

Health Reform & Children & Youth with Special Health Care Needs

The AMCHP Role

AMCHP supports state maternal and child health (MCH) programs and provides national leadership on issues affecting women and children. We work with partners at the national, state and local levels to promote women's health; provide and promote family-centered, community-based, coordinated care for women and children; and facilitate the development of community-based systems of services for women, children and their families.

The AMCHP National Center for Health Reform Implementation provides state MCH leaders and their partners with the information, tools and resources to optimize the opportunities presented by the Patient Protection and Affordable Care Act (ACA) for improving services, systems and health outcomes for MCH populations.

Introduction

Currently, there are major gaps in the health care coverage, financing and delivery system that prevent children and youth with special health care needs (CYSHCN) from accessing health care services or which impose significant financial hardship on their families. Strategies are urgently needed to improve the coverage and financing of care for CYSHCN; they can be grouped into four important areas:

- **Covering More Kids:** Reducing the number of CYSHCN who do not have public or private insurance coverage
- **Closing Benefit Gaps:** Enhancing benefits for CYSHCN whose health insurance coverage is inadequate to meet their needs
- **Paying for Additional Services:** Increasing the options available to finance [care coordination](#), [respite care](#), home modifications and other [wrap-around](#) services for CYSHCN that are critically important but not typically covered by insurance
- **Building Capacity:** Analyzing, monitoring and promoting stronger, more comprehensive systems of care for CYSHCN

The *Patient Protection and Affordable Care Act of 2010* (ACA) contains provisions to address each of these four areas of need. The law is designed to increase coverage, improve benefits and provide important new insurance protections for all Americans. Many of the law's provisions impact children, including CYSHCN. This fact sheet briefly describes certain provisions within the ACA that directly impact CYSHCN and offers recommendations on the role that state Title V MCH and CYSHCN directors can play to ensure that CYSHCN populations have access to high quality and affordable care.

CYSHCN Provisions in the *Patient Protection and Affordable Care Act*

Prohibition of Pre-Existing Conditions (Sec. 2704)

Insurers can no longer deny coverage to individuals with pre-existing conditions. Pre-existing condition exclusions are defined as a limitation or denial of benefits related to a condition, based on the fact that the condition



was present before the date of enrollment for the coverage, whether or not any medical advice, diagnosis, care or treatment was recommended or received before that date. The ACA prohibits insurers from excluding benefits associated with a pre-existing condition or from completely excluding people from a plan or coverage based on a pre-existing condition. It is still allowable, however, for a plan to not cover every service, as long as the plan does not cover that service for any beneficiary, not just for those with the pre-existing condition. Prior to the passage of ACA, pre-existing condition clauses made it difficult for families with CYSHCN to find adequate and affordable coverage for their child's health care needs, kept them from changing jobs if they received their insurance through their employer, and put them at risk for financial hardship and medical debt.

Under the ACA, insurance companies are now prohibited from using pre-existing conditions as a way to limit their financial responsibility to those they insure.

Removal of Lifetime Benefit Caps for Children and Adults (Sec. 2711)

Prior to the passage of ACA, private insurance companies could place annual and lifetime benefit caps on coverage. This practice resulted in children with high medical costs, in effect, becoming uninsured when they exhausted their benefits and put families at risk for medical debt and financial hardship. The ACA prohibits issuers from imposing lifetime or annual limits on the dollar value of health benefits. These protections apply to the essential health benefits (EHBs), which include outpatient care; emergency room visits; treatment in the hospital for inpatient care; care before and after a baby is born; mental health and substance use disorder services; prescription drugs; habilitative and rehabilitative services; laboratory tests; preventive services; and pediatric services, including oral and vision care. An issuer may impose annual or lifetime dollar limits per individual on specific covered benefits that are considered non-essential. The EHB provision is especially important for families of children with high medical costs, to help them maintain their private insurance coverage.

Coverage of Young Adults on Parent's Health Insurance Policy (Sec. 2714)

Young adults have the highest rate of uninsurance among all age groups. For those just starting careers and families, the cost of employer-sponsored health insurance can be prohibitive, assuming it is even available to them. Prior to the ACA, young adults could stay on their parent's plans in some states, but only if they were full-time students, single or receiving financial support from their parents. The ACA provision allows all otherwise independent young adults to continue to receive health care coverage through their parent's plan up until the age of 26. Note that insurers that offer dependent coverage for children must make this coverage available for children until the age of 26. Dependent coverage for those up to the age of 26 is not reliant on student status, residency, marital status, employment status, or financial support of the dependent.

