



PUBLIC INSURANCE PROGRAMS AND CHILDREN WITH SPECIAL HEALTH CARE NEEDS



A Tutorial on the Basics of

Medicaid and The Children's Health Insurance Program (CHIP)

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INTRODUCTION

Why This Tutorial?

According to the National Survey of Children's Health (2016), almost half of children with special health care needs (CSHCN) depend on Medicaid or the Children's Health Insurance Program (CHIP) for some or all of their health care coverage.¹ Title V of the Social Security Act has a mandate to facilitate the development of community-based systems of care for CSHCN and their families through the state block grant program. There are natural points of connection and opportunities for collaboration between Title V and Medicaid/CHIP, including:

- Providing gap-filling services to publicly insured CSHCN;
- Helping with identification of Medicaid/CHIP-eligible CSHCN and facilitating enrollment;
- Engaging in capacity-building activities that ensure quality health care services are available to CSHCN at the state and local level.²

Not only is collaboration between Title V and Medicaid/CHIP a good thing in terms of promoting the development of and access to a robust system of care and services for CSHCN, it is also required by several federal statutes and regulations.³

But communication and collaboration between these important programs serving CSHCN is not always easy. In our work with state Title V program staff, we have learned that the complexity of many Medicaid and CHIP rules and regulations, along with unfamiliar vocabulary can create barriers to effective collaboration.

Learning Objectives

By completing this tutorial, participants will:

- Increase their understanding of state Medicaid and CHIP programs and policies;
- Review examples of how partnerships can maximize Medicaid and CHIP program capacity to meet the needs of CSHCN;
- Identify specific opportunities to partner with the Medicaid and CHIP programs in their own state.

¹National Survey of Children's Health. NS-CH 2016. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved September 13, 2017 <http://www.childhealthdata.org/browse/survey/results?q=4562&r=1&g=638>. A Catalyst Center calculation based on preliminary NS-CH data. The calculation was performed using the population estimate of CSHCN with public insurance (n=5,739,375) and the population estimate of CSHCN with public and private insurance (n=1,049,865), divided by the estimate of the total CSHCN population (n=13,901,999).

²Michael C. Lu, et al (2015). Transformation of the Title V Maternal and Child Health Services Block Grant. *Matern Child Health J.* 19(5): 927–931. Retrieved August 2, 2017 from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4428533/>

³Including Title XIX of the Social Security Act §1902(a)(11)(B); the Code of Federal Regulation Title 42 - § 431.615 (Relations with State Health and Vocational Rehabilitation Agencies and Title V Grantees).

INTRODUCTION

We have created this tutorial to help directors, staff, partners and others serving CSHCN increase their knowledge of how both public benefit programs work. A more in-depth understanding of the program components and policies can help Title V staff build more effective partnerships with their state Medicaid and CHIP programs.

Content Overview

This tutorial gives a broad overview of Medicaid and CHIP, the many different populations these programs serve, the changes they are undergoing as a result of health care reform and some options to help readers think about opportunities to improve services for CSHCN through communication and collaboration with Medicaid and CHIP staff. The tutorial starts with an overview of how definitions of CSHCN may vary by agency or program, followed by eleven major topic areas and then recommendations for steps Title V programs can take to build successful partnerships with public insurance programs.

Partnerships in Your State

Each of the eleven topic areas (Sections 2-12) describes a component of the Medicaid/CHIP program and a brief description of the regulatory framework for each. It then identifies opportunities for Title V programs to use this information or interact with Medicaid/CHIP programs in this area. A brief set of questions, “Test your knowledge,” is provided at the end of each topic to reinforce the major learning points. An answer key is provided for each so that readers can check their content knowledge. Each topic concludes with a set of inquiries that provides direction for participants to find out more specific information about Medicaid and CHIP in their state.

- Section 1: How Do Different Systems Define and Think About Children with Special Health Care Needs?
- Section 2: The Basics: What are Medicaid and CHIP?
- Section 3: Building Partnerships: What Kinds of Partnerships Between Title V and Medicaid/CHIP Are Required and Feasible to Build?
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- Section 9: Changes to Medicaid and CHIP Under the Affordable Care Act (ACA)
- Section 10: Next Steps: Making the Case for Successful Partnerships in Your State
- Section 11: TEFRA/Katie Beckett Option: A Pathway to Medicaid for Children with Disabilities
- Section 12: Early and Periodic Screening, Diagnostic, and Treatment (EPSDT)

This document is part of *Public Insurance Programs and Children with Special Health Care Needs: A Tutorial on the Basics of Medicaid and the Children's Health Insurance Program (CHIP)*, available in its entirety at <http://cahpp.org/resources/Medicaid-CHIP-tutorial>

Is this tutorial helpful to you? Please take our survey at <http://bit.ly/2gXLyuy-catalyst-survey>

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Section 1

WHO ARE CHILDREN WITH SPECIAL HEALTH CARE NEEDS?

How Do Different Systems Think About Children With Special Health Care Needs?

Before we get into the details of how the Medicaid and Children's Health Insurance Program (CHIP) programs work and their importance to children with special health care needs (CSHCN), let's take a moment to consider what different people may think when they hear the term "CSHCN." We will begin with the federal Maternal and Child Health Bureau (MCHB) definition, and then compare this definition to the way Title V and Medicaid programs think about children with disabilities, chronic illnesses, and other special health care needs.

MCHB Definition

Most users of this tutorial are familiar with the federal MCHB definition of CSHCN, but it's worth reviewing in the context of the discussion to come. It describes CSHCN as *"those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."*⁴ This inclusive definition describes a lot of kids: approximately 19.4% of the U.S. child population, according to the National Survey of Children's Health 2016. It guides the work of many stakeholders in serving CSHCN as a population and improving the system of care for them. The Catalyst Center uses this definition in its work and in this tutorial, but it is not necessarily the definition that either individual state Title V or Medicaid programs use when thinking about the children for whom they have responsibility. It is important to recognize and understand these differences.

The MCHB definition is not necessarily used to determine eligibility for Title V programs or services.⁵ Most Title V programs that pay for health care services have more restrictive eligibility criteria, limiting services to children with specific conditions and/or at certain income levels. Some of this is a holdover from the historical origins of Title V, and much of this is due to the fact that Title V is not an entitlement program and its funding is capped. As

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“those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”

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⁴McPherson, M., Arango, P., Fox, H., Lauver, C., McManus, M., Newacheck, P.W., . . . Strickland, B. (1998). A new definition of children with special health care needs. *Pediatrics*, 102(1 Pt. 1), 137-140, pg. 138.

⁵Title V is used in this tutorial to describe the part of the Social Security Act that administers the Maternal and Child Health Block Grant, including policies and services that promote family-centered, community-based, coordinated care for children with special health care needs and facilitate the development of community-based systems of services for such children and their families.

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a result, there are limits to what services it can deliver and to whom. When not paying directly for services, however, Title V programs are expected to develop broad systems of care for CSHCN.

Medicaid Definition

CSHCN who receive Medicaid benefits are enrolled into different “eligibility categories,” which do not correspond directly with the MCHB definition of CSHCN either. Currently there are four major pathways to Medicaid eligibility for children. They are based on (1) income criteria; (2) disability criteria (functional limitations); (3) eligibility for institutional levels of care; or (4) out-of-home placement.

Income Criteria

Using the MCHB definition, any CSHCN in a very low-income family (below 100% of the federal poverty level) will be eligible for Medicaid based on income criteria, not because they are a child with special needs. Because the child is eligible due to low income, information about the child’s functional status may not be obtained during the enrollment process. A couple of states have incorporated a screening questionnaire for CSHCN⁶ into their Medicaid and CHIP enrollment forms, and thus can identify CSHCN at the point of enrollment. However, this practice is not widespread.

Disability Criteria

Disability is another important pathway to Medicaid eligibility, but the disability eligibility criteria are narrow as compared with the MCHB definition. For example, low-income children with significant disabilities who receive Supplemental Security Income (SSI) are eligible for Medicaid in most states. But the strict income limit for SSI means that many children who do meet the functional disability criteria are not eligible for Medicaid because their families are over-income, and the majority of CSHCN have disabilities or conditions that are not severe enough to meet the SSI definition.

Eligibility for Institutional Levels of Care

Some CSHCN from higher income families may be eligible for Medicaid if their disability is such that they qualify for an institutional level of care. These children may be enrolled in home and community-based service waiver programs for individuals with specific diagnoses such as developmental disabilities, traumatic brain injury, or those who are medically fragile. They may also be enrolled in TEFRA⁷ programs, sometimes known as Katie Beckett waivers, for children who qualify for an institutional level of care. However, the

There are four major pathways to Medicaid eligibility for children. They are based on:

1. Income criteria;
2. Disability criteria (functional limitations);
3. Eligibility for institutional levels of care;
4. Out-of-home placement.

⁶Bethell, C. et al., (2012). Summary Comparison of Children with Chronic Conditions and Elevated Service Use or Need (CCCESUN NHIS Variable) and the CSHCN Screener (MEPS linked). The Child and Adolescent Health Measurement Initiative. Retrieved August 16, 2017 from <http://bit.ly/2wXcAGt-CAHMI>

⁷In 1982, Congress created a new Medicaid state plan option for children who require an institutional level of care under Section 134 of the Tax Equity and Fiscal Responsibility Act (TEFRA).

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type, availability, and size of TEFRA programs and home and community-based waiver programs vary widely from one state to another, making it difficult to generalize about Medicaid eligibility for this group of children. For more about TEFRA, please refer to [Section 11](#) of this tutorial.

Out-of-home Placement

Finally, children who are placed in foster care or other out-of-home placements are also eligible for Medicaid. Many of these children have documented special health care needs, and it can be argued that all of them are at risk for special health care needs.

It may be useful to bear the differences in definition in mind as you proceed through the tutorial and work with the Medicaid program in your state. Both Title V and Medicaid provide vital services to CSHCN, but they may be thinking about different groups of children at different times.

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Section 2

THE BASICS: WHAT ARE MEDICAID AND CHIP?

Many children with special health care needs (CSHCN) are enrolled in one of two publicly funded health insurance programs: Medicaid, established under Title XIX of the Social Security Act, and the state Children's Health Insurance Program (CHIP), established under Title XXI of the Social Security Act. In some states, Medicaid and CHIP are administered together, and the programs are very similar in design. In other states, the programs are administered separately, or both together and separately for different populations. This is described in more detail below.

Medicaid and CHIP are funded jointly by the states and the federal government and provide health care coverage to almost thirty-seven percent of all children in the United States.⁸ Forty-eight percent of CSHCN are covered by Medicaid or CHIP.⁹

To participate in Medicaid and CHIP, each state submits a "state plan" for each program to the federal agency that oversees Medicaid and CHIP, the Centers for Medicare and Medicaid Services (CMS). The state plan describes these programs in detail. The state plan, or any changes to an already approved plan, must be approved by CMS. If a state, for example, seeks to change how eligibility for Home and Community-Based Services (HCBS) is determined, it must submit a state plan amendment (SPA) to CMS for approval.¹⁰

Medicaid

Medicaid is a public insurance program that is financed by both state and federal funds. The Federal Medical Assistance Percentage (FMAP) is the name used to describe the federal share of Medicaid provided to a state. FMAP is also called the "federal match." FMAP rates range from 50% - 76%, with a higher federal match going to those states with lower per capita incomes. Thus, a state with a 75% FMAP rate receives three federal dollars for each state dollar it spends on a Medicaid service. Unless the state has a waiver in place affecting a particular service or population (see [Section 3](#)), there is no cap on the federal dollars available.

⁸National Survey of Children's Health. NS-CH 2016. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved September 13, 2017 <http://www.childhealthdata.org/browse/survey/results?q=4562&r=1&g=638>. A Catalyst Center calculation based on preliminary NS-CH data. The calculation was performed using the population estimate of CSHCN with public or public and private insurance (n=6,789,240) and the population estimate of non-CSHCN with public or public and private insurance (n=19,439,526), divided by the estimate of the total CSHCN and non-CSHCN population (n=71,689,077).

⁹National Survey of Children's Health. NS-CH 2016. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved September 13th, 2017 <http://www.childhealthdata.org/browse/survey/results?q=4562&r=1&g=638>. A Catalyst Center calculation based on preliminary NS-CH data. The calculation was performed using the population estimate of CSHCN with public insurance (n=5,739,375) and the population estimate of CSHCN with public and private insurance (n=1,049,865), divided by the estimate of the total CSHCN population (n=13,901,999).

¹⁰State plan amendments can be found on the Centers for Medicare and Medicaid (CMS) website at <https://www.medicaid.gov/medicaid/by-state/by-state.html>

What's in a Medicaid State Plan?

- How the Medicaid program is administered;
- Specific Medicaid eligibility criteria;
- Scope, duration and amount of covered services;
- Quality control;
- Provider payments.

THE BASICS: WHAT ARE MEDICAID AND CHIP?

As a result, if a state's Medicaid caseload rises or if health costs rise, the state is entitled to the corresponding federal matching dollars. This is different from the block grant funding mechanism in Title V. In Title V, services are paid from a fixed annual amount decided by Congress and matched by the state. Unlike Medicaid, state Title V programs cannot obtain additional federal funds even if their funds are insufficient to meet the demand for services.

