



# State Health Watch

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The Newsletter on State Health Care Reform

May 2003



## In This Issue

**There's money in the system to cover the uninsured:** But the fight to get it allocated that way could be tough, according to the Urban League's John Holahan . . . . cover

**States could provide child mental health services more efficiently:** Time to choose a new policy to replace a failed one . . . . . cover

**Massachusetts searches for a better way:** A report by Consumer Quality Initiatives records the difficulties experienced by young adults who receive mental health treatment as adolescents and later transition to adult services . . . . . 6

**Smallpox vaccination preparations hurt other programs:** A survey of local public health agencies by the National Association of County and City Health Officials indicates the nation's smallpox vaccination program negatively affects other bioterrorism efforts . . . . . 8

**Early results from a new breast cancer screening:** The Breast and Cervical Cancer Prevention and Treatment Act of 2000 established a new state coverage option under Medicaid . . . . . 10

**Mental illness, meds, and Medicaid:** State and federal governments need to ensure continued access to effective medications for people with severe mental illnesses . . . . . 11

## Policy-makers must decide: Cover uninsured or pay a higher price

**T**here is a money available to subsidize health insurance for the uninsured, but it needs to come from money spent on uncompensated treatment, says a report presented by a coalition of groups looking to improve insurance coverage.

The coalition studies also reconfirmed the conventional wisdom that lack of health insurance leads inevitably to higher health care costs for the government and the rest of the population.

A study prepared for the Kaiser Commission on Medicaid and the Uninsured based in Washington, DC, and published by *Health*

*Affairs* says that uninsured Americans received about \$35 billion in uncompensated health care treatment in 2001, with federal, state, and local governments covering up to 85% of that total.

Urban Institute researchers Jack Hadley and John Holahan write that because about \$31 million in government money already is being spent to support care to the uninsured each year, it "should be possible to transfer a large share of these funds to a new program to subsidize the cost of providing insurance coverage for the uninsured. Our analysis

See **cover story** on page 2

## Families often suffer needlessly when making choices for treating mental health disorders

**A** recent report from the Bazelon Center for Mental Health Law in Washington, DC, paints a grim picture of the choices parents are forced to make to obtain mental health services for their children.

The advocacy group says that states are not using policy options available to them that would increase access to mental health services.

"States are failing children with mental health needs in many parts

of the country," says Chris Koyanagi, Bazelon policy director, who wrote *Avoiding Cruel Choices: A Guide for Policymakers and Family Organizations on Medicaid's Role in Preventing Custody Relinquishment*. "Laws already on the books could provide immediate relief for these families, yet few states are really using them."

Ms. Koyanagi tells *State Health Watch* that often those with private coverage face limits on the number of visits and the types of service that are covered.

See **Fiscal Fitness** on page 5

**Fiscal Fitness:  
How States Cope**



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

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

Editor: John Hope, (717) 238-5990,  
[johnhope17110@att.net](mailto:johnhope17110@att.net).

Senior Production Editor: Ann Duncan.

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## Cover story

Continued from page 1

demonstrates that a fair amount of money is already in the system and that a substantial portion of the cost of covering the uninsured is potentially available from existing government programs.”

The two researchers say the beneficiaries of expanded insurance coverage would be:

- newly insured people, who currently receive much less care than the insured and would have their coverage follow them through the system rather than having it buried in subsidies to a limited number of health care providers;
- hospitals, which deliver two-thirds of uncompensated care;
- private practice physicians, who account for more than half of the private subsidies that underwrite the cost of uncompensated care;
- state and local governments, which face increased financial pressure from uncompensated care during recessions, when tax revenues shrink and the number of uninsured people rises because of unemployment;
- the federal government, which would be able to both better target its payments for the uninsured and rationalize its Medicare and Medicaid payments to providers.

When asked by *State Health Watch* whether he has received support from policy-makers for his recommendations, Mr. Holahan says,

“There hasn’t been any contact, no one thanking us for pointing out where some dollars are. But that’s not surprising because the current environment is not one in which lots of money could be used to expand services,” he says.

Mr. Holahan says he believes the value of his work lies in the

indications it gives for a year or so from now when there may be more interest in addressing the plight of the uninsured. “We’ve pointed to ways that money could be reallocated,” he says, “although the political fight to go after these dollars could be quite tough.”

#### One in three not covered

The Princeton, NJ-based Robert Wood Johnson Foundation’s fact sheets ([www.coveringtheuninsuredweek.org](http://www.coveringtheuninsuredweek.org)) showed 41.2 million Americans lack health insurance coverage, up 1.4 million from 2000.

Of that total:

- 47% are white.
- 30% are Hispanic.
- 16% are black.
- 7% list other racial identifications.

A report from Families USA shows 74.7 million people younger than age 65 — nearly one person in three — were without health insurance for all or part of 2000 and 2001. Nearly two-thirds were uninsured for six months or more.

Other statistics from the report showed:

- About 25% of all uninsured people younger than 65 were uninsured for the full 24 months of the analysis period.
- 18.7% were insured for 13 months to 23 months.
- 9.8% were uninsured for nine months to 12 months.
- 12.5% were uninsured for six months to eight months.
- 24.9% were insured for three to five months.
- Only 10% of all uninsured people were without insurance for two months or less.

