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## Program Cuts Affecting Half of All State Title V Programs For Children With Special Health Care Needs

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Just over half of all state Title V Programs for Children with Special Health Care Needs (CSHCN) have made or plan to make program cutbacks in fiscal year 2002. This is due in large part to state budget shortfalls. Unlike state Medicaid programs and State Children's Health Insurance Programs (SCHIP), which rely heavily on federal matching funds, Title V CSHCN programs are much more dependent on state, and also local, revenues. Federal Title V block grants are small in comparison to Medicaid and SCHIP, and states have a good deal of discretion in structuring their programs. All state CSHCN programs participate in planning and systems development for children with special health care needs, and most purchase or provide evaluation, care coordination, and gap-filling specialized services for children with complex physical conditions. Few function primarily or exclusively as planning agencies.

To assess the extent of CSHCN program impacts resulting from state budget problems, the Maternal and Child Health Policy Research Center queried all state Title V CSHCN directors in December 2001-January 2002. Forty-six states participated, including the District of Columbia, giving us a response rate of 90%.<sup>1</sup> Five states did not participate in the study.<sup>2</sup>

This fact sheet, the second in a series that examines budget impacts on various state programs serving children and adolescents, is intended to provide a description of the fiscal situation state CSHCN programs are facing in the current fiscal year. It should be noted, however, that some states are still

in the process of assessing their budgetary and programmatic decisions for fiscal year 2002. Information received subsequent to the completion of the interviews suggests that there may be additional states experiencing budget reductions in their Title V CSHCN programs.

Of the 46 state CSHCN programs participating in our study, 24 (52%) had either reduced or were expecting to reduce their Title V CSHCN program expenditures in fiscal year 2002. An additional 11 states were as yet unsure if cuts would be occurring this fiscal year. We found that states experiencing program cuts are far more likely to be from the South than states not reporting cuts. In addition, they are somewhat more likely to draw a greater share of their program revenues from state and local sources.

Among the 24 states that reported program reductions, more than three-quarters (19 states) explained that they were due to anticipated shortfalls in their fiscal year 2002 budgets. Eleven states were able to estimate the size of their program cuts since all but one had received official notification. The state of Washington is experiencing the most dramatic budget cut -- 22%. Seven states -- Iowa, Maine, Missouri, Oregon, North Carolina, Ohio, and Maryland -- anticipate budget cuts between 7.6% and 10%. Three states -- Georgia, Kentucky, and Utah -- expect budget cuts of 5% or less. One additional state -- Arizona -- will be reducing its CSHCN budget between 2.6% and 5%, but does not anticipate having to reduce its current program. The main cause of CSHCN financial

difficulties is state general budget shortfalls. A handful of states cited a variety of other reasons, including new bioterrorism expenditures, larger-than-expected caseloads from S-CHIP and Medicaid, and accounting system problems.

### Reductions in Administrative Spending

Nineteen of the 24 states (79%) reporting that they would be reducing CSHCN expenditures in fiscal year 2002 were making administrative spending cuts. Eleven of these states reported that staff positions would be eliminated, reduced, or left vacant. Eight states planned to reduce expenditures for education and training. Special program initiatives were being reduced in 5 states and parent support activities in 1 state. Maryland, for example, is reducing support for its referral liaison function at each center of excellence, and also its telemedicine projects.

Other activities were slated for cuts in 5 states, most often, travel.

### Controls on Eligibility and Enrollment

Four states (17%) anticipate adopting controls on enrollment in fiscal year 2002. Arkansas plans to reduce the number of children who receive a broad set of CSHCN services by lowering its income eligibility standard from 300% of the federal poverty level (FPL) to 185% and also the number of children with high-cost catastrophic conditions who receive a limited set of CSHCN services by lowering income eligibility from 350% FPL to 250%. Texas is capping enrollment and decreasing outreach efforts. Montana also plans to cap enrollment, and Missouri intends to reduce outreach.