Medicaid benefits are available to certain groups of low-income individuals who meet eligibility criteria that are determined by federal and state law. Broadly speaking, eligibility groups include low-income families with children, children served by the foster care system, adults and children with disabilities, and

people aged 65 and over.¹¹ In addition to falling within an eligibility group, an individual must have low income to receive Medicaid. Income guidelines vary by state and are usually expressed as a percent of the federal poverty level (FPL). Below are some charts of the 2017 FPL guidelines for your reference.

Medicaid is an entitlement program for both the individual and the state: if an individual is eligible, he or she must receive the coverage allowed for under the state's plan, and the state must receive corresponding federal matching dollars. Because of this entitlement, a state cannot put a limit on the number of people it will cover under the Medicaid program if the state experiences a

2017 Federal Poverty Guidelines (Annual Income) 48 Contiguous States and D.C.						
Family size	100%	138%	185%	200%	300%	400%
1	\$12,060	\$16,643	\$22,311	\$24,120	\$36,090	\$48,240
2	\$16,240	\$22,411	\$30,044	\$32,480	\$48,720	\$64,960
3	\$20,420	\$28,180	\$37,777	\$40,840	\$61,260	\$81,680
4	\$24,600	\$33,948	\$45,510	\$49,200	\$73,800	\$98,400
5	\$28,780	\$39,716	\$53,240	\$57,560	\$86,340	\$115,120

2017 Federal Poverty Guidelines (Annual Income) Alaska						
Family size	100%	138%	185%	200%	300%	400%
1	\$15,060	\$20,782	\$27,861	\$30,120	\$45,180	\$60,240
2	\$20,290	\$28,000	\$37,537	\$40,580	\$60,870	\$81,160
3	\$25,520	\$35,218	\$47,212	\$51,040	\$76,560	\$102,080
4	\$30,750	\$42,435	\$56,888	\$61,500	\$92,250	\$123,000
5	\$35,980	\$49,652	\$66,563	\$71,960	\$107,940	\$143,920

2017 Federal Poverty Guidelines (Annual Income) Hawaii						
Family size	100%	138%	185%	200%	300%	400%
1	\$13,860	\$19,127	\$25,641	\$27,720	\$41,580	\$55,440
2	\$18,670	\$25,765	\$34,540	\$37,340	\$56,010	\$74,680
3	\$23,480	\$32,402	\$43,438	\$46,960	\$70,440	\$93,920
4	\$28,290	\$39,040	\$52,337	\$56,580	\$84,870	\$113,160
5	\$33,100	\$45,678	\$61,235	\$66,200	\$99,300	\$132,400

(The federal poverty levels are updated annually in March and are available here: <https://aspe.hhs.gov/poverty-guidelines>)

¹¹People 65 and over and people with disabilities who have very low income may receive Medicaid and Medicare at the same time. Medicaid covers those services that Medicare does not cover. Those with both Medicaid and Medicare are usually referred to as "dually eligible."

THE BASICS: WHAT ARE MEDICAID AND CHIP?

budget shortfall unless the state receives a waiver.

Medicaid covers a wide range of health care services, including physician services, home health care, hospital care, laboratory tests, and prescription drugs. Some of these services are required to be covered under federal law, and are known as “mandatory” services. Other services are considered “optional” services because a state may choose to offer them or not. For a more complete description of mandatory and optional services, see [Section 4](#).

While states receive federal dollars to help pay for Medicaid services, Medicaid is designed as a state-administered program, and each state historically has had some flexibility in setting its own eligibility standards, benefits packages, payment rates, and administration policies, as long as it complies with federal Medicaid law. As a result there are 56 different Medicaid programs—one for each state, territory, and the District of Columbia.¹² The Affordable Care Act (also known as the ACA) sets more uniform standards for eligibility, enrollment, and other aspects of the Medicaid program although, states will still have a great deal of discretion in many areas.

The Children’s Health Insurance Program (CHIP)

The Children’s Health Insurance Program (CHIP) is a public insurance program exclusively for uninsured children (and, if a state chooses, pregnant women) in families whose income exceeds the Medicaid income-eligibility limit.

Like Medicaid, CHIP is a state-federal partnership that is state-administered, and each state sets its own eligibility rules within federal guidelines. The maximum eligibility level that states can set and still receive the higher federal matching rate that CHIP provides is 300 percent of the federal poverty level. Currently, nine states (New York, New Jersey, Connecticut, Pennsylvania, Illinois, Alabama, Washington, Iowa, and Wisconsin,) have upper income eligibility levels above 305 percent of the FPL; five states have an upper income level at 305 percent of the FPL; 17 states have an upper income level between 206 and 288 percent of the FPL; five states have an upper income level at 205 percent of the FPL; and two states have an upper income eligibility level of less than 205 percent of the FPL.^{13,14}

CHIP is different from Medicaid in important ways. Unlike Medicaid, the federal dollars available to the states for CHIP are capped. States have greater flexibility in how they structure their CHIP programs than in Medicaid. For example, they can implement CHIP programs as Medicaid expansion programs, which then follow Medicaid rules; they can implement separate CHIP programs, which have more flexibility; or they can do a combination of both.

¹² Medicaid and CHIP Payment and Access Commission Report to Congress on Medicaid and CHIP, March 2017. Retrieved August 2, 2017 from <https://www.macpac.gov/wp-content/uploads/2017/03/March-2017-Report-to-Congress-on-Medicaid-and-CHIP.pdf>

¹³ Kaiser Family Foundation. Medicaid and CHIP Income Eligibility Limits for Children as a Percent of the Federal Poverty Level, January 2017. Retrieved August 2, 2017 from <http://www.kff.org/health-reform/state-indicator/medicaid-and-chip-income-eligibility-limits-for-children-as-a-percent-of-the-federal-poverty-level/>

¹⁴ January 2017 income limits reflect Modified Adjusted Gross Income (MAGI)-converted income standards and include a disregard equal to five percentage points of the federal poverty level (FPL) applied at the highest income level for Medicaid and separate CHIP coverage.

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THE BASICS: WHAT ARE MEDICAID AND CHIP? _____

Test your knowledge

1. What portion of CSHCN are enrolled in Medicaid or CHIP?
 - a. About one-tenth
 - b. Almost one-fourth
 - c. Almost half
 - d. About three-fourths
2. True or False: Children in CHIP have household income that is lower than children in Medicaid.
3. True or False: If a state Medicaid program is running short on funds (and the state has no “waivers” from the federal government), the state may put people who meet the state’s eligibility criteria on a waiting list to receive benefits.



Find Out in Your State

1. In your state, is CHIP operated as a Medicaid expansion, a separate program, or a combination of the two?
2. In your state, what portion of CSHCN are enrolled in CHIP or Medicaid? How does your state compare nationally? (See <http://chartbook.cahpp.org/>)

1. c 2. False 3. False, because Medicaid is an entitlement under federal law. See Program Structures: Pathways to Coverage Section for information on the limitations in waivers. 4. c



Section 3

BUILDING PARTNERSHIPS

What Kind of Partnerships Between Title V and Medicaid/CHIP Are Required and Feasible to Build?

Medicaid and Title V programs need each other; both have legal duties to assure that children with special health care needs (CSHCN) receive the best possible array of services. In every state the Medicaid program must:

- Enter into a coordination agreement with the state Title V program specifying the responsibilities of each;
- Make appropriate provision for reimbursing the Title V grantee agency for covered services provided to Medicaid beneficiaries.¹⁵

In addition, the Early Periodic Screening, Diagnosis, and Treatment program (EPSDT) is a key child health component of Medicaid. It is a mandatory service in almost every state¹⁶ for children under 21 years of age who are eligible for Medicaid.¹⁷ EPSDT requires that children are brought into care, periodically screened to identify needs, and that identified needs are treated. Treatment of identified needs must be provided even if the service is not listed in the state's federally approved Medicaid plan, so long as the treatment is determined to be medically necessary for an individual child.¹⁸ (See [Section 5 Covered Services](#) for discussion of medical necessity and the limits of EPSDT.)

Although states have more flexibility in administering their CHIP than their Medicaid programs, they also must describe in the state CHIP plan how they will coordinate with Title V and other health-related programs.¹⁹

Medicaid and Title V programs need each other; both have legal duties to assure that children and youth with special health care needs receive the best possible array of services.

In every state the Medicaid agency must:

- Enter into a coordination agreement with the state Title V agency specifying the responsibilities of each;
- Make appropriate provision for reimbursing the Title V grantee agency for covered services provided to Medicaid beneficiaries.¹³

¹⁵The charge to the Title V agency and the Medicaid agency to cooperate is established in Section 505(a)(5)(F) of the Social Security Act (http://www.ssa.gov/OP_Home/ssact/title05/0505.htm) (regarding Title V) and Section 1902(a)(11) (http://www.ssa.gov/OP_Home/ssact/title19/1902.htm) (regarding Medicaid). See also 42 Code of Federal Regulations Section 431.615.

¹⁶Technically, Oregon does not have an EPSDT program, although it provides many of the services to children. Instead, the state received a comprehensive waiver from the federal government giving greater flexibility in defining its benefits. Under the waiver, the state provides services specified by the Oregon Health Services Commission.

¹⁷Medicaid and CHIP Payment and Access Commission (MACPAC). (June 2017). *Report to Congress on Medicaid and CHIP*. Retrieved August 2, 2017 from <https://www.macpac.gov/wp-content/uploads/2017/06/June-2017-Report-to-Congress-on-Medicaid-and-CHIP.pdf>

¹⁸Most state EPSDT obligations, including the obligation to provide the service even if it is not in the plan, are set out in federal regulation at 42 Code of Federal Regulations Section 441.56. Learn more at <https://www.medicaid.gov/medicaid/benefits/epsdt/index.html>

Title V requires state Maternal and Child Health (MCH) programs to:

- Assist with coordination of EPSDT services, including the development of standards;
- Establish coordination agreements with their state Medicaid programs;
- Provide a toll-free number for families seeking Title V or Medicaid providers;
- Provide outreach and facilitate enrollment of Medicaid eligible children and pregnant women;
- Share data collection responsibilities, particularly related to infant mortality and Medicaid.

Title V programs were among the originators of the “medical home” concept that is now spreading through Medicaid.¹⁹

The Value of Medicaid, CHIP and Title V Partnerships

An important function of Title V programs is to promote coordinated care and facilitate community-based services for children with special health care needs and their families, whether or not the children are covered by Medicaid or the Children’s Health Insurance Program (CHIP). Because 48.8% of children with special health care needs nationally depend on Medicaid or CHIP for some or all of their health care coverage, partnering with these programs is essential to improving their care and coverage.²⁰ Title V programs can help Medicaid and CHIP use their purchasing power to improve the delivery of care for CSHCN. While Title V funding is much less than Medicaid and CHIP funding, the targeting of the Title V block grant to CSHCN allows states to use funds in strategic ways to address needs that are not met by Medicaid or CHIP programs.

Title V programs have much to offer Medicaid and CHIP programs at the program design and policy level. For example, Title V programs were among the originators of the “medical home” concept that is now spreading throughout Medicaid.²¹ Title V programs have important clinical expertise and data to inform how Medicaid and CHIP serve CSHCN. Title V staff can bring this knowledge to the design of Medicaid waivers, managed care programs, quality improvement programs, school-based health services, and more. For example, Title V can use the data from the National Survey of Children’s Health to educate themselves and Medicaid program staff about who the CSHCN are in your state, and what kinds of health care services they receive or need.

¹⁹Federal regulations require that states describe in the CHIP plans “[p]rocedures the State uses to accomplish coordination of CHIP with other public and private health insurance programs, sources of health benefits coverage for children, and relevant child health programs, such as title V, that provide health care services for low-income children.” 42 Code of Federal Regulations Section 457.80(c).

²⁰National Survey of Children’s Health. NS-CH 2016. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved September 13, 2017 <http://www.childhealthdata.org/browse/survey/results?q=4562&r=1&g=638>. A Catalyst Center calculation based on preliminary NS-CH data. The calculation was performed using the population estimate of CSHCN with public insurance (n=5,739,375) and the population estimate of CSHCN with public and private insurance (n=1,049,865), divided by the estimate of the total CSHCN population (n=13,901,999).

²¹Buxbaum, J. (2010.) *Making Connections: Medicaid, CHIP, and Title V Working Together on State Medical Home Initiatives*. Retrieved Dec. 22, 2011 from the National Academy for State Health Policy website: http://www.nashp.org/sites/default/files/Medicaid_Collaboration-FINAL.pdf

BUILDING PARTNERSHIPS

Other ways that Medicaid and CHIP programs can work with Title V programs include:

- Developing education materials for both patients and providers;
- Sharing data;
- Training Early Periodic Screening, Diagnosis, and Treatment (EPSDT) outreach workers;
- Developing and conducting needs assessments;
- Evaluating health care quality and performance;
- Engaging family leadership in policy discussions;
- Reaching out to pregnant women and parents to encourage enrollment in Medicaid.

Title V's partnership with Medicaid is also important at the service level. Federal Title V funds are often used for support services, care coordination, and for services designed to improve the health of the entire population. The impact of these funds and services can be maximized through closer coordination with the Medicaid program. This is particularly important because Title V is a block grant, and thus service funding is limited by the block grant award, while Medicaid, in most states, is an entitlement program that is not limited by a specific dollar amount. For example, because EPSDT requires coverage of all medically necessary services for children receiving Medicaid, Title V, as the payer of last resort, should only pay for services that are not available through Medicaid. Similarly, coordination agreements between CHIP programs and Title V programs should also specify that Title V only assists with services that are not covered under the state's CHIP program.

