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Health Reform and Children with Special Needs

BY KRISTINE GOODWIN

- Young adults can maintain health coverage under a parent's plan until age 26; marital and student status do not affect eligibility.
- Health care coverage cannot be denied to children with pre-existing conditions.
- Most employer-sponsored and individual insurance plans must cover specified children's preventive services, without cost-sharing, ranging from health screenings to immunizations.

Overview

The Affordable Care Act (ACA) changes health insurance regulations, expands access to coverage and requires improvements in health care services for certain groups, including for children with complex medical needs. Children and youth with special health care needs (CYSHCN) are at risk for chronic physical, emotional, behavioral or developmental conditions. Compared with children generally, children with special health care needs require more health care and related services.[1] Fifteen percent of children in the United States have a special health care need, and they account for 41 percent of child health costs.[2] According to a 2009 National Survey of Children with Special Health Care Needs, 34 percent of families with CYSHCN reported that their child's health insurance was not sufficient to cover needed services, and 22 percent of families indicated health care coverage for their child created financial hardship.

This brief summarizes major ACA provisions that significantly affect children and youth with special health care needs.

Key Federal Provisions

Private Insurance. Several ACA provisions increase access to health care coverage for children and youth with special health care needs.

The ACA also contains provisions that reduce the financial burden on the families of children with special health care needs. For example, the law prohibits insurance companies from imposing lifetime benefit caps, and as of January 2014, prohibits all annual benefit caps.

The ACA's provisions do not apply to all health insurance plans. Grandfathered and individual group plans are not subject to the new requirements for annual and lifetime benefit caps, essential benefits, out-of-pocket expenditures and preventive services. Grandfathered plans are those in place prior to March 23, 2010 that have not been altered significantly since the ACA's passage.

Health Insurance Marketplaces. The ACA required that health insurance marketplaces (also known as exchanges) be established in every state by January 2014. The online market-

places enable consumers to compare insurance benefits, purchase coverage and determine if they are eligible for Medicaid or subsidized health insurance. As of January 2014, families earning between 100 percent and 400 percent of the federal poverty guidelines ($23,850 to $95,400 for a family of four in 2014) may purchase insurance coverage through the exchanges and receive tax credits, based on their income. Health plans in the exchanges must cover "essential health benefits," several of which may especially benefit children and youth with special health care needs; for example, rehabilitative and habilitative services and devices, chronic disease management, prescription drugs, mental health care and pediatric services.

Medicaid and CHIP. Approximately one-third of children with special health care needs rely on Medicaid or the Children's Health Insurance Program (CHIP) for some or all of their health care coverage.[3] The ACA expanded Medicaid eligibility to cover individuals under the age of 65, with incomes up to 133 percent of the federal poverty guidelines ($31,720 for a family of four in 2014), a provision made optional by the June 2012 U.S. Supreme Court decision. As of July 2014, 27 states had expanded Medicaid under the ACA's provisions. Children currently enrolled in CHIP whose family income is below 133 percent of the poverty level shifted to Medicaid coverage—a move that offers access to a comprehensive set of Early, Periodic, Screening, Diagnosis and Treatment (EPSDT) benefits.

The ACA also contains provisions that may make it easier for families with CYSHCN to attain and maintain continuous coverage. The law required states to create a single, streamlined process that enables consumers to apply for, receive a determination and enroll in health coverage for which they are eligible. The law requires one single application for Medicaid and the health insurance marketplace, so people can apply for either and enroll in the coverage for which they qualify.

The federal law provides expanded Medicaid services for some of the most seriously ill children. Children enrolled in Medicaid with life-threatening conditions can receive hospice and curative care simultaneously under Medicaid. Also, Medicaid-enrolled children who have aged out of foster care are eligible to maintain coverage until age 26. The National Child Abuse and Neglect Data System estimates that more than 80 percent of foster care children have emotional, behavioral or developmental challenges. The American Academy of Pediatrics reports that children and youth in foster care are more likely to have a range of health conditions than any other group of children in the nation.

The ACA also offers states the opportunity to improve the coordination of health services for children with special health care needs. States have the option of providing "health home" services for individuals with multiple chronic conditions under Medicaid. Health homes are designed to increase access to and coordination of primary and acute physical health, behavioral health and long-term, community-based services. Better coordination of services may also reduce costs. To qualify, Medicaid-enrolled individuals must have one of the following: two chronic conditions, such as asthma, diabetes, obesity or a substance use disorder; one chronic condition and high risk for another; or one serious, persistent mental health condition.

Helping Families Navigate the Health System

The ACA appropriated nearly $5 million to support Family-to-Family Health Information Centers, which help families of CYSHCN navigate the health care system. In addition, states have the opportunity to strengthen existing programs or develop new ones to help consumers understand health plans and various benefit packages; to make them aware of their rights and responsibilities and the resources available to help them with questions or to file insurance complaints; and finally, to buy coverage.

State Roles in Implementation. Policymakers may want to consider the following issues when continuing to explore ACA implementation in their state:

- Explore ways to conduct outreach to additional children and youth with special health care needs and encourage insurance enrollment.
- Examine the state's role in developing and maintaining an adequate health care workforce—including specialists—to meet consumers' needs.
- Coordinate the new ACA requirements with current health care and insurance systems to improve access to services, assist in navigating health care systems, explore gaps in coverage and improve the health of children and youth with special health care needs.
- Investigate options, benefits and costs related to whether to expand the Medicaid program.

Endnotes

1. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, The National Survey of Children with Special Health Care Needs Chartbook, 2009-2010 (Rockville, Maryland.: DHHS, 2013).
2. Chevarly FM. Utilization and Expenditures for Children with Special Health Care Needs. Research Findings No. 24. (Rockville, MD.: Agency for Healthcare Research and Quality, 2006).
3. Georgetown University Health Policy Institute, Center for Children and Families, "Medicaid and its Role for Children and Youth with Special Health Care Needs: A Family Perspective," July 2011.

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