

## CHILDREN WITH SPECIAL HEALTH CARE NEEDS BEAR THE BRUNT OF THE ADMINISTRATION'S PROPOSED ACTIONS TO LIMIT THE SCOPE OF MEDICAID

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Over the last year, the U.S. Department of Health and Human Services Centers for Medicare and Medicaid Services (CMS) has proposed and in some cases implemented a deluge of regulations and administrative actions related to Medicaid and the State Children's Health Insurance Program (SCHIP) that, if not halted, will fundamentally change longstanding policy related to providing health care for our nation's neediest populations.

According to a recent report commissioned by First Focus and conducted by Sara Rosenbaum, Chair of the Department of Health Policy at the George Washington University School of Public Health and Health Care Services, the series of regulatory and administrative actions run counter not only to the long-standing history but also to the statutory provisions governing the Medicaid program. These provisions have been affirmed by Congress repeatedly over the last four decades in support of providing comprehensive, high quality care to children with serious and chronic health conditions. Furthermore, the report, which is entitled "CMS' Medicaid Regulations: Implications for Children with Special Health Care Needs," shows that the CMS regulatory and administrative actions contravene the Medicaid statute.

The report follows a recent study by the House Committee on Oversight and Government Reform showing that these actions would reduce federal payments to states by nearly \$50 billion over five years – over three times the impact estimated by CMS and the Office of Management and Budget (OMB).<sup>1</sup> The report's findings further highlight that the most severe impact of these actions will actually fall upon our nation's most vulnerable children, in particular, children with special health care needs (CSHCN).

**As a result, First Focus strongly urges Congress to take immediate action to halt and overturn the efforts by CMS to usurp Congressional authority through the issuance of this series of wholesale regulatory changes to long-standing Medicaid policy. Particularly, Congress should ensure that no child who is currently covered under SCHIP or Medicaid loses their health coverage or access to care as a result of these administrative actions.**

The leading findings of the Rosenbaum report include:

- The Administration's rehabilitation and case management rules contravene the Medicaid early and periodic screening diagnosis and treatment statute (EPSDT), which guarantees

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<sup>1</sup>U.S. House of Representatives Committee on Oversight and Investigations, "The Administration's Medicaid Regulations: State-by-State Impacts" (March 2008).

comprehensive health care and case management for children, from birth through age 21, particularly children who experience pre-birth or birth-related injuries and whose conditions are present at birth and affect growth and development.

- CMS regulations virtually eliminate public health nursing case management for special needs children. Public health nursing as a basic Medicaid management activity has been a hallmark of the Medicaid statute for children since 1967, as part of the same Congressional amendments that created EPSDT benefits.
- By prohibiting the use of schools to administer Medicaid, the regulations are contrary to the statutory requirement of efficiency, since they eliminate the most efficient means available to states to find and enroll children, as well as to manage care for children with special health care needs. As such, the rules directly contravene state agencies' EPSDT and public health nursing outreach and case management obligations under federal law.

## **CONCLUSION**

First Focus rejects CMS's regulatory and administrative efforts which attempt to chart a course for Medicaid and SCHIP that would propel these programs in a direction that is directly contrary to both longstanding federal statute and recent decisions by Congress rejecting these very policy recommendations when presented by CMS as statutory proposals. In particular, First Focus's leading concerns, which are addressed in the Rosenbaum report, include:

- The Administration's regulatory and administrative actions are in violation of the federal Medicaid statute, which guarantees comprehensive health care for children with special needs. In fact, the report shows these actions to be "a wholesale rewrite of the law" that "would result in the unlawful denial of payment for covered services."
- The regulatory and administrative actions will most profoundly impact the provision of health care and rehabilitation services for CSHCN, especially the use of public health nursing in home, school and other community settings.
- The Administration's actions "would seriously impair the ability of states to assure that special needs children in moderate income families can receive Medicaid or SCHIP." Moreover, the exclusion of schools as a source of administrative support for children receiving health care would deprive states of "one of the most *efficient* methods for carrying out their health care access duties."
- Children with special health care needs are particularly dependent on Medicaid. Thus, these individuals are most likely to be hurt by the regulatory and administrative actions of CMS.