Learn strategies for strengthening Title V and Medicaid Partnerships at: <http://bit.ly/2xXYnZ0-NASHP>

This document is part of *Public Insurance Programs and Children with Special Health Care Needs: A Tutorial on the Basics of Medicaid and the Children's Health Insurance Program (CHIP)*, available in its entirety at <http://cahpp.org/resources/Medicaid-CHIP-tutorial>

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CATALYST
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IMPROVING FINANCING OF CARE
for Children & Youth
WITH SPECIAL HEALTH CARE NEEDS

NATIONAL ACADEMY
for STATE HEALTH POLICY

Test your knowledge

1. Partnerships between Title V and Medicaid agencies are important because:
 - a. Medicaid doesn't provide EPSDT benefits.
 - b. CHIP always provides EPSDT benefits.
 - c. Medicaid's EPSDT covers all medically necessary services for children, so Title V programs can address other needs.
 - d. EPSDT benefits are very limited.
2. Title V can play an important role in supporting parents with CSHCN because:
 - a. Title V programs can help shape Medicaid and CHIP policies that affect CSHCN.
 - b. Title V programs can bring parents with CSHCN to the table in Medicaid policy discussions.
 - c. Some services parents need in caring for their children are not covered by Medicaid.
 - d. All of the above.
3. Which of the following is true:
 - a. Medicaid and Title V are both block grants.
 - b. Medicaid is an entitlement program and Title V is a block grant.
 - c. Medicaid and Title V are both entitlement programs.
 - d. Medicaid is a block grant and Title V is an entitlement program.
4. True or False: Title V programs can pay for services that are not covered by Medicaid.



Find Out in Your State

1. What is covered in the coordination agreement between Title V and Medicaid?
2. How does Title V assist Medicaid in coordinating EPSDT services?

1. c 2. d 3. b 4. True



Section 4

PATHWAYS TO COVERAGE

Any person has the right to apply for Medicaid or the Children's Health Insurance Program (CHIP) and to have eligibility decided promptly. A parent, caretaker relative, or guardian may apply for children in the household as well as for himself or herself. If a disability determination is involved, the state is required to take no longer than 90 days to decide (so long as the applicant has given the state all the necessary information); if disability is not being decided, the decision is required to take no more than 45 days. All applicants must receive written notice of the eligibility decision and the opportunity to appeal if he or she disagrees with the decision.

To receive Medicaid or CHIP coverage, the applicant must meet certain eligibility criteria. The two key factors in deciding who is eligible are 1) whether the person falls within a category of people who are covered by Medicaid or CHIP and 2) whether the person's household income meets the income eligibility threshold.

Medicaid Eligibility

Major Mandatory Eligibility Groups

Federal law has long required states to provide Medicaid coverage to people with household income below a certain level who are in specific eligibility groups (primarily children, their parents, people receiving SSI due to disability, and people over 65). States then have the option to extend eligibility to people who have higher income levels and to other groups of individuals.

Presently, states are required to provide Medicaid to children aged 0 through 18 in households with incomes under 138% of the federal poverty level (FPL).²² States have the option of extending Medicaid to children at higher income levels. All states also participate in the CHIP program (described below) to provide coverage for uninsured children at higher income levels. Using Medicaid or both Medicaid and CHIP, all but two states provide coverage to children in households with incomes up to at least 200% of the FPL.²³ It is important to note that Medicaid also covers youth age 18 and older (as a "family of one"), but often at a lower FPL.

The two key factors in deciding who is eligible for Medicaid or CHIP coverage are:

1. Whether the person falls within a category of people who are covered by Medicaid or CHIP;
2. Whether the person's household income meets the income eligibility threshold.

Some states also look at whether the household's assets are below a certain level.

²²The language of the Affordable Care Act (ACA) set the Medicaid income eligibility limit for the Medicaid expansion population at 133% of the Federal Poverty Level (FPL), but then instructs states to disregard a standard 5% of income in calculating eligibility. Throughout the Tutorial, we use 138% of FPL to account for the 5% Modified Adjusted Gross Income (MAGI) disregard. Affordable Care Act, Section 2001(a); Health Care and Education Reconciliation Act, Pub. L. No. 111-152 Section 1004(e).

²³In addition, thirty-three states and the District of Columbia cover pregnant women at or above 200% of the federal poverty level. Kaiser Family Foundation, (March 2017) *Where Are States Today? Medicaid and CHIP Eligibility Levels for Children, Pregnant Women, and Adults*. Retrieved August 2, 2017 from <http://www.kff.org/medicaid/fact-sheet/where-are-states-today-medicaid-and-chip/>.

PATHWAYS TO COVERAGE

Major Optional Coverage Groups

In addition, states may extend coverage to other optional groups, including:

- Children with severe disabilities who live at home, but qualify for an institutional level of care *without regard to the family's income*. This is often known as a TEFRA or Katie Beckett option and is provided in eighteen states and the District of Columbia.²⁴ For more about TEFRA, please refer to [Section 11](#) of this tutorial.
- Children who meet the SSI disability criteria with income under 300% of the FPL who pay a premium and “buy in” to Medicaid;
- Parents with children 18 or under in households with income above the level for which Medicaid coverage is federally required;²⁵
- “Medically needy” persons who would be eligible for Medicaid except their income is too high, but incur substantial medical costs in less than six months; they “spend down” until they reach a state-specified income eligibility level.

Waivers

States may cover other groups of individuals by requesting a waiver from the Centers for Medicare and Medicaid Services (CMS). The request to CMS asks for permission to “waive” certain requirements of the Social Security Act. Requests can be made to waive other federal rules such as statewide availability of services, freedom of choice of providers, and universal access to all benefits.

The three most common types of waivers are named after the section of the Social Security Act to which they refer, and include: 1) 1115 Research and Demonstration waivers to

demonstrate innovations in service delivery (using a 1115 demonstration waiver, states can cover people who do not fit into a Medicaid category—for example, adults without dependent children at home); 2) 1915 (b) waivers that forgo freedom of choice of providers, most commonly used to implement mandatory managed care programs; and 3) 1915 (c) waivers to provide Home and Community-Based Services (HCBS) to people living at home who otherwise would be eligible only if they reside in an institution.

Many states operate HCBS waivers for adults and children with developmental disabilities. These waivers sometimes raise the income eligibility level for Medicaid coverage, and may provide coverage for additional benefits such as family support services, care coordination, specialized equipment, medical supplies, respite care, and home modifications. Other waivers that include certain groups of CSHCN include autism waivers, waivers for children who are medically fragile or technology dependent, and waivers for individuals with traumatic brain injuries (see <http://cahpp.org/project/the-catalyst-center/financing-strategy/medicaid-waivers/>).

All waiver programs must cost the federal government no more than the amount projected if the state did not have the waiver. This is called “cost-neutrality.” States estimate the cost of providing services to each eligible individual under the waiver, and use this estimate to project the number of people that can be served under the waiver. In order to guarantee cost-neutrality, states often cap the number of people served under a waiver. This is why states often have waiting lists for their HCBS waiver programs even though the general Medicaid program, as an entitlement, is not permitted to have a waiting list.²⁶

CHIP Eligibility

The CHIP program provides coverage for uninsured children under 19 whose income is over the Medicaid

²⁴O'Malley Watts, M., Cornachione, E., and Musumeci, M. Medicaid Financial Eligibility for Seniors and People with Disabilities in 2015. (March 2016). The Kaiser Commission on Medicaid and the Uninsured. Available at <http://files.kff.org/attachment/report-medicaid-financial-eligibility-for-seniors-and-people-with-disabilities-in-2015>

²⁵States are required to provide Medicaid to parents who would have met the 1996 AFDC eligibility requirements in their state. This income level varies by state, but is very low – the median is 28% of the federal poverty level. Kaiser Family Foundation, Kaiser Commission on Medicaid and the Uninsured. (2011). *Federal Core Requirements and State Options in Medicaid: Current Policies and Key Issues*, Figure 1. Retrieved Dec. 21, 2011 from <http://www.kff.org/medicaid/8174.cfm> States have the option to cover parents above that level.

²⁶State waivers are listed on the Centers for Medicare and Medicaid (CMS) website: https://www.medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/waivers_faceted.html

PATHWAYS TO COVERAGE

eligibility limits, up to a limit established by the state and capped by the federal government. CHIP eligibility limits range from 170% of the federal poverty level in North Dakota to 400% of the FPL in New York.²⁷

Medicaid Eligibility and the Affordable Care Act (ACA)

In 2014, state Medicaid programs had the option of expanding Medicaid to most adults, ages 19 to 65, which meant many parents with dependent children were newly eligible for Medicaid. However, states were required to cover all children, birth through 18, with family income below 138% of the federal poverty level.²⁸ In states where Medicaid eligibility for children 6 to 18 was limited to 100% FPL, children enrolled in CHIP were shifted to Medicaid. This improved their benefits (see [Section 5 on Covered Services](#)). The ACA's "maintenance of effort" (MOE) provision, valid for children's Medicaid and CHIP through 2019, prohibits states from reducing Medicaid or CHIP eligibility limits below those in effect when the ACA was enacted on March 23, 2010. Under MOE, states may expand eligibility.

²⁷Kaiser Family Foundation, Kaiser Commission on Medicaid and the Uninsured. (2017). *Where are States Today? Medicaid and CHIP Eligibility Levels for Adults, Children, and Pregnant Women*. Retrieved August 3, 2017 from <http://kff.org/medicaid/fact-sheet/where-are-states-today-medicaid-and-chip/>

²⁸The language of the ACA sets the eligibility limit at 133% of the federal poverty level (FPL) in 2014, but then instructs states to disregard an amount of income that brings the household to 138% of the FPL. The Affordable Care Act (ACA), Section 2001(a); Health Care and Education Reconciliation Act, Pub. L. No. 111-152 Section 1004(e).

Where Are the Opportunities for Title V Programs?

As states revamp their eligibility and enrollment processes for Medicaid, as they are required to do under the ACA, Title V programs have the opportunity to partner with state agencies in charge of health care reform to assure that the needs of families with CSHCN are considered. Title V programs may want to partner with Medicaid and CHIP programs to:

- Provide input on new eligibility and enrollment systems to assure that CSHCN who are Medicaid eligible (particularly under categories like Katie Beckett, TEFRA or medically needy- see [Section 11](#) for more about TEFRA) are enrolled in Medicaid and therefore have services covered under the EPSDT benefit;
- Write into their cooperative agreement with the Medicaid and CHIP programs the type of outreach to potentially eligible CSHCN families that each program will conduct and how subsequent enrollment will occur; outreach efforts should address health literacy, culture, and language needs of racially and ethnically diverse families;
- Encourage Medicaid and CHIP programs to incorporate screening for special health care needs as part of the eligibility or health plan enrollment process in order to track eligibility and enrollment trends, create opportunities for cross referrals to Title V, and identify children who might benefit from care coordination or care planning.

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IMPROVING FINANCING OF CARE
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NATIONAL ACADEMY
for STATE HEALTH POLICY

Test your knowledge

1. As of 2014, states must provide Medicaid to children age 6-18 in households with incomes less than:
 - a. 200% of the FPL
 - b. 138% of the FPL
 - c. 133% of the FPL
 - d. 100% of the FPL
2. 1915c waivers for Home and Community-Based Services may be implemented to provide special services for:
 - a. Children with developmental disabilities
 - b. Children who are dependent on medical technology
 - c. Children with autism
 - d. Any of the above
3. True or False: States may provide Medicaid coverage to certain children regardless of their parent's income.



Find Out in Your State

1. What is the income eligibility limit for children in your state for Medicaid? For CHIP? What is the eligibility limit for their parents?
2. What does your state cooperative agreement between Title V and Medicaid include?
3. What waivers does your state Medicaid program currently have in place that serve CSHCN? How many CSHCN are served under these waivers? Is there a waiting list to enroll in these waivers?

1. d 2. d 3. True. Children living at home with disabilities severe enough to qualify them for care in an institution are eligible at state option in twenty-five states.



Section 5

COVERED SERVICES

What Will Medicaid and CHIP Pay For?

Medicaid pays for care delivered in a range of settings, including hospitals, outpatient settings, private practice settings, clinics, nursing homes, community health centers, schools, mental health clinics, and at home.²⁹ If a service is covered under the Medicaid state plan, it must be covered everywhere in the state unless the state obtains a federal “statewide” waiver.

Mandatory and Optional Benefits

Medicaid includes mandatory benefits that states are required to cover under federal law and optional benefits that states may choose to cover. Here is an overview:

Mandatory benefits include:

- Inpatient and outpatient hospital services;
- Physician services;
- Early Periodic Screening, Diagnosis, and Treatment (EPSDT) for children (which includes screening, diagnosis, and any services, even if they are otherwise optional, needed to treat identified conditions);
- Family planning services and supplies;
- Nursing facilities;
- Nurse practitioner services;
- Laboratory and X-ray services;
- Tobacco cessation for pregnant women;
- Transportation for non-emergency medical care;
- Home health services.

