallpox. Phase 2 covers approximately 10 million additional people who work in hospital intensive care units, infectious disease specialists, dermatologists, and first responders, including police officers, firefighters, and paramedics.

Secretary of Health and Human Services Tommy Thompson said his agency worked with state officials to decide who should be on the smallpox response teams.

Julie Gerberding, director for the Centers for Disease Control and Prevention, said that several thousand clinicians and public health officials received several hours of training in how to organize and conduct vaccination clinics **(see cover story)**, how to monitor side effects, how to safely store the vaccine, and other logistic elements necessary for the program to be conducted safely.

Ms. Gerberding said two types of response teams were envisioned. The first, known as public health response teams, consist of public health officials, doctors with special knowledge about skin conditions and smallpox, and disease detectives who will help understand the cause and source of an exposure. These teams may also include emergency medical personnel who help transport initial cases to treatment facilities and perform other tasks.

The second group, known as health care delivery system response teams, includes not only clinicians but also other hospital workers necessary to take care of an affected patient over a period of time, such as ED doctors, critical care physicians, infectious disease and dermatology specialists, housekeepers, some laundry workers, people who deliver services in intensive care units, and any others who are likely to come into direct contact with a patient with smallpox during their course of treatment.

Ms. Gerberding said the effort going into smallpox vaccination programs "is actually enhancing our entire preparedness system that we're using to respond to all kinds of terrorism threats as well as other public health emergencies. So our capacity to detect and mount large-scale responses to emerging health threats has certainly been enhanced through this whole effort. As a result, we can respond not only to the agents of bioterrorism, but also to other deadly diseases.

"This is a challenging endeavor, and there are going to be some bumps in the road," she said. "We expect to learn some lessons as we go forward, and we intend to be flexible, adaptive, and responsive. We will also have ongoing communication with our partners and the public, and we seek suggestions that strengthen our efforts and enhance our success."

(Download information from www.smallpox.gov.) ■

Physicians may understand smallpox risk, but the public hasn't a clue

A series of articles written for the Jan. 30, 2003, *New England Journal of Medicine* demonstrate the need for a massive public and professional education program about the threat of a smallpox release by terrorists and the nation's vaccination program.

Two physicians from Mount Auburn Hospital in Cambridge, MA, wrote that while the federal government's vaccination planning is based on mathematical modeling of smallpox attack scenarios, no statistical model can predict the thoughts of a terrorist and no analysis can tell how individuals or countries will act in a time of crisis.

"The public health question has changed from, 'Are we at risk from a smallpox attack?' to, 'Whom should we be vaccinating?' wrote Terry L. Schraeder and Edward W. Campion.

"Although physicians may be familiar with risk, the public is not. A risk of disease and death from a vaccine, no matter now small, may be unacceptable. The public needs to understand the risks associated with vaccination, including possible transmission to others. . . . The more people we vaccinate, the more likely we are to see serious complications. Media coverage and public outcry will most likely follow the first severe reactions to the vaccine. The information and perspective that physicians provide will affect how the public responds. Some may demand immediate access to the vaccine, and others may refuse it altogether. . . . The best decisions are made when all the facts are known. Many health care workers and much of the public still appear to be ill-informed about smallpox and the smallpox vaccine," they wrote.

A survey conducted by researchers from Harvard School of Public Health in Cambridge indicates just how difficult the educational process will be.

Lead researcher Robert Blendon said the Harvard team wanted to learn Americans' views on a number of key questions — whether frontline health workers should be vaccinated now, whether it is appropriate to make smallpox vaccination available to the general public, and whether states should be given additional emergency powers to respond to bioterrorist attacks. While there has been considerable discussion of these issues in the news media and professional journals, Blendon wrote, it hasn't been known how the general public views them. And prior research has shown that public opinion can strongly influence policy decisions.

A 61-question survey was given to 1,006 U.S. adults through telephone interviews, with a response rate of 65% and a sampling error of 3.1%. Blendon said the results **(see results below)** revealed "substantial misinformation among Americans about smallpox and smallpox vaccination. Our data show that the majority of the public would agree to vaccination and other measures to control smallpox, but that they would not agree to be vaccinated if physicians declined vaccination."