The Institute of Medicine, in its contribution to the report, said more than 80% of uninsured people younger than 65 are members of working families. Their jobs do not provide insurance coverage and

buying individual coverage frequently is too costly. **As shown in the graph below**, two-thirds of uninsured families earn less than 200% of the federal poverty level (roughly \$35,000 for a family of

four). Only 59% of persons with household incomes less than 150% of the federal poverty level are able to cover the entire family. In contrast, 90% of families with incomes above 200% of the federal poverty

level have all family members insured.

The Robert Wood Johnson fact sheets say widespread lack of health care coverage affects not only the uninsured and their families, but also the communities in which they live and the greater society.

“Both research and anecdote indicate that the lack of health insurance keeps people from getting care when they are sick,” the report says. “Lack of coverage also keeps people from getting routine preventive health services that can avert or detect serious illnesses early.”

The problems of the uninsured take a financial toll on everyone, according to the Robert Wood Johnson Foundation. Because the uninsured tend to wait longer to seek treatment, they often are sicker when they finally receive care. And when they do go for care, they frequently go to the nearest hospital emergency department, an expensive and inefficient way to receive care.

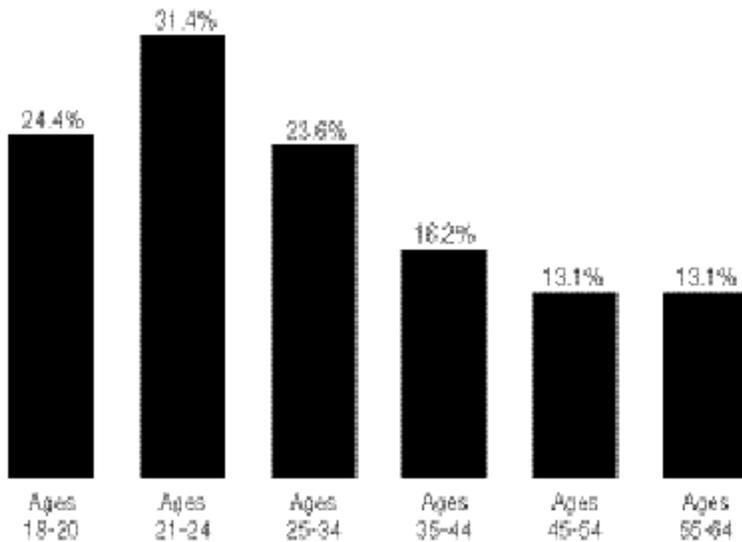
The Families USA report says the uninsured often go without screenings and preventive care, often delay or forgo needed medical care, are often subject to avoidable hospital stays, are sicker and die earlier than those who have health insurance, and require more costly care than those who are insured.

*‘I’m covered. Why should I care?’*

Arthur Kellerman, MD, chairman of the department of emergency medicine at Emory University School of Medicine in Atlanta, who led the Institute of Medicine committee that studied the uninsured, says many people with health coverage ask why they should care about the uninsured. “Your insurance is about as secure as your job, and maybe today people are less sanguine about that than they were two or three years ago,” he says.

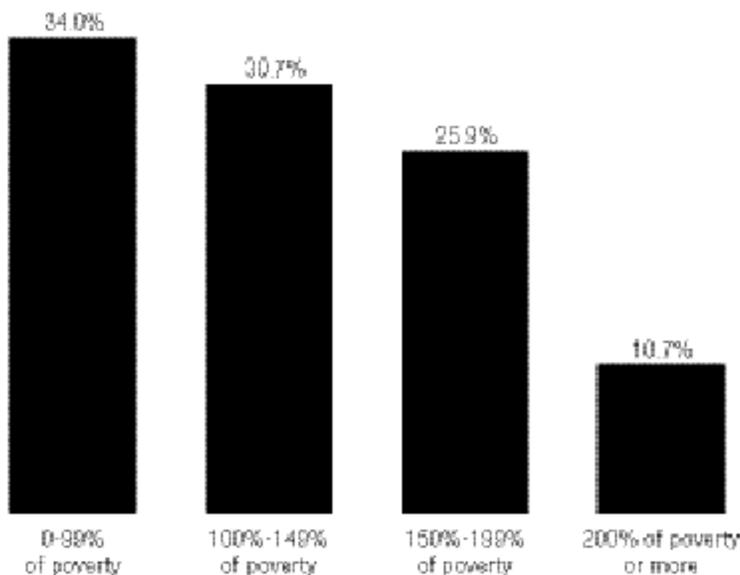
“Also, your access to health care is

### Distribution of the Uninsured in the U.S. by Age Group



Source: Robert Wood Johnson Foundation, Princeton, NJ.

### Distribution of the Uninsured in the U.S. by Poverty Level



Source: Robert Wood Johnson Foundation, Princeton, NJ.

as secure as the health care system in your community, and this report brings to focus that particularly in rural and urban areas where there are high numbers of uninsured, the health care system is under stress, under strain, and is not as capable as we want to think it is to provide the kind of care that we want to count on when the chips are down. That is an issue that I think should be troubling and of concern to everybody in the country, whether or not they themselves have health insurance," Mr. Kellerman adds.

