

Reforming Medicaid for Medically Complex Children

abstract

Children's hospitals play a central role in our child health care system. These hospitals face unique challenges under health care reform. They care for children with the most complex medical problems but often are not reimbursed for good preventive care, care coordination, or quality. We discuss a proposal by children's hospital leaders to create a network of Nationally Designated Children's Hospitals. These would be Centers of Excellence on which states and families could rely to care for a uniquely vulnerable and uniquely costly population of children. On a federal level, the proposal is focused on 3 provisions: (1) creating and delivering a national coordinated delivery model for children with chronic and complex conditions in Medicaid and the State Child Health Insurance Program; (2) developing pediatric-specific care coordination guidelines, quality metrics, and network adequacy standards to improve pediatric care delivery; and (3) producing cost savings by reducing fragmentation in care delivery, while providing a payment model that provides a significant measure of budget certainty for states and the federal government, either through a bundled payment or a shared savings payment method. We believe that this approach will ensure access to appropriate care without compromising the quality of care. It will also provide enhanced budget certainty for Medicaid and the State Child Health Insurance Program. *Pediatrics* 2013;131:S160–S162

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children's health, chronic, complex, health care, Medicaid, networks, reimburse

ABBREVIATIONS

ACA—Affordable Care Act

SCHIP—State Child Health Insurance Program

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Three years ago throughout our nation, town hall meetings, forums, and hearings were held to discuss the nation's number 1 issue: health care reform. But rarely in this debate were children ever mentioned. Most of us agree that children are our most treasured responsibility and that we should try to do everything possible to nurture and promote their health and development. But how did that translate in terms of health care reform for children? As with so many things, the devil is in the details. Medicaid and the State Child Health Insurance Program (SCHIP) cover more than 1 in 4 children today, making these programs together the single largest children's health insurance plan. Children represent more than one-half of all Medicaid recipients, yet they account for only 25% of the spending. The Medicaid program chronically underpays hospitals and physicians in comparison with their actual costs and 30% less than what Medicare would pay. Consequently, some hospitals and many physicians limit or do not accept Medicaid payments because they cannot afford to do so. This reality exacerbates wait times for appointments, contributes to the pediatric specialist shortages, and ultimately creates additional hardships for families.

We know that when children have health insurance coverage, they are healthier. Emergency department use decreases and health care needs are addressed in timely, cost-effective ways. In addition, we know that healthy children grow up to be healthy adults, which in turn helps our nation's economy. Therefore, expanding Medicaid coverage to all children is one necessary step, but to keep moving forward with the nurturing and promotion of the healthy growth of our children, we must ensure that Medicaid providers receive adequate reimbursement to continue providing services so that coverage does equal access.

Children's hospitals are uniquely positioned to guide and assist in the formulation of creative health care policies for children. Children's hospitals provide the highest quality, most-efficient care for children in our country. We are leaders in research, clinical care, and training, and we incorporate these subjects into our mission statements. Children's hospitals provide primary care and critical care for all children, and we are committed to unlocking cures to illness with a goal of ultimately eliminating childhood diseases. We are the nation's experts at managing children's health, and we have a unique and vital partnership with government as the safety net for our nation's most critically ill and injured children.

Today, with the passage and implementation of the Affordable Care Act (ACA), children's hospitals continue to inform and educate our government leaders about solutions we know will benefit children's health and produce savings in Medicaid and SCHIP. Although important and significant changes in children's health care were included in the ACA, there is more work to do. Some of the benefits for children in the ACA include insurance reforms that eliminate denials for preexisting conditions, the removal of annual lifetime caps, and allowing children to stay on their parent's or guardian's policy through age 26 years. In addition to ensuring that children have adequate insurance coverage, we must guarantee that access to that coverage is not diluted. We must ensure that the infrastructure that currently exists in this country to care for the most critically injured and ailing children is sustained, even during difficult times. We must ensure that, as a country, we continue to value our current pediatric medical infrastructure and invest to further the care provided to children.

The children's hospitals are focusing on these values and on ensuring that our

country and our nation's leaders continue to invest in children's health care. We anticipate that entitlement reform will be a focus in Washington in the coming months. A group of children's hospitals views this as an opportunity to find additional ways to improve access and quality of children's health care and to reduce Medicaid costs. This group of children's hospitals came together some 20 months ago with the sole purpose of offering solutions to Congress that would provide a means to achieve savings in pediatric expenditures in Medicaid. This proposal would be an alternative to some of the across-the-board cuts consistently floated in policy circles relating to Medicaid that would result in indiscriminate and disproportionate adverse impacts on children's health care. This informal group and its proposal have been embraced by the larger umbrella and experienced leadership of the Children's Hospital Association. As a member hospital of that founding group of children's hospitals, we believe now is the time to explore bold policy options under Medicaid, focusing on the most vulnerable children first.