Physician response is key

The findings, he said, have important implications for physicians and public health professionals since they highlight the central role that physicians will play in providing advice and care related to smallpox vaccination and treatment. If physicians are reluctant to be vaccinated, the researchers say, large numbers of Americans will be unwilling to do it voluntarily. And if there are deaths from side effects of the vaccine, the public will be less willing to be vaccinated and will look to their physicians for advice.

Blendon said the results also suggest the need for public education about smallpox, since many Americans have beliefs about the disease that are incorrect according to scientific views.

Interestingly, a third key survey finding is that while the current opinion of many public health leaders is that there is no need at this point for a mass vaccination of the general public, that view is at odds with the public's desire for access to the vaccine. "Health officials need to clarify to the public the basis for their judgment to limit access to the vaccine," Blendon wrote.

The researchers conclude that the Bush administration's decision to begin vaccinating military personnel and state response teams may make the issue more salient to the general public.

"As adverse reactions to the vaccine occur, members of the public may look to their physicians for guidance in weighing the risks of vaccination against the risk of a bioterrorist attack involving smallpox," they said.

Here are the survey results:

- **Concern about a smallpox attack.** 64% of respondents said they believe that an attack by terrorists using smallpox is likely if the United States takes military action against Iraq.
- **Knowledge about smallpox.** 89% of respondents knew that smallpox is a contagious disease, but 30% believed there had been a case of smallpox in the United States in the past five years, and 63% thought there had been a

case someplace in the world in the past five years. Some 78% believe there is a medical treatment for smallpox that would prevent death or serious effects after symptoms of the disease develop.

- **Beliefs about smallpox.** A majority of respondents said they believed it was likely they would survive if they contracted smallpox. 67% thought it was likely they would contract smallpox if they came within a few feet of someone who had the disease. Respondents were split on the aftereffects of smallpox, with 48% reporting that most people who contracted the disease and survived would have a full recovery, and 46% saying they would have permanent, serious aftereffects such as disfigurement and blindness.
- **Smallpox vaccine.** 66% of those interviewed believed they had previously been vaccinated against smallpox and 46% of those who reported a prior vaccination believed it would protect them from becoming seriously ill if there were a smallpox outbreak. 93% believed that the smallpox vaccine would be effective in preventing a person from contracting smallpox if the person received the vaccine before being exposed to the virus, but only 42% believed that vaccination within a few days of exposure could prevent a person from contracting the disease.
- **Vaccination policy.** A strong majority (81%) of respondents favored voluntary vaccination of doctors and nurses in preparation for a bioterrorist attack, and 65% favored offering the vaccine to the general public in preparation for such an attack. Many respondents believed they would not be able to get vaccinated quickly if cases of smallpox were detected in their community, and that there would not be enough vaccine for everyone in this country. Nearly three-fourths said that if it were not possible to vaccinate everyone, wealthy and influential people would get the vaccine first. 43% said they believed that distribution of vaccine would discriminate against the elderly, and 22% believed it would discriminate against blacks.

The researchers say that those responsible for public education about smallpox need to consider the degree and type of misinformation that was revealed in the survey. Although the last case of smallpox was reported in the United States in 1949 and in the world in 1977, a substantial proportion of respondents thought there had been cases in the past five years.