Jeanne Lambrew, a professor in George Washington University's Department of Health Policy in Washington, DC, says the number of uninsured is growing, and adds it may increase by 30% over the next decade. Erosion of employer coverage may worsen, even in an economic recovery, she says, and fewer people may be covered by Medicaid and other governmental programs.

To put the total uninsured figure of 41 million into perspective, Ms. Lambrew says that it is more than Canada's population, more than all the people on the U.S. West Coast, more than all elderly Americans and all African-Americans, five times more than the number of Americans with cancer, and 40 times more than the number of Americans with HIV/AIDS.

#### *Most uninsured are employed*

Contrary to conventional wisdom, most of the uninsured are employed (59% full time and 16% part time). While most have low income, the fastest growth is among those with higher incomes. The uninsured are disproportionately Hispanic, and are concentrated in the U.S. South and West.

Ms. Lambrew says 18,000 uninsured adults die each year because they don't receive proper medical

care and the risk of death for uninsured people with cancer is 50% higher than for the insured.

The uninsured paid, on average, \$1,200 for health care in 1999, a significant proportion of income for some. Health care costs are a major source of debt for the uninsured, with medical bills accounting for 40% of personal bankruptcy and a major source of credit card debt. Some 40% of the uninsured report having difficulty paying for basic living costs such as food, housing, and heat in 2001, compared with 12% of those with insurance, Ms. Lambrew says.

There is a societal impact, according to her research, because uninsured workers are more likely to miss work, less likely to use preventive services, less likely to exercise regularly, and less likely to receive appropriate care for chronic illnesses. Uninsured children are 25% more likely to miss school; three times more likely to not get needed medications, glasses, or mental health care; and less likely to play sports.

#### *Why people don't buy insurance*

The National Institute for Health Care Management (NIHCM) in Washington, DC, a foundation largely supported by Blue Cross and Blue Shield plans, says reasons that people do not purchase health insurance vary.

One study showed that many perceive premiums to be more costly than they, in fact, are and that nearly 25% would buy insurance if they knew the real price. Some of the nonpoor opt out of health insurance because they don't see a need for it, either for cultural reasons or because they don't see its value.

That report's authors say expanding coverage among this group likely will involve private sector initiatives

and programs that sometimes may be constructed in collaboration with or supported by government.

The NIHCM surveyed health plans for successes and lessons learned and reports that, generally, health plans that successfully reached the uninsured were affordable and attractive. And they marketed those products aggressively. In addition, they effectively managed situations in which people were transitioning out of one form of coverage into another, or to a new job.

Studies have found that most people who are price resistant don't want to pay more than \$100 or \$150 per month for individual insurance and not more than \$250 to \$300 a month for family coverage. Such pricing requires trade-offs, NIHCM says, and keeping health insurance affordable is no small task in a time of escalating health costs. Most of the successful initiatives identified in the NIHCM report used innovative product design, flexible and reduced benefits, enhanced cost sharing, and/or reduced profit margins to keep premiums as low as possible. A few of the successful plans depended on cross-subsidies within a health plan's scope of business.

#### *Multiple marketing strategies*

Also critical to success was marketing, particularly in the small group market. Small group initiatives attracting more than 10,000 members used direct mail; multiple brokers; the Internet; toll-free telephone numbers; and TV, print, and radio ads. Health plan administrators said that among all these strategies, brokers were critical for securing new members.

Recommendations based on lessons learned from the NIHCM report were:

- Use a multifaceted marketing

approach to reach a well-delineated population.

- Allocate sufficient resources to support aggressive marketing three months before product launch and one to two years after the program's introduction.
- Conduct research before creating products to determine the right mix of cost and coverage.
- Design benefits around price categories.
- Consider alternative methods to lower premiums such as rate stability, reduced profit margins, and enhanced cost-sharing mechanisms.
- Define the target population to support a multifaceted marketing approach — remembering that moderate income populations (more than 200% of poverty level) may yield higher enrollment.
- Use the same provider network as for other commercial products since a limited provider panel may diminish the product's value.
- Analyze whether creating a pilot rather than launching a full-scale product may become a barrier in reaching the uninsured due to limited health plan commitment.
- Partner with state programs for cross-referrals from public programs and to target people likely to be between sources of coverage.
- Allow "aged-out" dependents to remain on a parent's policy
- Make enrollment procedures easier by providing materials in multiple languages and limiting the length of the application form.

*[For information, go to these web sites: [www.coveringtheuninsuredweek.org](http://www.coveringtheuninsuredweek.org); [www.familiesusa.org](http://www.familiesusa.org); [www.iom.edu](http://www.iom.edu); [www.kff.org](http://www.kff.org); and [www.nihcm.org](http://www.nihcm.org). Contact Mr. Hadley and Mr. Holahan at (202) 261-5666.] ■*

## ***Fiscal Fitness***

*Continued from page 1*

"If a child has a serious disorder," she says, "it's not enough to have a few sessions or limited access to medication. Families need a lot of support. There is a need for a public system, but access is getting tougher and tougher. It's almost all Medicaid, and many families are not eligible because their income is too high but they still don't have the money for a residential program."

The report charges that many families who can't get mental health services for a child give up custody of the child to the state to be able to secure services.

"Custody relinquishment is absolutely devastating to the parent-child bond," according to Ms. Koyanagi. "It shouldn't have to be this difficult for families to get services, and it wouldn't be if states were making better use of Medicaid policy options for covering these children."