Coverage for Preventive Services with Prohibition on Cost-Sharing (Sec. 2714)

Preventive care is as important to CYSHCN as it is to any child. It is critical to detect new or worsening health problems through screening activities and to prevent the deterioration of physical or mental health by intervening early, in order to optimize a child's health and well-being. The ACA now requires health plans to provide coverage for recommended preventive services with no out-of-pocket costs such as deductibles, co-payments or co-insurance. Preventive care services that are important for CYSHCN are:

- Preventive items or services that have a current A or B rating from the U.S. Preventive Services Task Force (USPSTF).
- Vaccines recommended in the Immunization Schedules of the Centers for Disease Control and Prevention (CDC)
- Services recommended in the guidelines for preventive services for infants, children and adolescents, which include the [Periodicity Schedule](#) of the [Bright Futures Recommendations for Pediatric Preventive Health Care](#), and the Uniform Screening Panel of the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children

Medicaid Coverage Expansions (Sec. 2001, 2002 and 2004)

Prior to the passage of the ACA, childless adults in the majority of states were not eligible for Medicaid at any income level, unless the state created a waiver. In January 2014, a provision of the ACA went into effect that created a pathway to Medicaid for 19- to 65-year-old childless adults who are not pregnant, not disabled and whose income is less than 138 percent of the Federal Poverty Level (FPL). The Modified Adjusted Gross Income (MAGI) provision of the ACA standardized the way states calculate household income and established a five percent income disregard for certain populations. As a result, minimum income eligibility for the adult Medicaid population is now effectively 138 percent of the FPL.

On June 28, 2012, the U.S. Supreme Court ruled that the ACA was constitutional. However, the Court also said that the provision of the ACA that required state Medicaid programs to increase eligibility to childless adults contained a “coercive” penalty, whereby a state would lose all Medicaid funds if it did not expand Medicaid. Therefore, the Medicaid expansion provision is optional. States may choose to implement it, but it is not mandatory for them to do so. As of December 2015, 31 states, and the District of Columbia, have expanded Medicaid to include this new population of adults. This also expanded the income eligibility for the parents of dependent children in some states. The federal government will pay for the full cost of the expansion through 2016. Thereafter the federal share will gradually decrease to 90 percent by 2020.

Prior to January 2014, states were required to provide Medicaid to children birth to 6 years old with household income less than 138 percent of the FPL. The Medicaid benefit for 6- to 19-year-olds could be capped at 100 percent of the FPL. This was called stair-step eligibility. Although many states had income limits that were more generous than the federally required minimum, when the ACA was passed in March 2010, 21 states used the federal minimum of 100 percent of the FPL to determine Medicaid eligibility for 6- to 19-year-old children.

The ACA included a mandatory Medicaid expansion for 6- to 19-year-olds. Starting January 1, 2014, states that capped Medicaid eligibility at 100 percent of the FPL for this age range of children had to expand eligibility to 138 percent of the FPL. This change created a single income eligibility minimum for children from birth to age 19. As a result, more than 560,000 children moved from the Children’s Health Insurance Program (CHIP) to Medicaid. This age group of children now receives comprehensive Medicaid benefits, including the federally mandated child health benefit called [Early, Periodic Screening, Diagnostic and Treatment](#) (EPSDT).

In addition, families have reduced out-of-pocket health care costs, because states do not impose premiums or cost-sharing for children’s Medicaid when family income is less than 150 percent of the FPL. Another important Medicaid expansion under the ACA requires states to continue providing Medicaid coverage to children who have aged out of the foster care system but who are under age 26 (Section 2004). This provision offers former foster care children continuity in their health care as they transition to adulthood, and allows them access to a source of coverage comparable to or better than that offered to young adults under age 26 who can access their parent’s coverage under Section 2714. However, former foster care youth are only guaranteed Medicaid coverage in the state where they were in foster care at the time they aged out of the system.

Medicaid and CHIP Maintenance of Effort (Sec. 2001(b))

The “Maintenance of Effort” (MOE) provision requires states to keep the Medicaid and CHIP eligibility criteria and enrollment procedures for children and adults that they had in place on March 23, 2010, the day the ACA was signed. States cannot reduce the income eligibility for these programs, nor can they make it more difficult for families to enroll their eligible children. They can, however, raise the income eligibility and/or make enrollment easier.

Medicaid and CHIP are particularly important to CYSHCN, because of the comprehensive set of benefits offered (including EPSDT in Medicaid) and little or no cost-sharing in both programs. The MOE

provision prevents states from using changes in eligibility or enrollment to reduce spending in Medicaid or CHIP; those who are currently eligible or enrolled will remain so. However, states can use other mechanisms to reduce public benefit program spending that may have implications for CYSHCN. States can reduce provider payment rates, for example, which may in turn limit access to primary or specialty care. They can also increase cost-sharing for families as long as they stay within the current rules. This provision is in effect for children until September 30, 2019.

“No Wrong Door” Eligibility (Sec. 1413)

Under the ACA, a single, simplified form screens applicants for eligibility in their state’s Medicaid and CHIP programs and for premium tax credits through the Health Insurance Marketplace (Marketplace). Applicants can submit the application form either by mail, by telephone, in person or online, and it does not matter whether an application is submitted through Medicaid, CHIP or the Marketplace. States are required to have a secure data interface so that information is easily shared among the programs.