Harvard School of Public Health
Cambridge, MA

- **Vaccination decision.** 61% of respondents said they would choose vaccination (or revaccination) if it were offered as a precaution against a bioterrorist threat, while 36% said they would not take it. If there were a smallpox attack, 75% of respondents would choose to be vaccinated. If there were cases of smallpox in their community, the proportion of respondents who would be willing to be vaccinated increased to 88%. Actions of physicians influence the vaccination decision, with 73% of respondents saying they would be vaccinated if their own physician and most other physicians were vaccinated. Only 21% would be vaccinated if their own physician and many other physicians refused vaccination. Further, only 33% of respondents would choose to be vaccinated if they heard that "some people" had died from the smallpox vaccine; only 44% would be willing to be vaccinated if they had to stay out of work for two weeks.
- **Reactions to a smallpox attack.** Approximately half of the respondents said they would go to their own physician first for diagnosis and care if they thought they had smallpox, while 40% would go to a hospital emergency department, and 7% would go to their local health department. Most respondents expressed confidence that their personal physician would recognize the symptoms of smallpox. 95% of respondents said they would agree to be quarantined for two to three weeks if they were exposed to smallpox but did not have symptoms of the disease. 77% said that if they were told they had smallpox and had to be isolated in a special health facility with other smallpox patients for three to four weeks, they would agree to go.
- **State emergency powers.** The respondents offered a high level of support (87%) for legislation requiring hospitals and clinics to provide services to people who might have smallpox and requiring people with smallpox to be isolated in a special health facility (73%). Two-thirds believed that state governors should be able to use National Guard troops to prevent people from leaving areas with reported cases

of smallpox. A smaller majority (57%) favored quarantining people suspected of having smallpox, and respondents were divided on the question of whether a person should be required to undergo a medical examination or test to diagnose smallpox.

The researchers say that those responsible for public education about smallpox need to consider the degree and type of misinformation that was revealed in the survey. Although the last case of smallpox was reported in the United States in 1949 and in the world in 1977, a substantial proportion of respondents thought there had been cases in the past five years.

There is no specific treatment for smallpox, but a majority of respondents thought the disease could be effectively treated.

In many people, it is believed, immunity from a previous vaccination is likely to be negligible after 20 years and the U.S. vaccination program ended in 1972. But almost half of the respondents who had been vaccinated believed they were protected from the disease.

A majority of respondents did not know that vaccination within two to three days after exposure to smallpox can provide protection against the virus, and although serious adverse reactions to the smallpox vaccine are expected to be relatively rare in patients without contraindications to the vaccine, a substantial proportion of respondents thought that serious complications, including death, would be likely.

Government sources say there are enough doses of vaccine for everyone, but a majority of respondents said they did not believe that to be the case.

(The articles are available on-line at www.nejm.org.) ■

Fiscal Fitness

Continued from page 1

care, the PACE program pays for it and continues to coordinate care.

Care and services provided through PACE include adult day care that offers nursing, physical, occupational, and recreational therapies, meals, nutritional counseling, social work, and personal care; medical care provided by a PACE physician familiar with the history, needs, and preferences of each participant; home health care and personal care; all necessary prescription drugs; social services; medical specialists such as audiologists, dentists, optometrists, podiatrists, and speech therapists; respite care; and hospital and nursing home care when necessary.

Enrollees similar to other seniors

The National PACE Association (www.npaonline.org) says the typical PACE enrollee is similar to many recipients of long-term care — an 81-year-old widow, living alone or with relatives, with several chronic medical conditions, and more likely than not, suffering some degree of cognitive impairment. The typical enrollee requires help with personal care and with activities of daily living to maintain safety and security.

National PACE Association vice president for public affairs Robert Greenwood wrote in an issue brief for the Center for Medicare Education that a key to the PACE model is the combining of Medicare dollars with state Medicaid funds or an individual's personal resources to deliver a more comprehensive set of services.

"Medicare's traditional emphasis on reimbursing for acute care often prevents older individuals from accessing the kind of preventive and chronic care services they need," Mr. Greenwood said.

PACE relies on interdisciplinary teams of physicians, nurse practitioners, nurses, social workers, therapists, van drivers, aides, and others who meet regularly to exchange information and solve problems as the conditions and needs of PACE participants change. "This approach empowers those involved and allows more information to be available at the critical points when decisions are being made," according to Mr. Greenwood.

A capitated system that works

PACE receives a monthly capitated payment (Medicare combined with Medicaid or a patient's private resources) and is responsible for the care its participants need.

"The financial interests of the PACE program and the care needs of the persons it serves are aligned in a unique way," Mr. Greenwood said.