Among the many optional services are:

- Prescription drugs;
- Occupational, speech, and physical therapies;
- Optometry;
- Targeted case management (see page 26 on Case Management/Care Coordination for description);
- Skilled nursing facilities for children under 21;
- Rehabilitative services;

Medicaid includes mandatory benefits that states are required to cover under federal law and optional benefits that states may choose to cover. Whether optional or mandatory, each service provided must be adequate in amount, duration, and scope to “reasonably achieve its purpose.”

²⁹Medicaid and CHIP Payment and Access Commission (MACPAC). (2011, March). *Report to the Congress on Medicaid and CHIP March 2011*. Retrieved Dec. 21, 2011 from <https://www.macpac.gov/publication/report-to-congress-the-evolution-of-managed-care-in-medicaid/>

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- Personal care services;
- Dental services;
- Hospice services;
- Inpatient psychiatric services for children under 21;
- Medical and remedial care from other licensed providers, including psychologists.

All 50 states provide some variety of optional services. For example, every state provides prescription drugs, occupational and physical therapies, targeted case management, and optometry. Whether optional or mandatory, each service provided must be adequate in amount, duration, and scope to “reasonably achieve its purpose.”³⁰

Copayments and Deductibles

Medicaid is prohibited from imposing copayments, deductibles, co-insurance, or other fees (“cost-sharing”) on services for children whose family income is less than 150% FPL.³¹ States and managed care organizations have also been prohibited from imposing anything more than “nominal” cost sharing on adults receiving Medicaid.³²

Early Periodic Screening, Diagnosis, and Treatment (EPSDT)

The EPSDT program is a key benefit for children who receive Medicaid coverage. It requires that states provide screening, diagnosis, and treatment to prevent, ameliorate, or treat conditions and to promote development. The treatment of identified needs must be provided even if the service is not normally covered in the state’s Medicaid plan. Thus, for children covered by the Medicaid program, any medically necessary service is actually mandatory and must be provided.

This does not mean that Medicaid pays for *everything* a child needs under EPSDT. The service must be a medical service, delivered by a qualified health care provider, and it must be medically necessary. Thus, a child with significant oral health needs identified in an EPSDT screening would be covered for those oral health services even if those services are not listed in the state’s Medicaid plan. On the other hand, a teen with Autism Spectrum Disorder who needs support to learn a new job skill may find that the state Medicaid program denies coverage on the grounds that such support is an educational or vocational service

EPSDT

The Early Periodic Screening, Diagnosis, and Treatment program requires that states provide screening, diagnosis, and treatment to prevent, ameliorate, or treat conditions and to promote development. The treatment of identified needs must be provided even if the service is not normally covered in the state’s Medicaid plan.

³⁰In response to litigation, the Affordable Care Act of 2010 (Section 2304) clarified that it is not enough for a state to simply pay for or reimburse Medicaid enrollees for covered services; the state must ensure care is received.

³¹The Kaiser Family Foundation, (January 2017). *Medicaid and CHIP Eligibility, Enrollment, Renewal, and Cost Sharing Policies as of January 2017: Findings from a 50-State Survey*. Retrieved August 16, 2017 from <http://kaiserf.am/2fhskfZ>.

³²42 Code of Federal Regulations Section 447.54.

rather than a medical one. In short, while the EPSDT program provides comprehensive coverage for children, this coverage is limited by the rules that the services must be medically necessary and delivered by qualified providers.³³

Care Coordination/Case Management

Title V programs often fund care coordination services for CSHCN. Medicaid programs also fund care coordination services through Home and Community-based Services (HCBS) waivers, managed care plans, primary care case management programs (see [Section 7](#) for more detailed information on managed care and primary care case management), EPSDT, and targeted case management. Within Medicaid, care coordination is usually called case management. Sometimes case management involves a “gatekeeper” function designed to ensure that services are provided in the most cost-effective manner or in accordance with health plan utilization management guidelines. In other cases, case management services are similar to Title V-funded care coordination, helping children gain access to needed medical, social, educational, and other services.

Home and community-based services waiver programs are required to include case management as a covered service. This case management might include information and referral services, coordination across multiple care providers, and service allocation decisions, particularly if there is a concern that the cost of home and community-based services might exceed the cost of institutional care. Managed care and primary care case management programs also vary widely in their implementation and interpretation of case management. Targeted Case Management services (TCM) may be provided for specific groups of children with complex needs such as children in

out-of-home placement, children with developmental disabilities, or children with special health care needs. TCM regulations require that case managers take a client history, perform a comprehensive assessment, prepare a care plan, make referrals, and conduct monitoring and follow-up activities.³⁴

EPSDT will cover services such as information and referral, arranging for screenings, and arranging assessment and follow-up care. Sometimes Medicaid programs enter into agreements with Title V programs, using EPSDT or Targeted Case Management funding mechanisms to have the Title V programs deliver care coordination services to CSHCN and receive federal Medicaid matching dollars.

Not all states provide for case management in their CHIP programs. In the states that do not, Title V funds can provide critical “wraparound” services to ensure that CSHCN in CHIP have access to care coordination.

Home and Community-based Services

Some children and adults with serious disabilities receive Medicaid services through the Home and Community Based Services (HCBS) waiver or an HCBS option without a waiver. These programs assist children or adults with severe disabilities to live at home and avoid institutionalization. These are called waiver programs because they waive Medicaid rules regarding covered services and in some cases, income eligibility. Waiver services may include care coordination, attendant care services, community support services, home-based behavioral services, visiting nurse services, or other services that are not otherwise available under the state plan. The

³³See 42 Code of Federal Regulations Parts 440 – 441 for descriptions of covered services. Issues about what is reimbursable under Medicaid often arise related to school-based health services. Although medical services, such as occupational, speech, physical, and psychological therapies, are covered when provided in school, services are not generally covered by Medicaid or CHIP if they can be covered as special education services under the Education of the Handicapped Act (20 United States Code 1401 (16) and (17)). Services are also generally not covered if they are Vocational/Rehabilitation services available under the Rehabilitation Act of 1973 (29 United States Code 730). Difficulty delineating between educational services and medical services in schools has caused the Office of Inspector General (OIG) to audit school-based Medicaid services, resulting in significant state liability for federal Medicaid payments. See e.g., U.S. Department of Health and Human Services, Office of Inspector General (OIG). (2010). *Review of New Jersey's Medicaid School-Based Health Claims Submitted by Public Consulting Group, Inc.* Retrieved Jan. 13, 2011 from <http://oig.hhs.gov/oas/reports/region2/20701052.pdf> Medicaid services in schools must be part of the state Medicaid plan or EPSDT and provided by a qualified health care provider.

³⁴The regulation for TCM is found at 42 Code of Federal Regulations Section 440.169.

COVERED SERVICES

waiver restricts the availability of these services to individuals who are enrolled in the program; thus, unlike other Medicaid services, these services are not an entitlement. Historically these services have only been provided under waivers granted by the federal government. More recently, Congress has permitted states to deliver the same services simply by submitting a state plan amendment (SPA) and without going through the waiver process.³⁵ Because a state may cap the number of participants under a waiver, but not under a state plan amendment, the choice of a waiver or a SPA will impact the number of people who will be able to receive these benefits.

Premium Assistance Programs

Finally, many Medicaid and CHIP programs have “premium assistance” programs. In these programs, if the child’s parent has access to private health insurance for the child through his or her employer, the state may pay for the parent to purchase the private coverage through the employer. The state might do this in circumstances where it is less expensive to pay the employee’s share of the private insurance premium than to pay directly for the child’s care. The child maintains Medicaid or CHIP coverage to pay for those services not covered by private insurance. In this way, the parent often can obtain coverage as well.³⁶

CHIP Benefits

States with CHIP programs that are expansions of the state’s Medicaid program and governed by the same rules must offer the same mandatory services required by federal Medicaid law, including the periodic screenings for physical and mental

conditions, and vision, hearing and dental services required by EPSDT.

States that administer their CHIP programs separately from their Medicaid programs have greater flexibility in designing their benefit packages. The CHIP benefit package must offer:

- Benchmark coverage: coverage that is provided through one of three options including the Federal Employee Health Benefit Program, state employee coverage, or coverage offered by the HMO with the largest commercial enrollment offered in the state;
- Benchmark-equivalent coverage: coverage that is not provided by one of the three options described above but is equivalent to that level of coverage;
- Coverage approved by the Secretary of the U.S. Department of Health and Human Services; or
- Comprehensive state-based coverage that existed when CHIP was enacted (only in Florida, New York, and Pennsylvania).³⁷

In addition, all CHIP programs must cover well-baby and well-child care (including immunizations), inpatient and outpatient hospital services, physicians’ surgical and medical services, and laboratory, X-ray, dental, and emergency services. As with private insurance, if mental health services are provided, they must not be restricted any more than physical health services.

³⁵Social Security Act, section 1915(i).

³⁶Thirty-seven states have premium assistance programs. U.S. Department of Labor, Employee Benefits Security Administration, Premium Assistance under Medicaid and the Children’s Health Insurance Program (CHIP) OMB Control Number 1210-0137 (expires 12/31/2019) (current as of January 31, 2017). Retrieved August 4, 2017 from <https://www.dol.gov/sites/default/files/ebsa/laws-and-regulations/laws/chipra/model-notice.pdf>

³⁷Hess, C., Farrell, K., deLone, S., Grossman, L., Rao, N. and Osius, E. (2011). *Charting CHIP IV: A Report on CHIP Programs Prior to Major Federal Policy Changes in CHIPRA and ACA*. Retrieved Dec. 22, 2011 from the National Academy for State Health Policy website: <http://www.nashp.org/report-state-chip-programs/>

Separately administered CHIP programs are not as likely to cover some of the services most needed by CSHCN that are covered under Medicaid's EPSDT benefit.

Finally, more cost sharing, such as premiums and copayments, may be imposed on CHIP families than those in Medicaid; however, the total cost sharing may not exceed five percent of the family's income.

Covered Services for CSHCN and the Affordable Care Act

In 2014, EPSDT became available to more children in 20 states³⁸ because the ACA required states to raise Medicaid eligibility for children ages 6 to 19 from 100% FPL to 138% of the federal poverty level, shifting children from CHIP to Medicaid.³⁹ Other coverage changes are described in [Section 9](#).

Where Are the Opportunities for Title V Programs?

Title V programs have significant opportunities to collaborate with Medicaid agencies regarding Medicaid and CHIP benefits. For example, Title V programs may:

- Advise the Medicaid programs how to help parents of enrollees understand the EPSDT benefit that will be available to their children;
- Work with Medicaid and other state policy-makers to develop Medicaid buy-in programs or waiver programs to enhance benefits for CSHCN whose health and support service needs are above and beyond the services covered by private insurance, CHIP, or standard Medicaid programs;
- Work with the Medicaid agency to improve Medicaid-funded case management.

³⁸The 20 states are Alabama, Arizona, California, Colorado, Delaware, Florida, Georgia, Kansas, Mississippi, Nevada, New York, North Carolina, North Dakota, Oregon, Pennsylvania, Tennessee, Texas, Utah, West Virginia, and Wyoming. Farrell, K., Hess, C., and Justice, D. (2011). *The Affordable Care Act and Children with Special Health Care Needs: An Analysis and Steps for State Policymakers*, p. 25. Retrieved Dec. 22, 2011 from <http://cahpp.org/resources/the-affordable-care-act-and-children-with-special-health-care-needs-an-analysis-and-steps-for-state-policymakers/>

³⁹The language of the ACA sets the eligibility limit at 133% of the federal poverty level (FPL) in 2014, but then instructs states to disregard an amount of income that brings the household to 138% of the FPL. ACA, section 2001(a); Health Care and Education Reconciliation Act, Pub. L. No. 111-152 section 1004(e).

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IMPROVING FINANCING OF CARE
for *Children & Youth*
WITH SPECIAL HEALTH CARE NEEDS

NATIONAL ACADEMY
for STATE HEALTH POLICY

Test your knowledge

1. EPSDT stands for:
 - a. Early Piloting of Special Diagnostic Tests
 - b. Early Periodic Sailing is Definitely Treatment
 - c. Early Periodic Screening, Diagnosis, and Treatment
 - d. Early Partners in Diagnosis and Treatment
2. EPSDT is required by federal law in:
 - a. Medicaid, but not CHIP
 - b. CHIP, but not Medicaid
 - c. All Medicaid and CHIP programs
3. If a vision problem is discovered during an EPSDT screening, treatment for it is covered by:
 - a. CHIP in all states
 - b. Medicaid in all states
 - c. Medicaid in some states
4. In 2014 many children shifted from CHIP to Medicaid. Why did that happen and why does it matter?
 - a. It happened because states can reduce CHIP coverage, and it matters because CHIP provides EPSDT.
 - b. It happened because states are changing the name of CHIP, and it doesn't matter.
 - c. It happened because the ACA mandated that states raise Medicaid income eligibility for 6- to 19-year-olds from 100% FPL to 138% FPL.



Find Out in Your State

1. Was your state one of the 20 in which EPSDT became available to more children in 2014, because Medicaid eligibility will increase to 138% of the poverty level?
2. How is care coordination funded for CSHCN in your state?
3. What “optional benefits” are covered by your state Medicaid Plan?