Children's hospitals must work closely with Medicaid because, on average, >50% of our patients are insured by Medicaid. Approximately 7 million children suffer from chronic and complex conditions in this country. This group of children receives most (>80%) of their complex care from a small number of the nation's children's hospitals and subspecialists, and their care is financed predominantly by the Medicaid program. The children's hospitals believe that by focusing on improving care for this small group of vulnerable children, we can reduce fragmentation in their care delivery, improve their quality outcomes, and bend the cost curve in Medicaid expenditures. Studies we have conducted illustrate the fact that

medically complex children rely on specialized children's hospitals because of the uniqueness of their problems, and they often travel long distances, including over state lines, to see their pediatric specialists. Many of these children and their parents experience fragmentation and regional gaps in the health care delivery system. The patchwork quilt of >50 different Medicaid programs in our country hinders the improved care coordination, communication, and information sharing essential to saving money and advancing quality. These children usually require care from multiple providers, but because state-based Medicaid data lack the consistency associated with national data, best practice standards for quality do not exist.

We know that pediatric care coordination can improve quality and reduce costs for medically complex children. However, current payment systems do not support the services and programs necessary to advance more integrated care management, and they are therefore financially unsustainable. Moreover, states fail to reimburse or authorize necessary treatment consistently that must be accessed for these children across state lines. Often, parents and social workers are left to fend for themselves in fighting for access to necessary care, or hospitals and physicians who provide care are left fighting with Medicaid programs to support, reimburse, and ease the burdens of even those families truly entitled to the critical care provided.

Children's hospitals need stable, consistent, and adequate payment for services provided to children in Medicaid and SCHIP, and especially for children with chronic and complex needs.

This is a national issue that requires a national solution.

The children's hospitals group, therefore, recommends the creation of Nationally Designated Children's Hospital Networks in Medicaid and SCHIP for children with chronic and complex conditions. These would be Centers of Excellence on which states and families could rely and would be nationally designated centers authorized to care for the vulnerable population of children that qualify in this small but costly category which the proposal covers. On a federal level, the proposal is focused on 3 provisions: (1) creating and delivering a national coordinated delivery model for children with chronic and complex conditions in Medicaid and SCHIP; (2) developing pediatric-specific care coordination guidelines, quality metrics, and network adequacy standards to improve pediatric care delivery; and (3) producing cost savings by reducing fragmentation in care delivery, while providing a payment model that offers a significant measure of budget certainty for states and the federal government, either through a bundled payment or a shared savings payment method. In the end, we believe that focusing on the population and developing a medical home model linked to a comprehensive family-centered specialty network will result in ensuring access to appropriate care without compromising the quality of care and enhanced budget certainty for Medicaid and SCHIP.

States could, of course, opt in to the program, which would ensure that their children would have access to the pediatric Centers of Excellence and the regional networks developed to serve these medically complex children. States involved in this effort would adopt nationally consistent pediatric care coordination, quality, and network

adequacy standards for medically complex children. States would agree to pay for services provided by the Nationally Designated Children's Hospital Networks to children who received care, regardless of the state in which the care was provided. This national program would be phased in over 5 years.

The Nationally Designated Children's Hospital Networks would be required to provide medical homes for children with chronic and complex conditions and would be held accountable for their care. The intent is not to disrupt existing provider relationships but rather to enhance them in a manner that ensures the child and family receive the most appropriate care in the most appropriate provider setting. These networks would wrap the care coordination and enhanced access to pediatric-focused care around existing provider relationships.

Significant cost savings are possible and would benefit both federal and state budgets while protecting the health of our nation's most vulnerable children. Now is the time to pioneer this Medicaid reform model for medically complex children. We believe current conditions have resulted in a unique opportunity for government, on federal and state levels, to change the trajectory of rising Medicaid costs while improving health outcomes for our most vulnerable population: children with chronic and complex conditions. Proven positive results over time also could only lead to greater child health care populations achieving improved health while lowering costs. The children's hospitals group recognizes this is a multiyear project but remains committed to the proposal and to advancing the ideas on Capitol Hill and in our states to achieve a new beginning of Medicaid reform for children.

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