"Regardless of whether needed services would be reimbursed under traditional fee-for-service Medicare and Medicaid, PACE provides a comprehensive set of preventive, primary, acute, and long-term care services that are specifically tailored to the needs of each PACE participant to help him or her avoid hospital or nursing home placement to the greatest extent possible. The program is designed to monitor participants closely for even subtle changes in needs that, left unattended, could lead to costly acute care episodes," he added.

PACE participants regularly attend an adult day center, on average three days a week. The centers typically contain a health clinic with an on-site physician and nurse practitioner, physical and occupational therapy facilities, and at least one common room for social and recreational activities. Because PACE participants have regular contact

with primary care professionals who know them well, slight changes in their health status or mood can be addressed immediately.

A study of the PACE site in Chattanooga, TN, indicates that it is providing a 17% cost saving relative to the TennCare MCO/BHO and nursing facility system. The assessment reports that participant satisfaction levels and family member/caregiver satisfaction levels are extremely high (96.9% to 100%). Nearly three-fourths of disenrollments from the program are due to the death of the participant. Inpatient hospitalization rates are low, averaging 1,140 days per 1,000 and a 3.1-day average length of stay.

TennCare director of long-term care Joanna Damons, who conducted the March 2001 study, recommended that PACE enrollment be increased from 211 to 302 participants. She said data collected in the evaluation do not support an assumption that PACE participants have lower acuity levels than individuals in nursing homes, and concluded that enrollee clinical care quality can be increased through PACE, particularly use of preventive measures that prevent avoidable hospitalizations and use of community-based care to reduce the length of hospital stays.

Program saves money

A December 2000 study of the PACE program in Texas found that it saved state and federal government organizations an estimated 14% compared to nursing home and medical care. Texas comptroller of public accounts Carole Rylander recommended that the state expand PACE and noted legislation authorizing it to go from one site to a total of 16.

"Despite caring for a more frail population that Medicare in general. . . . PACE enrollees have fewer hospital admissions and shorter hospital stays," Ms. Rylander wrote. "PACE will help the state to meet growing demand for long-term care."

Praise for the program

Praise for PACE also has come from Centers for Medicare & Medicaid Services Administrator Thomas Scully. At an April 2002 meeting of the National PACE Association, Scully said, "More nursing homes are not the answer people want. We know that when people have a choice, they choose to stay home rather than move into a nursing home. I love PACE. . . . If a provider is having a problem getting a PACE program started, let me know if I can help. I would be glad to talk to a governor or state Medicaid director if that would be helpful. I am one of the PACE program's biggest fans. If there is something we need to address in regulations to help a rural PACE provider, let me know and we will take a look at it."

David Reyes, executive director of Total Longterm Care in Denver, runs one of the fastest-growing PACE programs. It started in 1990 with a small center on the garden level of a high-rise unit for the elderly that was owned by a hospital with which PACE contracted to provide the medical services for its clients.

A second center was opened on the western side of Denver in 1994, and a third center was opened in 1997 on the north side of town. Mr. Reyes also was responsible for the closure of the initial PACE site and occupancy of a new, larger site in the downtown area.

"We recently started construction on a center to serve the northeast quadrant of the city and that should open April 1," he tells *State Health Watch*. "And we've broken ground for what will be two sites sharing space to the west of the city. In the past two years, we've doubled in size and plan to double again in the next two years, by continuing to expand into new areas. We should end up with eight centers and 1,200 enrollees, up from about 220 enrollees when I came here in 1996."

Mr. Reyes says one reason the program is growing is that they did a marketing analysis on name recognition of PACE with the general public and the level of understanding health professionals had of what PACE was about.

"We kicked up our marketing efforts with media blitzes, ads, and other things to increase the general awareness that we exist," he says. "I cringe when I hear that we're considered the best-kept secret in Denver. We want people who have loved ones who could use our services to call us first. It's a snowball effect — the more people whose lives you touch, the more the word gets out."

Mr. Reyes' program also is participating in a demonstration project with the Department of Veterans Affairs (VA) in which they have a shared risk contract with the local VA center. Each entity provides some services to enrollees and some PACE staff are housed at the VA center.

Colorado's legislature has approved a law to expand PACE statewide, and a feasibility study is to be done to determine communities that can support a program.