Two available policy options covered in the report are the TEFRA (Tax Equity and Fiscal Responsibility Act of 1982) option and the Medicaid waiver that allows states to fund home- and community-based services. Use of either of these options would allow states to cover children with significant mental disorders and dramatically reduce pressure on families to give up custody.

Ms. Koyanagi's report cites statistics from the National Alliance for the Mentally Ill (NAMI) that some 20% of families of children with mental or emotional disorders were advised to give up custody to get help. When they do, NAMI says, they risk losing their children permanently since under federal law, states must work to place children who are in custody in adoption or back with their families within strict time limits.

Other parents are told to call the police and turn their children over to the juvenile justice system so they can receive mental health care. Ms. Koyanagi writes that reliance on the child welfare and juvenile justice systems tears families apart and misuses public funds. Among other consequences, children are led to believe they have been abandoned by their family, irreparably damaging the bond between child and family; parents are forced to make an unthinkable choice between retaining responsibility for and relationship with their child and giving decision-making authority and control to a state agency to get the help that is needed; public funds are wasted by keeping children as wards of the state when families who love them could provide for their basic needs; and children are forced into expensive residential placements rather than living in supportive families and receiving less costly community-based services.

### *Two available options*

So what can be done? Ms. Koyanagi points to two avenues that states could pursue.

- The TEFRA option (also sometimes known as the Katie Beckett option, after the child whose situation led to the policy) allows states to cover home- and community-based services for children with disabilities living at home. It is for children who would otherwise need the kind of skilled care provided in a medical institution. Eligibility for TEFRA is based on a child's disability and care needs, and not on family income. Children who qualify under TEFRA are given a Medicaid card, and all state Medicaid program rules apply, thus making them eligible for the full array of services covered for

*(Continued on page 7)*

## MA mental health study shows the way to better treatments

**A** new report issued by the Consumer Quality Initiatives in Dorchester, MA, records the difficulties experienced by young adults who receive mental health treatment as adolescents and later transition to adult services. The group finds that eligibility for adult services is stricter, and Medicaid dollars primarily support short-term acute care services.

In addition, most of the service options for adults are not appropriate to the age of the newly transitioned young adults, as they are geared to older adults with more severe disorders. Finally, a legal guardian no longer is responsible for the basic needs of these individuals, meaning that homelessness and criminal justice involvement become real possibilities.

Principal investigator Jonathan Delman, an attorney who lives with manic depression, says, “[The news] is not all bad. The Department of Mental Health has made youth transition a priority. Two young adults who assisted on this project have co-chaired the department’s youth development committee that is charged with developing transition planning for the State Planning Council, and the department has provided us with seed money to develop a peer-mentoring project for youth in intensive residential treatment programs. We also are talking to MassHealth officials about the inclusion of a strong transition component in a family-focused program that will provide support to youth through age 22.”

The report was drawn from 24 interviews with young adults 18 to 26 who had received adolescent public mental health services in the state. A large majority of the group was white and had been hospitalized and/or received therapy at some point during their adolescence.

There was a median age of 21, and males and females were represented in equal numbers.

Twelve of the respondents reported they currently were living in a group home or supported housing for people with mental health and/or substance abuse difficulties, with nine of them living in programs that focused on young adult needs. Of the remainder, four were homeless, three were in a state hospital, three lived with family, and two lived with roommates.

One-third of the respondents were working part time. About 75% had been graduated from high school or obtained a GED. Three of the group had taken college courses but dropped them for psychiatric reasons. Five were currently taking college courses, with two attending full time.

Before aging out, just over one-third were living in a group residential setting and one-third were in a locked intensive residential treatment program, with the remainder at home with family or with a foster family. Those aging out of the group or residential setting were most commonly discharged to another group home or family, although some were moved to a state hospital.

When asked to describe the process of aging out, a majority used words like “scary,” “stressful,” “hard,” “traumatizing,” and “awful,” reporting feelings of shock and helplessness. Five respondents reported positive experiences because they did not find adolescent services helpful or did not feel they were treated respectfully.

Themes emerging from those who found the experience difficult included:

- One-half of respondents said the process felt “unstable,” as though

the ground were moving out from under them. Several had little notice they were to be moved and didn’t have a chance to first visit their new adult setting and meet staff. Others found themselves homeless or in prison.

- One-third said they had an immediate loss of interpersonal support. Some no longer had substantial access to an adolescent case manager or therapist they had grown to know and trust. Others missed the general support they had as youth, such as being driven to movies and assistance with shopping.
- One-quarter commented on the shock of entering adult programs or hospitals with an older group of people with whom they did not identify.

When asked what types of help could have made the experience more positive, they usually mentioned adult independent skills training during the transition period such as money management, socialization skills, and job search skills; advanced planning for the transition; and involvement in planning for the transition.

Based on the interviews, Consumer Quality Initiatives makes the following recommendations to improve youth transition to adulthood:

- Start the transition planning process by at least age 16.
- Youth should not only be involved in planning their transition, but the process should be driven by their needs and desires, rather than the needs and desires of the system.
- There should be a consistent level of support for young people before and after they age out, with a strong independent living

*(Continued on page 7)*

- other Medicaid-eligible children.
- Home- and Community-Based Services Waivers are available for an expanded array of home- and community-based services to be furnished to children or adults with physical or mental disabilities as an alternative to institutional care that would otherwise be paid for by Medicaid. The waivers also permit states to provide Medicaid coverage to some children who otherwise would not be eligible for Medicaid. Children are eligible for waivers without regard to income. To receive federal approval for a waiver, states must show that the average cost of community care for all children in the waiver will

skills training component throughout.

