

August 3, 2011

The Honorable Kathleen Sebelius, Secretary
United States Department of Health and Human Services
200 Independence Avenue, S.W.
Washington, D.C. 20201

Dear Secretary Sebelius:

As organizations committed to the health and welfare of children, we write to express concern with many of the provisions of Utah's recent application for a demonstration waiver of Medicaid rules under Section 1115 of the Social Security Act. We urge you to approve a demonstration project only if it promotes the objectives of the Medicaid program, as required by Section 1115. Any demonstration must adequately protect children's access to medically necessary care, prevent their families from incurring unaffordable health care costs, and maintain key beneficiary protections like the freedom to maintain or change health plans.

Utah's demonstration proposal seeks to waive the requirement that the state provide Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) -- the Medicaid benefit for children. EPSDT embodies Medicaid's objective of providing children with the services that are medically necessary for their healthy growth and development. Utah proposes to limit the services available to children to a prioritized list whenever growth in per capita Medicaid spending exceeds growth in the state's general fund expenditures. While children constitute 57% of the enrollment in Utah's program, they constitute only 28% of the cost. During an economic recession, the need for Medicaid grows and overall spending on the Medicaid program will grow. At the same time, state general fund expenditures will slow. Thus, this benefit cut would be triggered at the time of greatest need for children to have the safety net of Medicaid coverage. Therefore, we urge you not to waive EPSDT benefits for children.

Utah also proposes to waive Medicaid's cost-sharing protections, potentially exposing very low-income families to unaffordable medical costs in some new and troubling ways. The proposal would give accountable care organizations the authority to set co-payment amounts up to a maximum specified in the proposal and to pick and choose what co-pays to charge to children to act as "client incentives." We do not believe it is appropriate for insurers to decide whether children have to pay more to access needed health services as a result of their (or more likely their parents') behavior.

The maximum co-payment amounts specified in the proposal would represent a dramatic increase in medical costs for the lowest income families in Medicaid. Currently, children below "mandatory" eligibility levels—the only children Utah covers in Medicaid—may be charged co-payments only for non-preferred prescription drugs and non-emergency use of emergency departments. The demonstration proposal sets no separate cost-sharing limits for children, so families could be exposed to costs for services delivered to their children up to the 5% of income cap on cost-sharing charges. Families with children with special health care needs may be particularly exposed to cost-sharing of as much as 5% of all outpatient hospital charges and the same for charges for medical equipment and supplies.

Research has shown that cost-sharing places a heavier burden on those with low income: they often delay or reduce their use of needed care, leading to poor health outcomes. Medicaid's cost-sharing protections assure that a family's lack of resources does not impose a barrier on access to care for the lowest-income children. CMS should not allow Utah's demonstration to introduce such barriers for these children, barriers that do not exist anywhere else in the country.

Other provisions of Utah's proposal have the potential for adverse effects on both child and adult beneficiaries. For instance, the proposal gives ACOs the authority to disenroll beneficiaries if they do not follow medical advice or do not "keep a good relationship" with a doctor. These subjective criteria could allow ACOs to disenroll higher-risk beneficiaries and could also disrupt care.

We urge CMS to reject these aspects of Utah's demonstration waiver proposal. Children are by far the single largest group affected by this demonstration proposal, yet their needs are not specifically discussed. As submitted, the proposal could remove important protections that help ensure low-income children have access to affordable care. Since a key objective of Medicaid is to assure access to care for such children, the proposal should move forward only if these concerns are addressed. Please contact Joan Alker or Joe Touschner at Georgetown Center for Children and Families for more information.

Sincerely,

American Academy of Pediatrics
American Dental Education Association
American Heart Association
Children's Defense Fund
Children's Dental Health Project
Community Catalyst
Cystic Fibrosis Foundation
Easter Seals
Families USA
First Focus
Georgetown University Health Policy Institute Center for Children and Families
March of Dimes Foundation
National Association of Pediatric Nurse Practitioners
National Council for Community Behavioral Healthcare
National Health Law Program
National Women's Law Center
Voices for America's Children
ZERO TO THREE

CC:

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Vikki Wachino, Director, Children and Adults Health Program Group
Richard Jensen, Director, Division of State Demonstrations and Waivers