"There's a huge endorsement for this model at the state level," he says. "I believe what we have is the future of health care for seniors."

[Contact Mr. Bloom and Mr. Greenwood at (703) 535-1565; Ms. Damons at (800) 342-3145; Ms. Rylander at (888) YOURTEX; and Mr. Reyes at (303) 869-4664.] ■

Fear, anxiety, frustration, and anger on the HIPAA road

There is "an extremely high level of confusion, misunderstanding, frustration, anxiety, fear, and anger" in a broad range of people and organizations as the April 14 compliance date for the Health Insurance Portability and Accountability Act (HIPAA) privacy rule nears.

That's the finding of the National Committee on Vital and Health Statistics, a statutory public advisory body to the secretary of Health and Human Services (HHS) in the area of health data and statistics.

The 18 private-sector individuals on the committee have, according to HHS, distinguished themselves in the fields of health statistics, electronic interchange of health care information, privacy and security of electronic information, population-based health research, purchasing or financing health care services, integrated computerized health information systems, health services research, consumer interests in health information, health data standards, epidemiology, and the provision of health services.

In a letter to HHS Secretary Tommy Thompson after three public hearings sponsored by the committee to learn about implementation activities of entities covered by HIPAA, the group said that despite widespread support for the goals of HIPAA and the privacy rule, there are many problems still to be resolved and not much time in which to address them.

The letter suggested that the HHS Office of Civil Rights (OCR) and the Centers for Medicare & Medicaid Services (CMS) improve their coordination of education, outreach, and technical assistance, by working more closely with different industries, states, and federal health care programs.

In particular, it said, OCR should improve its responses to HIPAA-related questions and enhance its web site to help explain the compliance process. And, it said, HHS should recommend that Congress provide financial assistance, through grants, increased reimbursements, and incentives for providers struggling to comply with HIPAA.

OCR guidance faulted

The committee reported that many witnesses at the hearings said they viewed OCR as not providing adequate guidance and technical assistance. In particular, they "lamented the lack of model notices of privacy practices, acknowledgments, authorizations, and other forms.

"Many witnesses also complained that general guidance was of limited value because of their special industry or professional circumstances. Witnesses conveyed a great sense of frustration that they could not obtain any clarifications from OCR or answers to the questions they submitted via OCR's web site."

Many witnesses indicated to the committee that issues of preemption made compliance much more difficult, costly, and complicated. To determine whether state privacy laws or the HIPAA privacy rule applies to many health privacy issues, covered entities have to obtain a comprehensive preemption analysis detailing whether state or federal laws apply.

The committee said the analyses often are lengthy documents that are expensive to research, highly technical, and not binding on any enforcement agency or the courts. Large, multistate covered entities need to have an analysis for every jurisdiction in which they do business, and there is no national coordination on the issue of preemption, and state and local efforts vary widely in their degree of completion and the cost to obtain copies. A related issue, the committee said, involves conflicts and overlaps between HIPAA and other federal laws dealing with privacy.

Based on testimony at the hearings, the committee declared that "the lack of clarity on compliance responsibilities, the unavailability of free and authoritative model forms, and the absence of widely available training materials have left many covered entities lacking the wherewithal to come into compliance."

Small providers giving up

Several witnesses told the committee that less than half of all small providers had made any effort to comply with the privacy rule and that some have no intention of trying to comply.

"One witness reported that some rural providers have given up on compliance and adopted the position that 'I can't do this; let them catch me,'" the letter said. "Even more troubling are the potential adverse effects on the health care system. Some witnesses said that some Medicaid and other safety-net providers may drop out of the system of providing care to indigent patients because they cannot afford to absorb the costs of complying with the privacy rule, and there is no way to pass along the costs."

The committee also cited fears of witnesses surrounding HIPAA. Many expressed concern about the possibility of overzealous enforcement by OCR and private lawsuits, both of which were expected to be costly to defend.

Other witnesses said that fear of violating HIPAA has resulted in negative health outcomes, including providers refusing to share patient medical information that would be helpful in treating another patient, and a decline in mandatory or permissive reporting of essential health data to public health agencies, tumor registries, and other entities.