### Reductions in Eligible Conditions or Services

More significantly, 11 of the 24 states (46%) reducing CSHCN expenditures said they planned to reduce or eliminate eligible conditions or services, while 6 more states were uncertain if they would have to implement service cutbacks. Oregon, North Carolina, and Washington are anticipating the most

substantial changes. Oregon is phasing out all of its direct services for children with special health care needs. This will include the elimination of its pediatric orthopedic special-needs clinic and reductions in services through its child development clinic. North Carolina is also planning to eliminate direct services and may be targeting specialty clinics, purchase of medical care program, community transition coordinate program, or other services. Washington plans to reduce its contract with Seattle Children's Hospital and 14 neurodevelopmental

centers throughout the state.

Among the remaining 8 states anticipating changes in their service or condition policies, different cost-cutting approaches are being pursued. Arkansas, in conjunction with its income eligibility changes, plans to eliminate coverage for attention deficit hyperactivity disorder and also respite services for Medicaid-insured children receiving private duty nursing. Delaware is reducing its discretionary fund which pays for items not covered by insurance, such as durable medical equipment, unpaid medical bills, and reimbursement for out-of-state travel for medical care. Georgia is capping its benefit amounts for durable medical equipment, surgeries, and other

STATE COST-CUTTING MEASURES					
State	Administration	Enrollment	Services/ Conditions	Cost- Sharing	Other
AL				X	
AR	X	X	X		
CO	X				
DE			X		
FL	X				
GA	X		X	X	
HI	X				
IL					X
IA	X		X		
KY	X				
ME	X				
MD	X		X		
MI	X				
MO	X	X			
MT		X	X		
NY	X				
NC	X		X	X	
OH	X				
OR	X		X		
RI	X				
TX	X	X	X		
UT	X				
VT			X		
WA	X		X		

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services. Maryland is reducing subsidies to its centers of excellence, genetics centers, and medical day care centers. Texas, because of an almost \$6 million budget shortfall and existing waiting lists, plans to implement numerous cost-saving measures, but has not yet decided which to implement – ending respite care, narrowing the definition of eligible conditions, or other strategies. Vermont is reducing the availability of respite care. Iowa and Montana reported that they will be eliminating clinic locations or hours. Illinois was the only state that mentioned decreasing reimbursement to a variety of providers.

### **Increases in Cost-Sharing Requirements**

Three of the 24 states (13%) reported plans to increase cost-sharing requirements as a way to reduce spending. Alabama is revising its family sliding-fee scale, and North Carolina is initiating a sliding-fee scale for assistive technology services. Georgia is applying consistent cost participation requirements for children in families with incomes between 150% FPL to 236%.

### **Effects on Planned Program Expansions**

When asked if budget shortfalls would have an effect on planned CSHCN program expansions, the vast majority of states making program cuts -- 20 states or 83% -- responded affirmatively. Three additional states not making cuts in FY 2002 -- New Mexico, Tennessee, and Wyoming -- are postponing program expansions.

State directors mentioned a range of possible program expansions that would not be implemented because of budget reductions. Maryland is unable to initiate a diabetes project and tandem mass spectrometry for newborn screening as well as long-term follow-up for infant hearing screening. In addition, Maryland's CSHCN program will not be able to expand eligibility to 300% FPL and may not be able to provide partial subsidies to its specialty clinics. Illinois plans to delay expansion of its care coordination services. Iowa's planned expansion into mental health will not occur. Michigan cannot pay enhanced dental reimbursement to improve access for children with special health care needs. Montana is unsure if it will be able to expand its regional clinics

and purchase hearing aids. North Carolina is not processing any training contracts and is postponing efforts to transition its program's focus to the Healthy People 2010 goals.<sup>3</sup> Texas expects that its contracted family support services will be reduced, and Vermont will be unable to expand respite services.