1. c 2. a 3. b 4. c



Section 6

FINANCING

How Do Medicaid and CHIP Dollars Flow?

In 2015, the Medicaid and Children's Health Insurance Program (CHIP) programs accounted for over 17% of total U.S. health care spending.⁴⁰ Medicaid expenditures nationally amounted to over \$545 billion in that fiscal year, while CHIP expenditures amounted to over \$14.6 billion.⁴¹ Medicaid usually consumes the largest or second-largest share of state budgets, ranging from a high of 41% in New Hampshire, to a low of 9% and 7% of state budgets in Alabama and Utah respectively.⁴²

Medicaid's State and Federal Funding

The federal government pays for at least half of the cost that states pay to purchase health care services under their Medicaid program. The federal contribution to Medicaid is called the federal medical assistance percentage, better known as FMAP or the "federal match." The FMAP ranges from 50 to 75.65% in FY 2017 for medical services, with most states receiving more than 50%. Under the funding formula, states with lower per capita incomes receive higher FMAP rates than states with higher per capita incomes. A state with 75% matching rate receives three dollars from the federal government for every dollar the state spends on Medicaid services.

States also receive 50% matching federal funds for the *administration* of their Medicaid programs (as opposed to the cost of health services, mentioned above). These administrative dollars can be spent to conduct outreach and provide education for families of children with special health care needs (CSHCN). Efforts to improve enrollment such as translating the application, enrollment, and Medicaid benefit materials into other languages, developing web-based application systems, and providing consumer-assistance helplines are all eligible for federal matching dollars. For every dollar the state spends reaching out to enroll people in Medicaid, the federal government contributes another dollar.

⁴⁰National Health Expenditures Accounts (NHEA), Table 5: National Health Expenditures and Table 21: Enrollment and Per Enrollee Estimates of Health insurance Retrieved August 14, 2017 from <http://go.cms.gov/2xlawu0>

⁴¹National Health Expenditures Accounts (NHEA), Table 21: Expenditures, Enrollment and Per Enrollee Estimates of Health insurance Retrieved August 14, 2017 from <http://go.cms.gov/2xlawu0>

⁴²Kaiser Family Foundation, State Health Facts. Distribution of State General Fund Expenditures (in millions) 2015. Retrieved August 14, 2017 from <http://www.kff.org/other/state-indicator/distribution-of-general-fund-spending/>

The Medicaid and CHIP programs account for over 17% of total U.S. health care spending.⁴⁰ Medicaid expenditures nationally amounted to over \$545 billion in fiscal year 2015, while CHIP expenditures amounted to over \$14.6 billion.⁴¹

State agencies such as Title V may engage in these outreach or consumer assistance activities and thus may be able to claim federal Medicaid matching dollars. These activities and Medicaid payment for them can be built into cooperative agreements between Medicaid and the Title V program.⁴³

While the federal matching dollars are crucial, states still make a large financial contribution to the Medicaid program. The state share ranged from \$29 billion in California to \$284 million in Wyoming in FY 2016.⁴⁴ This wide variation stems from differences in population size, eligibility criteria for Medicaid coverage, the scope of Medicaid coverage, and state-specific health care costs and provider practices. To find out how much your state spent on the Medicaid program in FY 2016, look at the table on the Kaiser Family Foundation State Health Facts website at <http://www.kff.org/medicaid/state-indicator/federalstate-share-of-spending>

The state share of Medicaid is usually financed by state general funds, most of which are raised from personal income, sales, and corporate income taxes.⁴⁵ Medicaid spending tends to rise in tough economic times when states suffer from declining revenue and budget deficits. When unemployment rises and employers cut back on insurance coverage, more people become eligible to enroll in Medicaid or CHIP, leading to increased expenditures. States may be hard-pressed to cover these costs, especially with shrinking revenues. As a result, states often seek opportunities to scale back Medicaid and CHIP spending in difficult budget climates.

Medicaid Funding and the Affordable Care Act (ACA)

When Medicaid eligibility expanded in 2014, the federal share of Medicaid spending for the newly eligible individuals was 100%. This lasted through 2016 when the federal matching rate began to phase down annually from 100% to 90% for those newly eligible by 2020.

CHIP Funding

Unlike Medicaid, federal CHIP funds are capped and allotted for two years based on a formula that changes from year to year. Regardless of program design, states' CHIP spending is reimbursed by the federal government at a matching rate that is higher than Medicaid's.^{46,47} The Medicare Access and CHIP Reauthorization Act of 2015 (MACRA, P.L. 114-10) extended federal

When Medicaid eligibility expanded in 2014, the federal share of Medicaid spending for the newly eligible individuals was 100%. This lasted through 2016 when the federal matching rate began to phase down annually from 100% to 90% for those newly eligible by 2020.

⁴³However, Title V dollars, being federal dollars, cannot be used as the state Medicaid share to obtain matching federal Medicaid dollars. Only state dollars can be matched by federal Medicaid dollars.

⁴⁴Kaiser Family Foundation, State Health Facts. Federal and State Share of Medicaid Spending 2016. Retrieved August 14, 2017 from <http://www.kff.org/medicaid/state-indicator/federalstate-share-of-spending>

⁴⁵Medicaid and CHIP Payment and Access Commission (MACPAC). (2011, March). *Report to the Congress on Medicaid and CHIP March 2011*, Figure 1-1. Retrieved Dec. 21, 2011 from <https://www.macpac.gov/publication/report-to-the-congress-on-medicare-and-chip-311/>

CHIP funding for two years through FY 2017. As of September 2017, Congress is working on legislation that will extend CHIP funding over a longer period of time, potentially at a lower match rate. MACPAC estimates that all states would exhaust federal CHIP funding at some point in FY 2018.⁴⁸

Where Are the Opportunities for Title V Programs?

Understanding the financing of Medicaid and CHIP in your state is important because it allows Title V programs to:

- Assess the financial implications of efforts to enroll more CSHCN in Medicaid or CHIP;
- Examine their own state-funded activities to determine whether they have administrative costs or medical services costs for Medicaid enrollees that could be matched with federal Medicaid dollars.

⁴⁶For the enhanced federal match rate for CHIP in FY2018 by state, see <http://www.kff.org/other/state-indicator/enhanced-federal-matching-rate-chip>

⁴⁷For the federal match rate for Medicaid in FY2018 by state, see <http://www.kff.org/medicaid/state-indicator/federal-matching-rate-and-multiplier>

⁴⁸The Medicaid and CHIP Payment and Access Commission.(2017, July). *Federal CHIP Funding: When Will States Exhaust Allotments?*. Retrieved September 13, 2017 from <https://www.macpac.gov/publication/federal-chip-funding-when-will-states-exhaust-allotments/>

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for STATE HEALTH POLICY

Test your knowledge

1. True or False: The percent of the Medicaid program paid for by the federal government varies from one state to another based on the number of people living in the state.
2. If a Medicaid program pays a \$100 bill from a doctor or therapist for a patient on Medicaid, the portion of that bill that is reimbursed by federal dollars (depending on the state's federal matching rate), ranges from:
 - a. \$50 to \$75
 - b. \$75 to \$95
 - c. \$25 to \$50
 - d. \$0 to \$100
3. If a state Medicaid program pays \$100 in administrative costs to provide outreach to enroll children in Medicaid, the portion of that bill that is reimbursed by federal dollars is:
 - a. \$ 0
 - b. \$ 25
 - c. \$ 50
 - d. \$75



Find Out in Your State

1. What is your state's federal match rate for Medicaid? For CHIP?
2. Does your state Title V program currently receive Medicaid reimbursement for either direct health services or administrative activities?
3. Could any of your state's Title V services or activities currently funded through state dollars be supported through federal funds by the Medicaid match?

1. False: It is based on the average per capital income in the state 2. a 3. c



Section 7

SERVICE DELIVERY MODELS

How Do States Deliver Health Care Services to Children Enrolled in Medicaid and CHIP?

Most states deliver Medicaid and CHIP health services by 1) contracting with a managed care organization (MCO) to manage care and pay providers, 2) paying health care providers directly on a traditional fee-for-service basis for each service they provide, or 3) a combination of both.

Managed Care

As of March 2017, Medicaid beneficiaries in 38 states and the District of Columbia received care through prepaid capitated MCOs.⁴⁹ In these models, the MCO is paid a set amount per person per month to run the program and pay providers for the care of people enrolled in the program. In health insurance language, the payment is called a “capitation rate” or a “per-member-per-month” (PMPM) payment. In contrast with the fee-for-service payment system where providers are paid a set fee each time they provide a service, capitation payments place the MCO at financial risk if it provides more services than the capitation payment covers.

Managed care organizations offer several potential opportunities to improve the delivery of care for children with special health care needs (CSHCN). For example, they may expand provider choice by contracting with physicians or other providers who do not typically provide services to children enrolled in Medicaid. Many MCOs place a priority on access to primary care, with an emphasis on wellness and prevention. MCOs have spurred much of the progress in the monitoring and improvement of health care quality because they can collect and analyze service utilization data and laboratory results and feed this information back to their contracted providers. Some MCOs also offer one-stop health care shopping in multi-specialty clinics.

In addition, capitation payment methodology reduces the financial incentive to deliver as many services as possible, regardless of their utility or cost, an incentive that is prevalent in the fee-for-service health care system. If MCOs can control service utilization and costs, they retain the saved dollars. MCOs implement numerous strategies to control costs and promote efficiency in service delivery. To achieve these goals, MCOs may decide to emphasize wellness and prevention, require prior approval for certain types of treatments, initiate programs to reduce emergency department use, reimburse for benefits not typically covered, or encourage the use of generic drugs. Techniques for managing health care are

Most states deliver Medicaid and CHIP health services by

1. Contracting with a managed care organization (MCO) to manage care and pay providers;
2. Paying health care providers directly on a traditional fee-for-service basis for each service they provide; or
3. A combination of both.

⁴⁹Kaiser Family Foundation, State Health Facts, Total Medicaid MCOs (March 2017). Retrieved August 15, 2017 from <http://www.kff.org/medicaid/state-indicator/total-medicaid-mcos/>

SERVICE DELIVERY MODELS

rapidly evolving in both managed care and in traditional fee-for-service programs.

Federal regulations establish certain standards and safeguards in managed care, because of the concern that MCOs will limit service use in order to control costs. These standards include the adequacy of the MCO's provider network to serve their enrollee population, the monitoring and evaluation of health care quality, and the ability of Medicaid beneficiaries to appeal decisions about health care benefits if they believe they have been denied a service wrongfully. In addition, states can require MCOs to meet specific quality benchmarks or implement special programs or services as part of the managed care contract.

In some states managed care enrollment is mandatory, and in other states it is voluntary. Within a given state, enrollment may be mandatory for some groups but voluntary for others. In the past, if a state wanted to mandate enrollment in managed care, they needed to seek a 1915(b) "freedom of choice" waiver from the federal government, because they would be restricting provider choice through managed care. However, the Balanced Budget Act (BBA) of 1997 changed the rules governing the Medicaid program to allow states to mandate Medicaid managed care enrollment through their Medicaid state plan rather than seeking a waiver. Many CSHCN were excluded from this new rule, such as children receiving SSI benefits, children receiving foster care or adoption subsidies, institutionalized children, and children recognized as having special needs under the Maternal and Child Health Title V Block Grant Program.⁵⁰ States are still required to obtain a federal waiver in order to mandate the enrollment of these groups of CSHCN in Medicaid managed care.

States vary as to which groups of Medicaid beneficiaries they require to enroll in a managed care plan. States require a waiver to make managed care enrollment mandatory for

disabled SSI recipients. However, many children enrolled in Medicaid managed care plans may still have special health care needs, as 48.8% of CSHCN are covered by Medicaid or CHIP.⁵¹

In other states, children who are exempt from mandatory enrollment in managed care may enroll voluntarily, or they may be excluded from managed care enrollment entirely. When CSHCN are not enrolled in managed care, states pay for their health care directly using the traditional fee-for-service system.

States also vary as to which benefits and services are managed and paid for by the MCO and which are "carved out" and paid for on a fee-for-service basis or through a different managed care plan. Often, services that are less typically managed by insurance companies or are unique to Medicaid, such as home-based services, medical supplies, dental care, or services delivered in the schools, are carved out of the managed care plan. The contract between a state and a managed care organization should always spell out what services the MCO is responsible for providing and which services Medicaid will cover on a fee-for-service basis. This is particularly critical with services that tend to be unique to Medicaid, such as Early Periodic Screening, Diagnosis, and Treatment (EPSDT) or home and community-based services.

Capitation rates paid to MCOs must be "actuarially sound" - developed by professional actuaries and based on previous health care expenditure experience for the enrolled population. However, states can set payment rates for different groups based on their expected costs. This is an element of risk adjustment. Risk adjustment is a methodology that levels the playing field for plans that attract more expensive populations by redistributing gains and losses. This is especially important when plans cover enrollees with special health care needs, disabilities and

⁵⁰Kaiser Family Foundation, Kaiser Commission on Medicaid and the Uninsured. (1997, October). *Comparison of the Medicaid Provisions in the Balanced Budget Act of 1997 (P.L. 105-33) with Prior Law*. Retrieved Dec. 22, 2011 from <http://www.kff.org/medicaid/2091-index.cfm>

⁵¹National Survey of Children's Health. NS-CH 2016. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved September 13, 2017 <http://www.childhealthdata.org/browse/survey/results?q=4562&r=1&g=638>. A Catalyst Center calculation based on preliminary NS-CH data. The calculation was performed using the population estimate of CSHCN with public insurance (n=5,739,375) and the population estimate of CSHCN with public and private insurance (n=1,049,865), divided by the estimate of the total CSHCN population (n=13,901,999).