- There should be age appropriate congregate living services for the youth in transition.
- A peer mentor program should be established with mentors who are young adults who have experienced mental illness and can help youth set goals, find resources that will move them toward their goals, and advise in a supportive and friendly way.
- A youth in transition citizenship web site should be developed so mentors and youth could collaboratively seek resources and navigate the health system and locate rehabilitative resources.
- A youth advocacy training curriculum should be established for those who have experienced the mental health system so they may develop a sustained and formalized voice to inform policy-makers about their needs and how the system can best respond to them.

(To download the report, go to: [www.mass-cst.org](http://www.mass-cst.org)) ■

not exceed the average cost of the institutional care that would be paid by Medicaid. A significant advantage of the waiver route is that states may expand the array of services for the children in the waiver. In three states with home- and community-based waivers for children with mental or emotional disorders, expanded services include respite care for the families caring for children at home, other family support services, and skill building.

Ms. Koyanagi says the TEFRA option has an important advantage over the waivers — TEFRA creates an entitlement for children who qualify, while under a waiver a state may limit the number of children who benefit. No one can be excluded from the TEFRA option based on limited state resources, diagnosis, or for any other arbitrary reason. An advantage of waivers over TEFRA is that states can expand the array of services available to children and families. States also may find waivers more attractive because they can accurately estimate the cost of the waiver and limit costs to funds available for their match of federal Medicaid dollars.

The report indicates that only 12 states use either approach to improve access to services for families whose children have a serious mental or emotional disorder and even in those states, the number of children benefiting from the policies is very small.

Only three states (Kansas, New York, and Vermont) have pursued a federal waiver for children with mental or emotional disorders; by contrast, 49 states have such waivers for people with developmental disabilities. Ms. Koyanagi says that many states considered seeking a waiver for children with mental or emotional problems but dropped it when they ran into barriers such as

lack of state funds to pay the state share of Medicaid costs, a federal rule that prevents children in or at risk of placement in a residential treatment center from being eligible, and a requirement that community services be no more expensive than alternative institutional placement. She reports that experience of the three states that do have waivers shows that these barriers can be addressed and the per-child costs under the waiver are quite low.

Twenty states opted for the TEFRA option, but half of them have no children who qualified as a result of a mental or emotional disorder. Even in states with the TEFRA option, very few children participate, according to Ms. Koyanagi, and in most of those states, children with mental or emotional disorders are a small percentage of the small overall numbers. Compared to the total enrollment in Medicaid, enrollment in TEFRA is minimal.

Ms. Koyanagi says she is surprised that 30 states and the District of Columbia have not adopted the TEFRA option for children with disabilities since if the state requires a family to relinquish custody, it would be taking on responsibility for the entire cost of the child's care, in contrast to the large federal share paid under TEFRA. It appears, she says, that state officials could benefit from learning more about the program and its use. From states already using the option, other state officials would like to know the number of children who have qualified, expenditures on services for these children, specific TEFRA rules used, characteristics of children who use the program, source of funds for state match, and plans and proposals developed to justify its use.

Ms. Koyanagi tells *State Health Watch* that in many states, the problem is one of priorities, with mental

health very low in their scheme of things, and children very low within the mental health system. She says start-up costs often get in the way, as does the need to be willing to make an investment in community-based services as an approach.

Advocates for families of children with mental or emotional disorders are urged to review their state policies on TEFRA and home- and community-based waivers and push policy-makers to make changes needed to help families keep their child with a mental disability at home. In states that have not adopted either approach, policy-makers should be asked to choose and adopt one. In the 10 states that have the TEFRA option but no qualifying children with a primary diagnosis of mental disorder, advocates should urge changes in the rules and criteria and greater effort to publicize the option to potentially eligible families.

In states that do have the TEFRA option and children with a primary diagnosis of mental disorder, check the number of children who qualify and if it seems low, urge state officials to make greater efforts to publicize the option to potentially eligible families. In states without a waiver, policy-makers should be urged to review its practicality for children with mental and emotional disorders.

Ms. Koyanagi says that making greater use of the TEFRA and waivers could dramatically reduce pressure on families to give up custody of their children. "It is a shame that so many families are suffering needlessly when we could so easily reduce the need to choose between a child's mental health and preservation of the family," she says.

*[To see the report, go to: [www.bazelon.org](http://www.bazelon.org). Contact Ms. Koyanagi at (202) 467-5730, ext. 118.] ■*

## Local agencies say smallpox vaccinations hurting other efforts

A survey of local public health agencies by the National Association of County and City Health Officials (NACCHO) in Washington, DC, indicates the nation's smallpox vaccination program negatively impacts other bioterrorism preparedness activities such as development of response plans, disease surveillance systems, and epidemiologic capabilities.

According to the survey results, local public health agencies find it difficult to maintain routine public health services such as vaccination clinics, maternal and child health programs, and environmental health programs, while meeting the demands of planning and implementing the smallpox vaccination program and other bioterrorism related activities.