Another key area in the remaining months will be training, the committee said. "Millions of health care workers will need to be trained in the next few months, but there is a shortage of expertise, materials, and funding. Overwhelmingly, witnesses said that generic training will not work; to be successful it must be customized by industry, entity, and job description.

In addition, consumers have received virtually no information about HIPAA, and it will be difficult for them to understand the basis or context for the myriad notifications, authorizations, and other forms with which they will soon be presented. Public education is complicated by consumers' varying levels of education, cognition, and language proficiency."

The committee said it is aware of the limited resources available to the department, and urged that as much as possible be given to OCR so it can accomplish the massive technical assistance, outreach, and education efforts needed in the coming months to ensure successful privacy rule compliance efforts.

[Download hearing testimony and other materials from the committee's web site at www.ncvhs.hhs.gov.] ■

Cost-cutting: States shift to long-term care

With their budget crises showing no signs of abating, states are looking at long-term care costs as an area ripe for redesign to improve quality, increase consumer choice, and they say, save money in Medicaid.

At a November 2002 meeting of the National Conference of State Legislatures, Virginia Dize, associate director for the National Association of State Units on Aging said that the demand for long-term care now represents 35% of state Medicaid spending and the costs are expected to increase significantly in the next few decades.

Drivers for a state evaluation of long-term care, she said, include the U.S. Supreme Court decision in the *Olmstead* case, which has an impact on choice and service waiting lists, and the administration's New Freedom initiative that calls on federal agencies to look for barriers to home- and community-based services.

"The biggest barrier to home- and community-based service delivery is Medicaid's institutional bias," Ms. Dize declared. "Those who have a right to services in an institutional setting don't have an affirmative right to get services in the community. As a result, states are using waivers to be able to provide the services." States, she said, are showing an increased interest in quality and also are evaluating lessons learned from nursing homes. "No matter how wonderful your home- and community-based system is, if people can't get access to it, and if they don't know about it, it's no good because you're not serving the people you need to serve."

Ms. Dize added that if states maximize the ability of consumers to get information so they can make informed decisions about their options for home- and community-based services, they will be doing a lot to ensure that those consumers don't end up in nursing homes. She also called attention to demonstration "cash-and-counseling" programs in which clients are able to hire neighbors, friends, and relatives to be their caregivers and don't have to wait for an agency worker to be available.

More home/community focus

Sandy Newman, policy specialist for the Family Caregiver Alliance, reported that Pennsylvania has dramatically increased spending on home- and community-based care, successfully making the case to the legislative and executive branches that spending more money in communities, where most people would like to stay, should result in less of a financial drain and less stress on Medicaid.

The results of a 10-state study of the National Family Caregiver Support Program show that it's working, Ms. Newman said.

"Families are getting the help they need. Families are getting information. They are going to support groups. They're getting respite care. They're getting all of the things that they need to remain in their caregiving role," she pointed out. "For many states, providing support services to caregivers is a paradigm shift. They're used to creating a care plan around the person who has a chronic or disabling illness. They're not used to serving caregivers." ■

Oral health services sink their teeth into grants

With a growing recognition that tooth decay is the leading childhood condition among low-income, minority, and disabled populations **(see *State Health Watch*, January 2003, p. 10)** — five times more common than asthma — the Robert Wood Johnson Foundation in Princeton, NJ, has awarded three-year grants of up to $1 million each to six states to address the problem of inadequate access to oral health care services.

The program will be managed by the Center for Health Care Strategies (CHCS) of Lawrenceville, NJ, and is intended to test a number of comprehensive, innovative approaches to improve access to oral health services for low-income, minority, and disabled populations served by Medicaid and the State Childrens Health Insurance Program (SCHIP) in Arizona, Oregon, Pennsylvania, Rhode Island, South Carolina, and Vermont. CHCS sources say the six states have already made significant improvements to oral health through Medicaid and SCHIP.

Developing strategies

The grants will help them develop more comprehensive strategies in at least two of these areas — further developing state financing and purchasing strategies; broadening provider networks; expanding the dental safety net; and enhancing consumer and provider education.