SERVICE DELIVERY MODELS

chronic illnesses, such as CSHCN. By definition, CSHCN use more health care services than children typically do, and are consequently more costly to cover.⁵²

If a child with special health care needs is in a managed care plan where the capitation rate is set, for example, on the average cost of care for all children in the plan, he or she will likely cost more than the average child. Thus MCOs may have an incentive to discourage CSHCN from enrolling in their plan because it is likely that CSHCN will cost more than the average child. This is known as “selection bias.” Selection bias may result if it becomes known that a particular plan makes it difficult to obtain specialty care or requires multiple approval processes to obtain therapies or medical equipment. Selection bias may also result if an MCO excludes certain pediatric providers from its provider network.

Risk-adjustment strategies may counteract selection bias. When MCOs are paid more than the average rate for CSHCN, plans will find it easier to finance the comprehensive care that CSHCN need.

The following issues are important for Title V programs to address with Medicaid programs that are designing or redesigning managed care programs and contracting with MCOs:

- Are CSHCN going to be required to enroll in managed care, will it be optional, or will they all receive care on a fee-for-service basis?
- If CSHCN are enrolled in managed care, which services must they obtain through the MCO and which will be available through the Medicaid program on a fee-for-service basis or a carve-out plan?
- Will the MCO or the Medicaid program be responsible for EPSDT, dental coverage, or mental health coverage?
- What is the process for ensuring that the appropriate pediatric providers are included in the provider network?
- What is the process for authorizing specialty care and services that are uniquely used by CSHCN?
- How do the grievance and appeals processes work when a child is denied a service?

These are some of the issues that should be addressed in the managed care contract between the Medicaid program and the MCO. Title V programs are in a good position to participate in the process of developing the Request for Proposals (RFPs) that Medicaid programs issue when procuring MCO services. The RFP and contract development process is often when these decisions are initially made and is a good time for Title V programs to bring their expertise and judgment to some of these decisions.

States can set payment rates for different groups based on their expected costs. This is called “risk adjustment.” Risk adjustment allows states to pay more for more costly populations and less for less costly populations.

⁵²McPherson, M., Arango, P., Fox, H., Lauver, C., McManus, M., Newacheck, P., Perrin, J., Shonkoff, J., Strickland, B. *A New Definition of Children With Special Health Care Needs*. Pediatrics Jul. 1998, 102 (1) 137-139).

Primary Care Case Management

Primary Care Case Management (PCCM) programs are common delivery systems used by state Medicaid programs that combine some aspects of managed care with fee-for-service care. With PCCM every beneficiary must choose a primary care provider (PCP), such as a pediatrician or family practice physician. The PCP agrees to deliver primary care services, manage access to specialty services, and coordinate care. Typically, in PCCM, the primary care provider refers patients to specialty services, and these referrals may be required in order to access care. In this system, the health care providers are paid each time they deliver a service on a fee-for-service basis. In addition, the primary care provider is paid an additional fee per person for managing the care.⁵³ This is usually a set amount such as \$2 or \$5 per member per month (PMPM). Sometimes the management fee comes in the form of enhanced payment for certain visits or a performance bonus for meeting certain quality goals or implementing care plans.

The process of developing standards for PCPs also provides an opportunity for Title V programs to bring their expertise to the Medicaid program to help improve care for CSHCN. States can structure their payments to PCP practices to encourage better quality outcomes, better screening, referral and preventive care, same-day access to the practice for sick care, or better care coordination when children have complex health care needs.

The ACA and Service Delivery

The Affordable Care Act (ACA) offers several opportunities to change the way care is delivered for CSHCN in order to align financial incentives with the delivery of high-quality care rather than simply a high volume of care. These include a new option to implement “health homes” for children with certain chronic conditions, the possibility of contracting with pediatric Accountable Care Organizations to provide care and meet certain health goals, and funding to create incentives for health behaviors. More detail is provided in [Section 9](#).

Where Are the Opportunities for Title V Programs?

Bringing the expertise of Title V programs to help shape Medicaid policies that affect the delivery of care to CSHCN is critical. Assessing and addressing the gaps in services for CSHCN is also important. Primary care practices are not usually staffed or compensated for care coordination. They may need help accessing appropriate resources for further diagnosis and treatment. Title V programs may be able to partner with Medicaid programs to identify and fill these gaps and promote better quality of care for CSHCN. For example:

- Title V programs can help Medicaid develop contracts with managed care plans and help set and monitor standards for the managed care networks.⁵⁴
- Title V programs can participate in building the medical home model and

Primary care practices are not usually staffed or compensated for care coordination. They may need help accessing appropriate resources for further diagnosis and treatment. Title V programs may be able to partner with Medicaid programs to identify and fill these gaps and promote better quality of care for CSHCN.

⁵³Hanlon, C. (2010). *Improving the Lives of Young Children: Opportunities for Care Coordination and Case Management for Children Receiving Services for Developmental Delay*. Retrieved Jan. 12, 2012 from the Urban Institute website: <http://www.urban.org/publications/412289.html>

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improving preventive and developmental care in pediatric primary care practices.⁵⁵

- Title V programs can help design and administer the health home option (Section 2703) under the ACA for children with certain chronic conditions.⁵⁶
- Title V programs can play a role in linking pediatric primary care providers who provide Early Periodic Screening, Diagnosis, and Treatment (EPSDT) screenings to referral resources for diagnosis and treatment, and, conversely, assure that community and educational programs that screen children link back to the children's health care providers.⁵⁷
- Title V programs, based on historically strong relationships with providers of CSHCN services, can ensure managed care provider networks include critically important service providers.

⁵⁴NASHP, (2017). Strengthening the Title V-Medicaid Partnership: Strategies to Support the Development of Robust Interagency Agreements between Title V and Medicaid. Retrieved August 16, 2017 from <http://www.nashp.org/strengthening-the-title-v-medicaid-partnership/>

⁵⁵National Center for Medical Home Implementation: Title V & Medicaid collaboration around implementation of Medical Home. Retrieved August 16, 2017 from <https://medicalhomeinfo.aap.org/tools-resources/Pages/Webinars.aspx>

⁵⁶Centers for Medicare and Medicaid Services. Health Home Information Resource Center. Retrieved August 15, 2017 from <https://www.medicaid.gov/state-resource-center/medicaid-state-technical-assistance/health-homes-technical-assistance/health-home-information-resource-center.html>

⁵⁷Centers for Medicare and Medicaid Services. The State Medicaid Manual. Chapter 5: Early and Periodic Screening. Retrieved August 15, 2017 from <https://www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/Paper-Based-Manuals-Items/CMS021927.html>

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Test your knowledge

1. True or False: If a child with special health care needs is in a primary care case management (PCCM) system, the primary care provider takes on the risk that care for the child will be more expensive than predicted.
2. In a comprehensive managed care program, states must assure in their contracts with Managed Care Organizations (MCOs) that:
 - a. Beneficiaries have adequate access to providers
 - b. Beneficiaries can appeal if they believe they have wrongfully been denied a service
 - c. An independent organization monitors and measures the quality of care
 - d. All of the above
3. Which of these is NOT correct: The Affordable Care Act provides states with the following opportunities:
 - a. To design health homes for people with chronic conditions
 - b. To design and provide incentives for healthy behaviors
 - c. To give managed care organizations the right to refuse patient access to emergency department services
4. In a typical comprehensive Medicaid managed care program where the managed care organization (MCO) is paid a capitated rate, who bears the risk or reaps the rewards if health costs for participants are more or less than projected?
 - a. The state Medicaid program
 - b. The beneficiaries
 - c. The federal government
 - d. The MCO



Find Out in Your State

1. Does your state provide services for CSHCN through managed care organizations, fee for service, PCCM or more than one of these service delivery options?
2. If MCO's are enrolling CSHCN, are any services "carved out" of the MCO contract? If so, which services are carved out and how are they delivered?
3. Does your state provide targeted case management services for CSHCN?
4. Has your state considered the health home option (Section 2703) for children with chronic conditions?

1. False. The PCP and the child's other providers are paid on a fee-for-service basis for all medically necessary care. The PCP is paid an additional fee for managing the care.
2. d 3. c 4. d



Section 8

QUALITY MEASUREMENT AND IMPROVEMENT

Quality measurement and improvement are important components of both Medicaid and the Children's Health Insurance Program (CHIP). State Medicaid and CHIP programs are increasingly interested in developing value-based purchasing strategies to ensure that beneficiaries receive high-quality services at reasonable cost. Both programs offer opportunities for collaboration with Title V around quality improvement for children with special health care needs (CSHCN).

Medicaid State Plan Reporting Requirements

State Medicaid agencies are required to report annually on the delivery of Early Periodic Screening, Diagnosis, and Treatment (EPSDT) services (see [Section 12](#)). The annual report provides basic information on the number of children (by age and Medicaid eligibility category) who receive medical and dental screens and the number referred for diagnostic or treatment services. (The Centers for Medicare and Medicaid Services offer more general information about EPSDT on their website: <https://www.medicaid.gov/medicaid/benefits/epsdt/index.html>). The federal benchmark for developmental screening of children who receive Medicaid benefits is 80%.⁵⁸ Although there are some criticisms about this reporting system, these data are important for determining if children are routinely screened and whether children identified receive appropriate follow-up.

Each state is also required to list the quality measures it is using and how they will be measured in the CHIP state plan and to report on these measures annually to the U.S. Department of Health and Human Services (HHS).⁵⁹ States must report data regarding access to primary and specialty services, access to networks of care, and care coordination using quality care and satisfaction measures from the Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey.⁶⁰

Quality Assessment Requirements for Managed Care

In addition, states with Medicaid managed care programs that contract with managed care organizations (MCOs) are required to put provisions in the MCO contracts to assess the quality and appropriateness of care and services furnished by the MCOs. One such procedure is the requirement to evaluate care provided to children and adults with special health care needs. When an MCO is paid

State Medicaid agencies are required to report annually on the delivery of Early Periodic Screening, Diagnosis, and Treatment (EPSDT) services. Each state is also required to list the quality measures it is using and how they will be measured in its CHIP state plan and to report on these measures annually to the U.S. Department of Health and Human Services (HHS).⁵⁹

⁵⁸Centers for Medicare and Medicaid Services, The State Medicaid Manual, Chapter 5: Early and Periodic Screening. Retrieved August 15, 2017 from <https://www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/Paper-Based-Manuals-Items/CMS021927.html>

⁵⁹Social Security Act, Section 2107.

⁶⁰Social Security Act, Section 2108(e)(4).

QUALITY MEASUREMENT AND IMPROVEMENT

on a per-member-per-month (PMPM) basis for each enrollee, both Medicaid and CHIP are required to engage an independent External Quality Review Organization (EQRO) to evaluate the quality, timeliness, and access to care furnished by the MCO.⁶¹

One of the ways that EQROs evaluate the quality of care is through Performance Improvement Projects (PIPs).⁶² PIPs are a structured process to identify an issue, collect data about the topic, and then make improvements. State expenditures for these activities are eligible for enhanced federal matching funds. States can choose their own PIP topics and several states have focused PIPs on issues of relevance for CSHCN, such as measuring and improving coordination between mental health and medical providers (Utah) and coordination of care with community-based services (Oregon).

Child Health Care Quality Measures

Under the Children's Health Insurance Program Reauthorization Act of 2009 (CHIPRA), the federal government is required to develop a set of child health care quality measures for voluntary use by states in both Medicaid and CHIP. HHS published a set of 24 initial core measures in 5 areas:

- Prevention and health promotion;
- Management of acute conditions;
- Management of chronic conditions;
- Family experience of care;
- Availability of care.

Some of the measures include screening for developmental delays, immunizations, weight assessment and nutritional counseling, dental care, emergency department visits, central-line associated blood stream infections, follow-up care after a hospitalization for mental illness, and more. The core measures were identified by the Agency for Healthcare Research and Quality (AHRQ) and can be found at <http://www.ahrq.gov/policymakers/chipra/pqmpback.html>.

In addition to the 24 core measures that states are encouraged to report to CMS, CHIPRA requires CHIP programs to report annually on consumer satisfaction measures. Many states use AHRQ's Consumer Assessment of Healthcare Providers and Systems (CAHPS) Child Medicaid Survey to measure consumer satisfaction. As of December 31, 2013, all CHIP programs are required to submit CAHPS data. Medicaid reporting of CAHPS data is voluntary.⁶³ It is important to note that CAHPS has a set of questions for assessing satisfaction

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⁶¹Social Security Act, Sections 1932(c)(2) and 2103(f); see 42 Code of Federal Regulations Part 438, Subparts D - E.

⁶²42 Code of Federal Regulations Section 438.240(b)(1).