### **Other Changes Affecting Access to Services**

As a result of states' current fiscal situation, more than a quarter of all state CSHCN programs expect a substantial increase in the number of children requesting services from their program. This increased demand will likely result in waiting lists in 7 states. Still, however, about 60% of all state directors reported other changes that will likely affect access to services for children with special health care needs. The 2 most commonly cited factors were higher rates of uninsurance (reported in 20 states) and reductions in provider availability (in 17 states). Medicaid cuts were reported in 6 states, private health insurance coverage reductions in 2 states, and S-CHIP cutbacks in 2 states.

When asked about possible changes in other state programs serving children with special health care needs, many directors reported statewide cuts in early intervention, special education, developmental disabilities, and mental health. Among the 14 states reporting cuts in early intervention programs, almost 80% were also experiencing Title V CSHCN reductions. Although Title V CSHCN directors were not as knowledgeable about anticipated changes in special education, developmental disabilities, and mental health programs for children and adolescents, 12 states reported cuts in one or more of these programs. As one state Title V director stated, "This is the worst year for programs that I have experienced in my 7-year tenure. There is no state money to fall back on."

Despite the challenging fiscal environment that just over half of state Title V CSHCN programs are faced with, several states commented on positive changes being taken to improve coordination and integration of services for children with special health care needs. Four states described care coordination initiatives. Florida is revising its care coordination guidelines to align more closely with the concept of

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medical home and Massachusetts is also integrating its care coordination program with medical homes. Georgia is working with Medicaid to secure reimbursement for case management. Mississippi, with federal MCHB funding, is partnering with their state's Coalition of Citizens with Disabilities to improve coordination of services for adolescents making the transition to adulthood. Three states discussed efforts to improve interagency collaboration. Connecticut has set up a statewide task force to review agency collaboration around the provision of services for children with special needs. North Carolina is working to better integrate the Title V CSHCN program with early intervention and mental health and to improve planning and collaboration with families across all state health divisions. In addition, North Carolina is examining ways to reorganize its services and redirect them according to the federal Maternal and Child Health Bureau's model of direct, enabling, population-based, and infrastructure-building services. Two states are undertaking programmatic activities to implement 2010 goals. Alabama hosted a statewide summit on the Healthy People goals, and 6 work groups, composed of many diverse public and private

agencies, have been formed around each goal. Missouri has also focused on the 2010 goals and, as a result, has made changes in services, care plans, and family advisors in each region. Other program improvements were described. Arizona has initiated telehealth projects. Iowa has started a community-based children's mental health program with a telemedicine and educational component. Virginia is establishing centers of excellence throughout the state for children with special health care needs.

Overall, our study revealed that 52% of all state Title V CSHCN programs are adopting cost-cutting measures in fiscal year 2002. Of the 24 states cutting their budgets or programs, 11 states appear to be making the most significant reductions. They are Arkansas, Georgia, Iowa, Maine, Maryland, Missouri, Montana, North Carolina, Ohio, Oregon, and Washington. A handful of states mentioned that cuts in CSHCN programs, coupled with proposed reductions in Medicaid, S-CHIP, early intervention, special education, developmental disabilities, and mental health will adversely affect access to children with special needs.

## Endnotes

<sup>1</sup> The Title V CHSCN directors in Puerto Rico and the U.S. Virgin Islands also participated in this study. Puerto Rico is experiencing a budget shortfall that will result in spending cuts for the CSHCN program before the end of FY 2002. The U.S. Virgin Islands' CSHCN director did not know if the program would be experiencing a budget shortfall or program cutbacks this fiscal year.

<sup>2</sup> These states are Indiana, Louisiana, New Jersey, South Carolina, and West Virginia.

<sup>3</sup> These 2010 goals are as follows: 1) All children with special health care needs will receive coordinated, ongoing

comprehensive care within a medical home. 2) All families of children with special health care needs will have adequate private and/or public insurance to pay for the services they need. 3) All children will be screened early and continuously for special health care needs. 4) Families of children with special health care needs will partner in decision-making at all levels and will be satisfied with the services they receive. 5) Community-based service systems will be organized so families can use them easily. 6) All youth with special health care needs will receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

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