Of 539 agencies responding to a question about whether smallpox preparation efforts had taken away from other bioterrorism activities, 79% said there had been a negative impact.

"Efforts to prepare for chemical, biological, and radiological terrorism have been taken off track in order to meet the demands of the smallpox vaccination program," NACCHO says in a research brief. "Many respondents cited limited resources and staffing, the complexity and resource-intensity of the program, and the lack of additional bioterrorism funds as a cause. [The local agencies] expressed concern about the country's vulnerability to attacks from agents other than smallpox, such as ricin, dirty bombs, and anthrax."

About half of the agencies that responded to the survey said bioterrorism preparedness planning has

taken away from their other public health programs and activities. Most of those who offered a more detailed explanation said staff, resources, and funds had been diverted from other public health activities to help with smallpox vaccination planning and implementation. A significant number of local agencies said they deferred, delayed, or cancelled specific public health programs and activities due to smallpox vaccination planning and implementation.

Interestingly, one-third of the respondents said that bioterrorism and other preparedness planning had helped their other public health activities, especially through establishing better relationships with community partners.

### *Vulnerability could increase*

NACCHO concludes that limited resources and growing workloads are preventing local public health agencies from giving equal attention to maintaining current levels of service, developing a smallpox vaccination program, and preparing for bioterrorism events. Continued diversion of resources, it says, will increase communities' vulnerability to ongoing public health threats such as influenza, West Nile virus, contaminated drinking water, food-borne illnesses, and chronic diseases.

"Notably, this level of disruption to the local public health system occurred before a single volunteer was vaccinated" the report says. "It can be expected that, without additional resources, the negative impact of the smallpox vaccination program on general bioterrorism preparedness activities and routine public health services will increase."

Some relief may be on the way as the Department of Health and Human Services (HHS) announced March 20 that \$1.4 billion was to be provided to states this year to help them enhance preparations against terrorism or other public health emergencies. Tommy Thompson, secretary of Health and Human Services, also announced special provisions under which states could get up to 20% of their 2003 funding immediately to support current activities, including smallpox vaccination for selected health workers and emergency responders.

Thompson said some states need a share of their 2003 funds right away, while others will want to receive them later, following their planning process, and the decision will be left to the states.

The funding is part of a total of about \$3.5 billion in HHS funding this year for bioterrorism, preparedness, including research into potential bioterror disease agents, and potential treatments and vaccines.

American Public Health Association (APHA) associate executive director for public affairs Kelly O'Brien tells *State Health Watch* that his group supports the early release of funds.

"But," Ms. O'Brien says, "additional resources are needed to ensure that we proceed without shifting resources from other preparedness requirements and to ensure that we maintain our ongoing programs that protect Americans from everyday health threats. We urge Congress to make sure that adequate dollars are appropriated."

#### *Groups call for legislation*

Before that announcement was made, several public health associations joined in a call for passage of national legislation to address impediments to the smallpox preparedness effort. Three critical needs

identified by the groups (the American Public Health Association, the Association of State and Territorial Health Officials, and NACCHO) were: (1) a national smallpox vaccination compensation program to provide compensation to those who may be injured as a result of volunteering to be vaccinated; (2) additional liability provisions to provide necessary protection from costly legal action for organizations and individuals who participate in the vaccination program; and (3) new federal funding to support smallpox preparedness efforts at the state and local levels.

The three groups urge Congress and the administration to approve a comprehensive national smallpox injury compensation program to provide easily accessible compensation to anyone who becomes ill, injured, or disabled, or who dies as a result of the vaccine, either through primary or secondary transmission. They also asked for a broader definition of those entities covered by liability protection under the Homeland Security Act.

Addressing the overall funding issue, the groups strongly agree that funding remains a great concern and additional funds will be needed if state and local public health agencies are to carry out all their responsibilities.

At about the same time that the organizations were calling for a smallpox vaccination compensation plan, Thompson said the government would create a program to provide benefits to public health and medical response team members who are injured as a result of receiving the smallpox vaccine. Elements in the plan, said to be similar to one already available to police officers and firefighters, are a permanent and total disability benefits; death benefits; temporary or partial disability benefits; and

health care benefits.

HHS also proposes to provide compensation to third parties who contract vaccinia from public health and medical response team workers who have been vaccinated.

Ms. O'Brien from APHA tells *State Health Watch* of a number of ways a compensation plan could be strengthened:

1. A national program should provide timely first-dollar compensation for medical care and lost wages, rather than function as a system of last resort.
2. The program should not be limited in time. (It currently proposes a 120-day time limit.) There will be a need for full protections for volunteer vaccinees for as long as it is national policy to maintain preparedness for smallpox.
3. Lump-sum payments for death and disability should include lost wages. The incidence of permanent disability and death is likely to be extremely low. Therefore, providing an expanded benefit that more accurately reflects lost income will not be costly and will ensure greater confidence among volunteers that they and their families would be protected.
4. Volunteers who are helping our nation address terrorism preparedness should receive compensation for all lost wages. Compensation should begin immediately without any period of delay, should be 100% rather than 66%, and should not be subject to a cap.