## **Health Implications**

The systematic changes proposed by CMS would be especially harmful for CSHCN because Medicaid plays a critical role in maintaining their health and well-being. The report specifically highlights some of the critical health care needs of these children:

- While health insurance is essential for all children, it is particularly important for children with special needs. In order to be healthy and to continue to improve their health status, CSHCN benefit most when they have access to routine care. According to the data, parents of insured

special needs children are significantly less likely to report that their children are without a usual source of care, lack a regular clinician or after-hours coverage, or that they are dissatisfied with one or more aspects of their care. While 79.2 percent of parents of uninsured children with special needs report having a regular source of care, that figure rises to 97.6 percent and 95.3 percent, respectively, in the case of privately insured and publicly insured children.<sup>2</sup>

- The costs associated with caring for CSHCN also make it more likely that parents will delay seeking care for their child. Nearly 1 in 5 parents of uninsured children with special needs report delaying health care because of cost, while reported delays decline to 4.3 percent in the case of privately insured children and 3.5 percent in the case of publicly insured children. Notably, families at all income levels report barriers related to the cost of coverage (more than 74 percent of respondents) and inability to obtain coverage because of health problems (slightly more than 1 percent of respondents).<sup>3</sup>
- The most endangered group of children may be those who were born prematurely and at very low birthweight who may require both immediate and ongoing services throughout their lives as a means of achieving maximum rehabilitation from birth injury.<sup>4</sup> It is these children for whom public health nursing in homes, schools, and communities is critical, and it has played an especially strong role in the history of federal and state Medicaid administration, directly contravening the letter and spirit of federal law in numerous respects.
- CMS' regulatory and administrative actions would restrict the provision of some services related to the Early Periodic Screening, Diagnosis, and Treatment (EPSDT) provisions of the Medicaid statute. EPSDT has been part of the Medicaid law since 1967 and guarantees that all categorically needy children under age 21 have access to comprehensive health coverage. The Administration's regulations would eliminate federal matching funds for a broad range of EPSDT-related activities.

### **Education, Child Welfare Impacts**

Unfortunately, the problems associated with the regulations and administrative actions go beyond the healthcare issues highlighted in this report. On the education front, schools, which are on the front lines to help students get access to critical health services – e.g. speech and physical therapy for Medicaid-eligible students – **would no longer be reimbursed for providing those services.** At the same time, schools will continue to be required by law to ensure that children get the services they need to learn. As a result, the regulatory changes serve only to shift the cost burden to schools which ultimately would be forced to cut back on other programs to offset the loss of these federal funds.

In addition, the proposed changes to Medicaid policy would have a devastating impact on our most vulnerable children by hampering the delivery of critical services to foster care children. Specifically, the administrative actions narrow the definition of allowable rehabilitative services eligible for

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<sup>2</sup> Newacheck, P. et. al. (2000). Access to health care for children with special health care needs. *Pediatrics* 105(4), 760, 764

<sup>3</sup>Id. 764

Newacheck, P. et. al. (2000). Access to health care for children with special health care needs. *Pediatrics* 105(4), 760, 764

<sup>4</sup> Wang, C.J. 2008. Population-Based Assessments of Ophthalmologic and Audiologic Follow-up in Children with Very Low Birth Weight Enrolled in Medicaid: A Quality of Care Study *Pediatrics* 2:121 e278-e285 (Feb.)

federal reimbursement and limit access to therapeutic foster care and critical services provided for special needs adoptions by social service agencies. CMS' administrative actions also would restrict the delivery of needed care to foster care children by undermining states' abilities to coordinate needed medical, social and educational services.

### **Need for Action**

While the Administration estimates that the regulatory changes would result in \$15 billion in savings to the Medicaid program, the House Oversight Committee recently found that federal payments to states would be reduced by approximately \$49.7 billion over the next five years, more than three times the Administration's estimate.

As echoed by the nation's governors to during their February 2008 meeting with Congress in Washington, D.C., these regulatory actions represent a direct cost-shift to the states at a time when governors already are working to counteract the effects of the recent economic downturn.

First Focus urges Congress to act immediately to halt the Administration's efforts to usurp Congressional authority by imposing wholesale changes to longstanding federal statute. In particular, Congress must work vigorously to ensure that no child who is currently covered under SCHIP or Medicaid loses their health coverage as a result of the Administration's unilateral regulatory actions.

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