Anne Weiss, senior program officer of Robert Wood Johnson Foundation, says that many factors, such as a lack of awareness about the importance of oral health, combine to limit access to oral health services. "The selected grantees have proposed truly innovative projects to expand access to dental care and to organize, finance, and deliver health care services," she says.

A summary of the projects by state are listed below:

- **Arizona.** The state will establish a registered dental hygienist (RDH) program with the Arizona School of Health Sciences in partnership with three community colleges located within rural communities; build an RDH case management program for high-volume Medicaid oral health practices; develop a social marketing campaign to improve consumer awareness; design a curriculum for non-oral health practitioners emphasizing early detection and referral to the dentist; and train local dentists on issues relating to oral health care for people with disabilities.
- **Oregon.** The state proposed to expand and enhance preventive programs for low-income pregnant women and children up to 24 months of age in three demographically different communities. Partnerships will be developed with health plans, the private dental community, non-oral health practitioners, and federally qualified community health centers, including the Indian Health Service.
- **Pennsylvania.** Pennsylvania proposed to expand the provider network and dental safety net for low-income persons with special needs through a partnership with the Pennsylvania Dental Society, oral health training institutions, and the Primary Care Association to expand the numbers of expanded function dental assistants, which will give dentists additional time for patients. Also, a partnership with the state Department of Public Welfare and its contracted Medicaid managed care organizations will expand a successful multidiscipline safety net clinical model for efficient and comprehensive treatment for special needs patients from Philadelphia to another part of the state.
- **Rhode Island.** Rhode Island will develop a performance-based dental benefits manager contract to expand dental services to all of its Medicaid recipients. The state has partnered with the community-based Rhode Island Foundation to develop a free-standing pediatric dental residency, to provide grants for expansion of safety-net clinics, and to expand school-based health center RDHs.
- **South Carolina.** The state has collaborated with a broad base of stakeholders to develop these

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

strategies: integrate oral health within medical homes and link with dental providers; train dentists to care for children and individuals with disabilities; coordinate with a faith-based project to provide case management and education to consumers; and expand the dental safety net in selected rural public health districts.

- **Vermont.** Vermont will expand oral health care education to consumers and providers; establish a primary care dental home for children in custody; link registered dental hygienist assessments of school children with community dentists; and collaborate with the Area Health Education Council to recruit and retain dentists.

[Contact the Center for Health Care Strategies at (609) 895-8101, and the Robert Wood Johnson Foundation at (888) 631-9989.] ■

Clip files / Local news from the states

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

HHS approves PA plan to help disabled adults live at home

WASHINGTON, DC—HHS Secretary Tommy G. Thompson announced approval of Pennsylvania's plan to expand the number of disabled adults who receive assistance through Medicaid so they can remain in their homes and out of nursing facilities. The change will increase the number of people served by the waiver from 8,385 to 10,049. Pennsylvania's newly amended home and community-based services waiver will provide services to adults ages 60 and older who otherwise would require care in a nursing home. Services offered under the waiver include home support, personal care services, respite care, transportation, and home-delivered meals. State officials have the authority to increase the waiver to as many as 14,123 individuals.

—HHS Release, Dec. 2, 2002

TennCare cut targets 50,400 more

NASHVILLE, TN—Another 50,400 Tennesseans were notified they're losing TennCare coverage, bringing to 138,410 the number cut from the state's health program for the poor and uninsurable. Another 77,000 had until Dec. 29 to either get through TennCare's complex reverification process or lose health coverage, and at least 26,000 other cases are pending. More than 17,000 have filed appeals of their cutoffs. All of TennCare's 577,000 non-Medicaid enrollees had to complete reverification before Jan. 1 to find out if they still qualified for the scaled-back TennCare program. But the process has been so fraught with problems that TennCare advocates, legislators, and Gov.-elect Phil Bredesen agreed it was fundamentally flawed and cut off people who qualify for the program and desperately need coverage.

—*Memphis Commercial Appeal*, Dec. 5, 2002