Meanwhile, a coalition of parents and health care providers organized as Americans for Vaccine Safety and Accountability, asked that Congress separate reform of the Child Vaccine Injury Compensation Program from bioterrorism legislation. A coalition news release says the group opposes inclusion of Vaccine Injury

Compensation Program reforms in a bill that targets funding for development of new bioterrorism vaccines and compensation for health care workers injured by smallpox vaccine.

“Wedging reform of the federal vaccine injury compensation for children into a fast-tracked bioterrorism bill is no way to get the job done right,” said coalition president Barbara Fisher.

“Congress made a social contract with the parents of America in 1986, and that contract was that if parents vaccinated their children, then the government would provide federal compensation if a child was injured. The no-fault, expedited, fair, and generous compensation system that Congress envisioned has not lived up to its promise, and we owe it to all children to do it right this time around,” she added.

[To download government information, go to: [www.cdc.gov/smallpox](http://www.cdc.gov/smallpox) and [www.hhs.gov](http://www.hhs.gov). Contact NAC-CHO at (202) 783-5550; Ms. O'Brien at (202) 777-2501; and Ms. Fisher at (703) 038-0342.] ■

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

Alabama	p. 10
Alaska	p. 10
Georgia	p. 10
Illinois	p. 10
Iowa	p. 10
Kansas	p. 7
New Hampshire	p. 10
New York	p. 7
Massachusetts	p. 6
South Dakota	p. 10
Utah	p. 10
Vermont	p. 7
Washington	p. 10
Washington, DC	p. 7
West Virginia	p. 10

## *New cancer program combines population screening with public health intervention*

The Breast and Cervical Cancer Prevention and Treatment Act of 2000 established a new state coverage option under Medicaid that permits states to extend Medicaid to any uninsured woman under age 65 who was screened and diagnosed with breast or cervical cancer through the National Breast and Cervical Cancer Early Detection Program funded by the Centers for Disease Control and Prevention (CDC).

Creation of this coverage option has been seen as a groundbreaking effort to use population-wide public health screening programs as pathways for publicly funded health insurance.

The Centers for Medicare & Medicaid Services (CMS) contracted with George Washington University's Center for Health Services Research and Policy to conduct an 18-month study to analyze initial steps by states to implement the act. The intent was to determine: (1) how states are taking advantage of the new Medicaid option; (2) how state Medicaid agencies and Title XV grantees (which are responsible for administering the detection program) are collaborating on implementation; (3) whether and how implementation of the treatment act is affecting operation of the screening; (4) what procedures are involved for enrolling women in Medicaid; and (5) states' experience in implementing the treatment act.

### *Disease-based coverage category*

Principal investigator Kathleen Maloy tells *State Health Watch* that after the screening program got under way, it became evident that many women were uninsured or

underinsured for treatment following their free screening. The Breast and Cervical Cancer Prevention and Treatment Act creates a Medicaid coverage category that is unusual because it is disease-based rather than income-based. Some 48 states have adopted the treatment program as an optional Medicaid service and so far have given it a lot of support, Ms. Maloy says. Women in the program have access to all Medicaid services and the coverage lasts for as long as they have a cancer diagnosis.

### *Making a difference for women*

She says the ultimate goal of the evaluation is to demonstrate that the program makes a difference for women and that there will be better outcomes if women have health care coverage through Medicaid. The first step in that process is to document that the program has been put in place in states and to look at how states implemented the new coverage category.

The first 10 states to implement and be analyzed were Alabama, Alaska, Georgia, Illinois, Iowa, New Hampshire, South Dakota, Utah, Washington, and West Virginia.

Initial findings have been that the Title XV and Title XIX agencies in the 10 states were working well together to adopt the prevention and treatment act and on relatively equal footing, although the Title XV agencies generally took the lead on implementation and worked through questions with the CDC and CMS.

States reported having a lot of confusion about the meaning of the three screening options in particular as well as other aspects of implementation. The three options are: (1) CDC Title XV funds paid for all or

part of the costs of screening services; (2) the woman was screened under a state Breast and Cervical Cancer Early Detection Program in which her particular clinical service was not paid for by Title XV funds but was done by a provider funded at least in part by Title XV; and (3) the woman was screened by any other provider and/or entity and the state agency that received a Title XV grant has elected to include screening activities by that provider as screening activities pursuant to Title XV. The researchers say that confusion about the screening options “did not appear to constrain these states’ decision making about implementation.”

States, they say, considered and selected screening options largely based on the design and scope of their existing Title XV National Breast and Cervical Cancer Early Detection Program screening network. Moreover, they decided what their screening network would be and then determined which option seemed to fit their choice.

The initial report says that state

experiences with enrollment and expenditures for the coverage varied, and it is difficult to generalize about the experiences. Four states reported greater than anticipated enrollment.

According to the report, the researchers found substantial variability regarding states’ capacities for data collection and monitoring. The uncertainty about data capacity and quality is likely to present future challenges for designing a data-based impact evaluation.

Ms. Maloy says the question about data collection will come into play more next year as the research starts to look at documented outcomes of the care provided under the new law. Resolving data collection issues could be difficult, she says, because it might mean a very large information technology expenditure for only a small number of beneficiaries.