⁶³U.S. Department of Health and Human Services, Center for Medicare and Medicaid Services (CMS). (2011, Feb. 14). *CHIPRA Quality Measures*. [Letter to State Health Officials from Cindy Mann: SHO # 11-001 CHIPRA #20]. Retrieved Aug. 21, 2015 from <https://www.medicaid.gov/Federal-Policy-Guidance/downloads/SHO-13-002.pdf>

QUALITY MEASUREMENT AND IMPROVEMENT

with care for children with chronic conditions that includes a five-item screener to identify children with chronic conditions.⁶⁴

Where Are the Opportunities for Title V Programs?

Medicaid, CHIP, and Title V can collaborate on quality and performance measurement. For example:

- Title V programs can collaborate with their CHIP and Medicaid counterparts in interpreting children's health quality data across all programs and potentially for all children.
- Title V programs can monitor the screening ratios tracked by Medicaid programs and collaborate on strategies to reach the 80% screening benchmark.
- Title V programs can also analyze service utilization data for children with special health care needs enrolled in Medicaid and CHIP to better inform care delivery and contracting. (<http://mchb.hrsa.gov/epsdt/>).
- Title V programs can collaborate with their Medicaid and CHIP counterparts to develop PIPs on quality measures that particularly impact CSHCN.
- Title V programs can work with their Medicaid and CHIP programs or Managed Care Organizations to train primary care providers in caring for CSHCN. For example, Georgetown University's Bright Future's program worked with both Medicaid and Title V programs in training primary care health professionals and Connecticut's Title V and Medicaid programs worked with the Yale Center for CSHCN to train pediatric residents in care of children with chronic illness and disabilities. See more examples of how Title V and Medicaid programs are working together to ensure children receive EPSDT at <http://cahpp.org/project/the-catalyst-center/financing-strategy/epsdt/>.
- Title V programs can collaborate with Medicaid programs on how the state's targeted case management and EPSDT services are structured to improve care coordination for CSHCN.

⁶⁴<https://cahps.ahrq.gov/surveys-guidance/item-sets/children-chronic/index.html>

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Test your knowledge

1. EQRO stands for:
 - a. External Queries about Readmissions and Operations
 - b. External Quality Review Organization
 - c. Egalitarian Quagmires for Reviewing Organizations
 - d. Extent and Quality of Results in Operations
2. Under CHIPRA, Congress directed CMS to establish core pediatric quality measures for:
 - a. Medicaid and CHIP
 - b. Just Medicaid
 - c. Just CHIP
 - d. Medicaid, CHIP, and the State Health Insurance Marketplace (Exchange)
3. What is the EQRO's role in Medicaid and CHIP?
 - a. States may hire an EQRO to review the performance of the Medicaid state agency.
 - b. States must hire an EQRO to evaluate quality, timeliness, and access to health services in the Medicaid fee-for-service system.
 - c. States must hire an EQRO to evaluate quality, timeliness, and access to health services in state PCCM systems.
 - d. States must hire an EQRO to evaluate quality, timeliness, and access to health services in comprehensive Medicaid and CHIP managed care systems.



Find Out in Your State

1. What data on service utilization and outcomes does your agency have for children with special health care needs who are enrolled in Medicaid or CHIP?
2. If your state Medicaid program operates under a managed care environment, who is the contracted EQRO? Does or will CHIP use the same EQRO?
3. What pediatric quality measurement and reporting is required from providers or plans by your state Medicaid agency?
4. What kind of training is provided in your states for primary care providers who care for CSHCN? Who provides this training?
5. What is your state's EPSDT screening rate?



CHANGES TO MEDICAID AND CHIP UNDER THE AFFORDABLE CARE ACT (ACA)

Eligibility for Medicaid and the Children's Health Insurance Program (CHIP)

Medicaid eligibility changes in the ACA are best understood in the context of the goal for health care reform: that nearly everyone would have either public or private health coverage after 2014. At that time a single system for eligibility screening, enrolling individuals and families in individual private plans or public coverage, and ensuring smooth transitions across coverage types became available in the form of the Health Insurance Marketplaces or Exchanges.

Several important provisions of the ACA first went into effect in 2014. Medicaid programs could cover people with income below 138% of the federal poverty level (FPL).⁶⁵ Children who had been enrolled in CHIP and whose family income was under 138% of FPL were shifted to Medicaid, which expanded their access to certain services because of Medicaid's unique Early Periodic Screening, Diagnosis, and Treatment (EPSDT) benefit. In addition, young people who were in foster care at the time they turned 18 became eligible to maintain their Medicaid benefits until they turned 26. This should help ease the transition from foster care to adult lives, including access to higher education and employment, by guaranteeing continued health care coverage. Finally, states had the new option to offer CHIP coverage to eligible children of state employees. Previously, it was assumed that all state employees had access to affordable coverage, and thus this group of children was barred from enrolling in CHIP. Under the ACA, if a state can demonstrate that it has maintained its own contribution toward family coverage but the annual premiums and cost-sharing for a family exceed 5% of their income, children of low-income state employees can enroll in CHIP. The ACA also included a "maintenance of effort" (MOE) provision that prohibits states from reducing Medicaid or CHIP eligibility limits below those in effect when the ACA was enacted on March 23, 2010. MOE was required for adults until 2014 and for children under 19 through September 30, 2019.⁶⁶ Under the ACA almost everyone is required to enroll in some form of public

Medicaid eligibility changes in the ACA are best understood in the context of the goal for health care reform: that nearly everyone would have either public or private health coverage after 2014.

⁶⁵The language of the ACA sets the eligibility limit at 133% of the federal poverty level (FPL) in 2014, but then instructs states to disregard an amount of income that brings the household to 138% of the FPL. ACA, Section 2001(a); Health Care and Education Reconciliation Act, Pub. L. No. 111-152 Section 1004(e).

⁶⁶Center for Medicaid, CHIP and Survey & Certification. (2011). Maintenance of Effort. Retrieved August 16, 2016 from <https://www.medicaid.gov/federal-policy-guidance/downloads/smd11001.pdf>

CHANGES UNDER THE ACA?

or private coverage following 2014.⁶⁷ This is called the “individual mandate.” People who are over income for Medicaid or CHIP and who do not have employer-sponsored insurance are able to purchase private coverage through a Health Insurance Marketplace (also known as an Exchange). Marketplace enrollees are eligible for federal help to pay for the cost of coverage if their income is below 400% of the FPL. If someone applies through the Marketplace and is found to be eligible for Medicaid or CHIP, he or she will be referred to or enrolled in the appropriate program.

The manner in which states calculate Medicaid and CHIP eligibility for most people was another important change under the ACA.⁶⁸ In 2014, states began determining whether most people are eligible for Medicaid or CHIP by counting a family’s income using a formula called Modified Adjusted Gross Income (MAGI). MAGI changes two key factors in the eligibility calculation: the definition of household (affecting whose income counts in the eligibility calculation) and what applicants can deduct from income in calculating eligibility.

The shift to MAGI in calculating eligibility for Medicaid and CHIP aligns with the calculation used to determine eligibility for premium subsidies within the Marketplaces. This makes any transition between Medicaid, CHIP and the Marketplaces, which are all income-sensitive, easier for both consumers and coverage administrators. Using a consistent definition of income for calculating eligibility for Medicaid, CHIP, and the Marketplace, a single application can be used to determine eligibility for any of these programs.

The change in calculating eligibility for Medicaid will NOT impact many people who have special health care needs, including:

- Children or adults who qualify for Medicaid due to disability or because they receive SSI or are low-income and over the age of 65;
- People receiving long-term care services, home and

community-based waiver services, home health or personal care services, or other home and community-based services;

- Children who qualify for Medicaid under the TEFRA or Katie Beckett option (For more about TEFRA, please refer to [Section 11](#) of this tutorial); or
- Children who qualify for Medicaid because they are in foster care.⁶⁹

Finally, the Children’s Health Insurance Program Reauthorization Act of 2009 (CHIPRA) and the ACA also included provisions to simplify and improve enrollment in Medicaid and CHIP, including provisions requiring or allowing states to:

- Establish a system of enrollment and enrollment renewals via a website as well as by phone or in person;
- Coordinate eligibility determination for Medicaid and CHIP along with determination of eligibility for tax credits to purchase private insurance in the Marketplace;
- Conduct outreach to vulnerable populations, including families with CSHCN, to enroll in Medicaid and CHIP;
- Permit hospitals to make “presumptive eligibility” determinations for Medicaid, to be verified later by the state Medicaid program;
- Permit Medicaid and CHIP eligibility for children to be decided by public “express lane” agencies – agencies that use household income to determine eligibility for other programs such as WIC, subsidized housing, or school lunch programs.⁷⁰

⁶⁷Some people are exempt from any penalty if they fail to enroll. The most typical exemptions are for those with income too low to be required to file federal income tax returns and those for whom the lowest cost health plan available exceeds 8% of their income.

⁶⁸The language of the ACA sets the eligibility limit at 133% of the poverty level in 2014, but then instructs states to disregard an amount of income that brings the household to 138% of the poverty level. Affordable Care Act, Section 2001(a); Health Care and Education Reconciliation Act, Pub. L. No. 111-152 Section 1004(e).

⁶⁹National Health Law Program. (n.d.). *Analysis of the Health Care Reform Law: PPACA and the Reconciliation Act*, Part II, p. 9. Retrieved August 16, 2017 from Retrieved August 16, 2017 from <http://www.healthlaw.org/issues/health-care-reform/nhelp-analysis-of-aca-and-reconciliation-act-part-II-role-of-public-programs>

⁷⁰CHIPRA, P.L. 111-3, Section 203, codified in, 42 U.S.C. Sections 1396a(e)(13) and 1397gg(e)(1)(B).

CHANGES UNDER THE ACA

Covered Services for CSHCN

Under the ACA, states are encouraged or required to adjust benefits in numerous ways. Significantly, Early Periodic Screening, Diagnosis, and Treatment (EPSDT) became available to more children in 20 states in 2014,⁷¹ because Medicaid eligibility for children ages 6 to 19 increased in those states to 138% of the federal poverty level, shifting children from CHIP to Medicaid.⁷² The remaining states already covered these older children under Medicaid. Depending on the benefits covered by their state's CHIP program, this age group also became newly eligible for assistance with nonemergency transportation for medical appointments. Another important service change under the ACA is that families of terminally ill children enrolled in Medicaid or CHIP may elect to receive hospice care without having to forgo potentially curative care.

Financing Changes

As described above, many more people became eligible for Medicaid in 2014. Health coverage for people who were newly eligible in 2014 was financed at 100% by the federal government through 2016; then the federal matching rate began to phase down annually from 100% to 90% in 2020.

Unlike Medicaid, federal CHIP funds are capped and allotted for two years based on a formula that changes from year to year. Regardless of program design, states' CHIP spending is reimbursed by the federal government at a matching rate that is higher than Medicaid's.^{73,74} The Medicare Access and CHIP Reauthorization Act of 2015 (MACRA, P.L. 114-10) extended federal CHIP funding for two years through FY 2017. As of September 2017, Congress is working on legislation that will

extend CHIP funding over a longer period of time, potentially at a lower match rate. MACPAC estimates that all states would exhaust federal CHIP funding at some point in FY 2018.⁷⁵

The ACA offers state Medicaid programs significant financial incentives to improve the quality of health care while controlling costs. These opportunities include:

- Expanded access to preventive care;
- Care for people with disabilities in the community instead of in institutions;
- Restructuring provider payment arrangements to include incentives to improve health outcomes;
- Creating "health homes" for people with certain chronic health conditions. Health homes are similar to medical homes - see more under the Service Delivery section below.

Service Delivery

Health reform offers state Title V programs opportunities to realign health care delivery for CSHCN, promoting high-quality care rather than simply a high volume of services. For example:

- Beginning in January 2011, states had a new option to implement health homes for Medicaid-eligible adults and children with chronic conditions to better integrate physical and mental health and to coordinate care and promote efficiencies.⁷⁶

⁷¹The 20 states are Alabama, Arizona, California, Colorado, Delaware, Florida, Georgia, Kansas, Mississippi, Nevada, New York, North Carolina, North Dakota, Oregon, Pennsylvania, Tennessee, Texas, Utah, West Virginia, and Wyoming. Farrell, K., Hess, C., and Justice, D. (2011). *The Affordable Care Act and Children with Special Health Care Needs: An Analysis and Steps for State Policymakers*, p. 25. Retrieved Dec. 22, 2011 from <http://cahpp.org/resources/the-affordable-care-act-and-children-with-special-health-care-needs-an-analysis-and-steps-for-state-policymakers/>

⁷²The language of the ACA sets the eligibility limit at 133% of the poverty level in 2014, but then instructs states to disregard an amount of income that brings the household to 138% of the poverty level. ACA, Section 2001(a); Health Care and Education Reconciliation Act, Pub. L. No. 111-152 Section 1004(e).