The coordinated application process, also known as “no wrong door,” is designed to minimize the administrative burden families of CYSHCN currently experience when applying to multiple programs. This also helps them secure the coverage their children qualify for and stay on it as long as they are eligible. This coordinated application should also help minimize gaps in coverage as family income or other circumstances change and enrollees move from one program to another, facilitating continuity of care. Families whose individual members qualify for different programs should find it easier to maintain their enrollment and access their various benefits.

The addition of special health care needs screening questions to the streamlined application may benefit CYSHCN. These screening questions are designed to help families more effectively access pathways to coverage based on disability, such as the Family Opportunity Act’s Medicaid buy-in program or a TEFRA state plan option.

Application Assistance/Navigation (Sec. 1002)

To help connect individuals to coverage, all Marketplaces are required to set up consumer assistance programs. These programs provide individualized counseling to help consumers understand their coverage options, and choose and apply for a qualified health plan (QHP). Consumer assisters are known by various names: navigators; in-person assisters (IPAs); and certified application counselors (CACs). All of these people can provide impartial information about QHP options, help consumers compare and select a QHP, and help them complete and file applications. They can also help consumers report changes during the coverage year; assist consumers with renewing coverage; and connect consumers who have grievances, questions or complaints to the appropriate agency for resolution. Consumer assisters receive federal training on methods to address the needs of underserved and vulnerable populations, basic information on QHPs, eligibility and enrollment rules and procedures, and privacy and security requirements. States can provide additional training as well. Insurance agents, brokers, and certain federally qualified health centers also can help people choose and enroll in QHPs.

Note that, in contrast to other consumer assisters, insurance agents and brokers are not required to offer impartial assistance when it comes to selecting a QHP. Benefits counseling is an important activity of many Title V MCH and CYSHCN programs. The state consumer assistance programs should be a helpful and independent resource that ensures that CYSHCN and their families get the coverage they need. In return, Title V MCH and CYSHCN program staff may be able to provide valuable information and education to the consumer assistance programs on the unique needs of this vulnerable population.

Hospice Care for Children under Medicaid (Sec. 2302)

Children with a terminal illness (those with a medically-certified life expectancy of six months or less) enrolled in Medicaid and in CHIP programs operating as Medicaid expansions have access to coverage for hospice care, either as an optional benefit or through the application of EPSDT. Before

the ACA, their families had to decide to end curative care before they could access hospice services. This sometimes meant a curative treatment that had palliative benefits was no longer available. Families had to make a difficult emotional decision that in turn could limit timely access to helpful services through hospice. Section 2302 of the ACA, also called “[Concurrent Care for Children](#),” now allows children to receive both types of care at the same time, including pain and symptom management and family counseling. Removing the requirement to stop curative care should increase the use of hospice services by terminally ill children and their families. States with stand-alone CHIP programs can offer hospice care as an optional benefit; however, if they choose to do so, they are required to comply with this provision as well.

The Title V Role in Ensuring Coverage for CYSHCN

Statistics indicate that federal health care reform has reduced the number of uninsured Americans. Strategies for continuing to reduce the number of uninsured through the ACA include expanding eligibility requirements for public benefit programs, requiring individuals to obtain and keep coverage, and providing financial assistance through premium subsidies. Title V and MCH professionals must continue to monitor the causes of underinsurance.

According to the National Survey of Children with Special Health Care Needs, 96.5 percent of CYSHCN have coverage, either through a private plan, through a public benefit program such as Medicaid or CHIP, or through a combination of the two. However, 34.5 percent of families indicate their insurance coverage is inadequate in meeting their child’s needs, and 21.6 percent of families indicate their child’s special health care needs have caused them financial problems.

As the law continues to be clarified at the state and federal level, professionals serving CYSHCN should be monitoring issues that are especially important to this population, including how the definitions for essential health benefits will continue to be defined, operationalized and enforced. State

Title V programs must offer leadership and expertise to ensure that the promise of health care reform is realized for CYSHCN and their families.

Resources

- **Association of Maternal & Child Health Programs:** [Standards for Systems of Care for Children and Youth with Special Health Care Needs](#)
- **Catalyst Center:** [The ACA and Children with Special Health Care Needs](#)
- **Maternal and Child Health Bureau, HRSA:** [Title V Maternal and Child Health Services Block Grant](#)
- **National MCH Workforce Development Center:** [The Affordable Care Act: A Working Guide for MCH Professionals](#)

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AMCHP Contact Information

This fact sheet is part of an AMCHP series of tools, documents and resources on implementation of the ACA and its impact on maternal and child health populations. For more information, please visit the [National Center for Health Reform Implementation](#). All AMCHP staff can be reached by phone at (202) 775-0436.