She says the ability of various state agencies to work together synergistically for this program has implications for other efforts in the future if there is interest in further

extending insurance coverage by disease. It seemed to work well to involve the Title XV agency at the front end, to gather eligibility information and transmit it to the Medicaid agency. Other lessons learned, she says, are that it’s important to look carefully at the screening network, what the outreach activities are like, and those who are likely to be brought into coverage. And it’s important to make eligibility and enrollment as easy as possible so more women are encouraged to apply and obtain coverage.

“It’s good to see how excited state officials are about this program, how important it is to them in dealing with women who have a hard time finding providers,” Ms. Maloy tells *State Health Watch*. “There’s a strong sense of support and excitement for implementing the screening and enrolling women for treatment.”

[Contact Ms. Maloy at (202) 296-6922. E-mail: [kmaloy@gwu.edu](mailto:kmaloy@gwu.edu).] ■

## The mentally ill, effective meds, and Medicaid

State and federal governments need to ensure continued access to effective medications for people with severe mental illnesses even though Medicaid programs are trying to save money by controlling prescription drug use, according to the National Alliance for the Mentally Ill (NAMI) in Arlington, VA.

Michael Fitzpatrick, NAMI Policy Research Institute director, says the group’s recommendations need to be followed because “in too many cases, state efforts to control drug costs are penny-wise and pound-foolish. Too many times in the past, people with mental illnesses have been neglected or abandoned, at a terrible cost. As a society, we know how to treat mental illnesses, but too often, the investment is too little, too late. Restrictions on access to effective medication are acts of budget desperation not enlightened leadership. They will compromise recovery and lead to greater costs elsewhere. They represent bad medicine and Medicaid malpractice.”

NAMI says that some 45 states are considering or instituting restrictions on Medicaid drug benefits through preferred drug lists, fail-first requirements, pill-splitting, increased copayments, and other measures.

A number of states have adopted or are considering restrictions on access to certain types of expensive medications, including psychotropics. NAMI says the various types of prior authorization restrictions can pose significant threats for Medicaid recipients with serious mental illnesses trying to access medications prescribed by their treating physician.

“While NAMI understands that states must make tough decisions in the face of the current budget crisis,” the group’s report says, “these programs will jeopardize consumer health if they restrict access to needed medications.

“It is clear to the NAMI Policy Research Institute that the consequences for people with serious mental

*(Continued on page 12)*

illness will be devastating if Medicaid prior authorization programs and other cost-control initiatives become more commonplace,” the report continues.

“Based on costs rather than health and safety, prior authorization programs, preferred drug lists, and fail-first procedures often force physicians and consumers to choose medications that they would otherwise not prescribe. Restrictions on access to psychotropic medications not only jeopardize consumer health, but they fail to reduce overall health costs. Multiple studies have shown that in the long run, such policies actually increase costs in hospitalization as well as emergency and primary care.”

NAMI’s 10 recommendations cover:

1. an increase in the federal Medical Assistance Percentage to help states cope with the current difficult budget times;
2. legislative initiatives to expand prescription drug coverage for Medicare beneficiaries;
3. systemwide health care reform to reduce fragmentation in the delivery of mental health services and ensure access to the most effective treatment;
4. increased funding allocations to the National Institute for Mental Health to gain better insights on access to new medications and research into evidence-based practice;
5. opposition to state Medicaid prior authorization programs;
6. carve-out programs for anti-psychotic, anti-depressant, anti-anxiety, and anti-convulsant medications if there are prior authorization programs;
7. research by drug companies to develop new medications, but with opposition to pricing practices that make new medications unaffordable;

8. development of notification, grievance, and appeals procedures to protect Medicaid recipients with serious mental illness;
9. participation in class-action suits to oppose restrictions on Medicaid clients’ access to prescription drugs through prior authorization programs;
10. support for “polypharmacy education programs,” which are aimed at reducing the over-prescribing of medications as an alternative to restrictive cost-containment programs and development of explicit treatment protocols with rigorous follow-up assessments.

Mr. Fitzpatrick tells *State Health Watch* that the medications taken by those with mental illness often are different from those taken by people with medical problems in that psychiatrists often need to try several of the new so-called atypical medications with patients until they find one that is effective and with tolerable side effects so that the patient will be willing to take the medication.

“NAMI and other advocates fought for years for these drugs,” he says, “so that side effects can be controlled and people will take them.”

When states make use of preferred drug lists or fail-first requirements, he says, psychiatrists don’t have the opportunity to get to the

best medication for the patient.

Among the 10 recommendations, according to Mr. Fitzpatrick, NAMI particularly is involved in working at the state level to oppose any efforts to go to a fail-first requirement. And if states do intend to institute a pre-authorization, NAMI will urge that mental health medications be carved out.

#### *Treating life span illnesses*

When asked how he justifies treating mental health medications differently, Mr. Fitzpatrick points out that schizophrenia is a “life span illness” and that when patients don’t get the specific medication they need, their life “is a disaster.”

It is similar to the case made by HIV/AIDS patients, he says, in that if you don’t get the medication you die. “Policy-makers have some understanding of this need,” he tells *State Health Watch*.

Mr. Fitzpatrick says it can be difficult to argue NAMI’s case because the battle takes place at several venues — governors’ offices, legislative halls, the media, and the public police arena. “It’s a hard thing to get your arms around,” he says, “unlike some things that are just legislative issues.”

[For more information, go to: <http://www.nami.org>. Contact Mr. Fitzpatrick at (207) 353-9311.] ■

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