⁷³For the enhanced federal match rate for CHIP in FY2018 by state, see <http://www.kff.org/other/state-indicator/enhanced-federal-matching-rate-chip>

⁷⁴For the federal match rate for Medicaid in FY2018 by state, see <http://www.kff.org/medicaid/state-indicator/federal-matching-rate-and-multiplier>

⁷⁵The Medicaid and CHIP Payment and Access Commission. (2017, July). Federal CHIP Funding: When Will States Exhaust Allotments?. Retrieved September 13, 2017 from <https://www.macpac.gov/publication/federal-chip-funding-when-will-states-exhaust-allotments/>

⁷⁶Affordable Care Act (ACA), Section 2703, "State option to provide health homes for enrollees with chronic conditions." See also, U.S. Department of Health and Human Services, Center for Medicaid and Medicare Services. (2010, Nov. 16). *Health Homes for Enrollees with Chronic Conditions*. [Letter to State Medicaid Directors and State Health Officials from Cindy Mann: SMDL# 10-024 ACA # 12]. Retrieved Jan. 12, 2012 from <https://www.medicaid.gov/Federal-Policy-Guidance/downloads/SMD10024.pdf>

CHANGES UNDER THE ACA

- Health homes receive a 90% federal match for the first two years of operation. After that, the state receives its regular Federal Medical Assistance Percentage (FMAP) for the Health Home enrolled population. To be considered a health home, a practice or clinic must offer comprehensive care management, patient and family support, comprehensive transitional care from a hospital or institution to home, referrals to community and social support services, use of health information technology to link services, care coordination, and health promotion.
- Health homes can be implemented either through a contract with a managed care organization or through a contract directly between the Medicaid program and a practice or clinic. States have broad flexibility in designing health homes and may claim the 90% match for health home-related services provided to people with serious and persistent mental health conditions or to people with two or more of the following conditions: a mental health condition, substance use disorder, asthma, diabetes, heart disease, or being overweight. With approval from CMS, states may specify additional conditions, such as autism or pediatric asthma.⁷⁷
- The ACA also contains language to implement demonstration projects at the state level for pediatric Accountable Care Organizations (ACOs). ACOs are organizations of providers that are being developed to align the financial incentives of providers with better health outcomes for patients. For example, a hospital might combine with physician practices to contract with Medicaid or an insurer to share any savings that result from better management of chronic diseases or a reduction in emergency department visits.
- Many state Medicaid programs have applied for newly available grants designed to create incentives for healthy behaviors and prevent chronic diseases.⁷⁸
- New measures to prevent fraud and abuse in Medicaid may affect the delivery of care for CSHCN. For example, patients must now have a face-to-face encounter with a physician to receive a prescription for durable medical equipment or home health services. This could become a barrier to care if providers and patients are not accustomed to meeting the new requirements. In addition, prescribed drugs and services will only be covered by Medicaid if the prescriber is enrolled as a Medicaid provider. This could cause serious problems for CSHCN and others who obtain prescriptions from doctors who are not enrolled in Medicaid as individual providers.

⁷⁷See U.S. Department of Health and Human Services, Center for Medicare and Medicaid Services. (2010, Nov. 16). *Health Homes for Enrollees with Chronic Conditions* [Letter to State Medicaid Directors and State Health Officials from Cindy Mann: SMDL# 10-024 ACA # 12]; Buxbaum, J. (2010). *Making Connections: Medicaid, CHIP, and Title V Working Together on State Medical Home Initiatives*. Retrieved Dec. 21, 2011 from the National Academy for State Health Policy website: <http://www.nashp.org/publication/making-connections-medicaid-chip-and-title-v-working-together-state-medical-home-initiatives>

⁷⁸See the Center for Medicare and Medicaid Services Overview of Medicaid Incentives for Prevention of Chronic Diseases Program at <https://innovation.cms.gov/initiatives/mipcd/>

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CHANGES UNDER THE ACA

Test your knowledge

1. Since 2014, children who turn 18 while in foster care are eligible for Medicaid until they are how old?
 - a. 19
 - b. 21
 - c. 26
 - d. 28
2. Under the Affordable Care Act, if a state has opted to implement the Medicaid expansion, most people under 65 became eligible for Medicaid in 2014, if:
 - a. They have a disability
 - b. They are under 21
 - c. They are a parent
 - d. They are an adult without children at home
 - e. They are any of the above (it doesn't matter which) and their income is under 138% of the federal poverty level
3. On October 1, 2015, the federal matching rate for CHIP increased by how many percentage points?
 - a. 3
 - b. 13
 - c. 23
 - d. 33
4. The opportunity for Medicaid programs to develop health homes for people with chronic conditions in the Affordable Care Act is funded with:
 - a. 75% federal matching dollars over four years
 - b. 80% federal matching dollars over three years
 - c. 100% federal dollars over one year
 - d. 90% federal matching dollars over two years



Find Out in Your State

1. How does your state coordinate enrollment in Medicaid, CHIP and Marketplace?
2. Has your state developed (or is it developing) a state plan amendment for health homes? Does it include children? If yes, which children?
3. Has your state received any grants to create incentives for healthy behaviors and prevent chronic diseases?

1. 2. 3. 4. 5.



Section 10

NEXT STEPS: MAKING THE CASE FOR SUCCESSFUL PARTNERSHIPS IN YOUR STATE

Learning the specific features of Medicaid and the Children's Health Insurance Program (CHIP) in your state is a critical step for Title V programs.⁷⁹ Medicaid and CHIP staff may need comparable education about Title V to develop effective partnerships. With a shared understanding, partners can identify the potential benefits of working together for each agency and the children they both serve. Common goals will likely include improved care, reduced cost growth, and better support for families.

Steps for developing and improving upon agency partnerships will depend on the relationships and systems in each state. Here are some suggestions:

Find Out More About the Specifics of Your State's Medicaid Program

- What are the income eligibility criteria for children in Medicaid and CHIP in your state? Are there many eligible children who could be enrolled, but are not? To what extent are their parents eligible for coverage?
- Does your state have a TEFRA (Katie Beckett) option for children with severe disabilities? If so, how does the Medicaid program decide whether a child is eligible? For more about TEFRA, please refer to [Section 11](#) of this tutorial.
- Do Medicaid or CHIP fund care coordination for children with special health care needs (CSHCN)? If yes, is it through a medical home? In managed care? Through a home and community-based services waiver? Through targeted case management? Through a contract with Title V?
- How does the Medicaid agency track the screening, diagnosis, and treatment services required by Early Periodic Screening, Diagnosis, and Treatment (EPSDT)? When needs are identified, is there a mechanism to track referrals and follow-up care?
- What cooperative agreements already exist between Title V and Medicaid? Do they need amending and updating?
- What quality data are collected by the Medicaid program, managed care organizations, external quality review organizations, or primary care case management programs?

Suggestions for developing and improving upon agency partnerships will depend on the relationships and systems in each state:

- Find out more about the specifics of your state's Medicaid program;
- Develop or expand key contacts;
- Work with agency contacts to identify targeted "do-able" improvement projects for CSHCN;

(cont.)

⁷⁹See the Catalyst Center's interactive worksheets for Title V program staff, family leaders, and other stakeholders. Each worksheet includes resources you can use to find and insert state-specific information to help demonstrate the importance of Title V, Medicaid and CHIP for children with special health care needs (CSHCN). <http://cahpp.org/resources/title-v-medicaidchip-interactive-worksheets/>

NEXT STEPS: MAKING THE CASE FOR SUCCESSFUL PARTNERSHIPS_____

- Is your state planning to expand its managed care program? If yes, will CSHCN be included? If yes, what are the plans for the procurement? Will it be a competitive bid? Will there be requirements for care coordination and care planning? What are the requirements for the provider network? How will the transition from fee-for-service to managed care take place? Is there consumer participation? What are the financing arrangements? Will there be risk adjustment, risk sharing, or stop-loss provisions?

Develop or Expand Key Contacts

- Who in the state Medicaid program or within your state's managed care organizations (MCOs) works on quality measurement and implements the CHIPRA quality measures? What are the challenges in collecting and using the data?
- Who is in charge of eligibility and enrollment in Medicaid and CHIP? What are they doing to implement the Medicaid and CHIP benefit and eligibility provisions of health reform?
- Who are the “go-to” people for obtaining data from the Medicaid and CHIP systems?
- Who is providing the leadership in your state that will improve the quality of care for CSHCN?

Work with Program Contacts to Identify Targeted “Do-able” Improvement Projects for CSHCN

- Where are the opportunities for improvement – where do the concerns of all agencies and consumers align?
- Based on your knowledge of the experience of children and families in the state, can you identify a small change in state policy that will make a big difference in their ability to access care?

Create Effective Formal or Informal Cross-agency Committees or Work Groups

- Is there a health reform working group or committee addressing issues of relevance to CSHCN or for all children or all persons with chronic conditions or disabilities that could include attention to CSHCN?
- Is the Medicaid agency considering adopting the health home option under the ACA? If so, where are they in the planning process, and what populations are they interested in including in the health home initiative?

Engage Patients and Families

- What agency is the designated [Family-to-Family Health Information Center](#) in your state?

- Create effective formal or informal cross-agency committees or work groups;
- Engage patients and families.

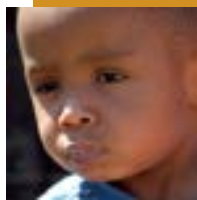
NEXT STEPS: MAKING THE CASE FOR SUCCESSFUL PARTNERSHIPS



NEEDS



ENROLLMENT



EFFICIENCIES



DATA

- How is this agency involved in working with primary care and other providers to improve care for CSHCN?
- Could the Title V model of employing parents of CSHCN work in Medicaid and CHIP programs?

A Last Word

Title V programs can assist Medicaid and CHIP agencies to fulfill their responsibilities, and at the same time ensure that children with special health care needs receive the services they need. NEED is the operative word here. There are four things to keep in mind when working with Medicaid and CHIP agencies:

Needs	Keep the needs of CSHCN in mind when designing, evaluating, and improving managed care and other service delivery contracts.
Enrollment	Assure that CSHCN are properly enrolled and receiving the appropriate services.
Efficiencies	Develop the most efficient financing mechanisms for services.
Data	Help analyze and respond to outcome data in order to improve the quality of

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Section 11

TEFRA/KATIE BECKETT OPTION: A PATHWAY TO MEDICAID FOR CHILDREN WITH DISABILITIES

For most people, low income is the primary pathway to Medicaid coverage. This means children's eligibility (including children with disabilities) for this important public benefit is based on their family's income. However, the Centers for Medicare and Medicaid Services (CMS), the federal agency that oversees Medicaid, allows states to use other eligibility criteria, such as age and disability status, to create alternative pathways to Medicaid for defined populations. One of these alternative pathways to Medicaid eligibility is the TEFRA/Katie Beckett option.

When a child with a disability receives extended care in an institutional setting, such as a hospital, pediatric nursing home, or other long-term care facility, family income is disregarded as a qualification for Medicaid.⁸⁰ However, if the child is cared for at home and in the community, Medicaid eligibility is based on his or her family's income.

The TEFRA/Katie Beckett option is one of several types of alternative pathways to Medicaid that states may adopt. It refers to a provision of the Tax Equity and Fiscal Responsibility Act (TEFRA) of 1982 that created a state plan option⁸¹ to allow children with disabilities who require an institutional level of care, but who live in families with incomes that are traditionally too high, to qualify for Medicaid so they can receive comprehensive services in their homes instead of in an institution.

One of the most important Medicaid benefits that the TEFRA option provides to children with disabilities is the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit, which requires that all medically necessary services be covered under a state's Medicaid program.⁸² [See Section 5 Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) for more information on the EPSDT benefit.] Thus, the TEFRA option ensures that not only do more CSHCN qualify for Medicaid, but they also receive all the services they need.

TEFRA/Katie Beckett refers to a provision of the Tax Equity and Fiscal Responsibility Act (TEFRA) of 1982 that created a state plan option⁸¹ to allow children with disabilities who require an institutional level of care, but who live in families with incomes that are traditionally too high, to qualify for Medicaid so they can receive comprehensive services in their homes instead of in an institution.

⁸⁰ MACPAC: Users of long-term Services & Supports. Retrieved August 16, 2017 from <https://www.macpac.gov/subtopic/long-term-services-and-supports-population/>

⁸¹ The state option is commonly referred to as the Katie Beckett Provision because the original waiver program was created to serve a medically fragile child named Katie Beckett. For more information on the background of TEFRA and Katie Beckett, please see: Catalyst Center. (2012). The TEFRA Medicaid state plan option and Katie Beckett waiver for children. Retrieved from <http://cahpp.org/resources/tefra-medicare-state-plan-option-katie-beckett-waiver-children/>

⁸² See Section 12: EPSDT for discussion of medical necessity and the limits of EPSDT.

TEFRA/KATIE BECKETT OPTION

If a child with disabilities has other health insurance, Medicaid will pay the costs that the family incurs from the child's deductible, copayments, and co-insurance. And, the EPSDT benefit covers additional services that the primary insurance plan may not include.

TEFRA/Katie Beckett Option Eligibility Criteria

For a child to enroll in Medicaid under the TEFRA/Katie Beckett option, he or she must meet the following eligibility criteria^{83,84}:

- Be younger than 18
- Have family income that exceeds the state's Medicaid eligibility for children
- Require an institutional level of care, but have health care needs that can safely be provided at home, rather than in an institution
- Have medical, mental, and emotional health needs that are described by the childhood [listing of impairments on the Social Security website](#)
- The cost of care in the community does not exceed the cost of institutional care

Each state has its own criteria for determining what qualifies as an institutional level of care,⁸⁵ so eligibility for Medicaid under the TEFRA/Katie Beckett option may differ from state to state. However, the TEFRA/Katie Beckett option is not just for children with medical complexity or those who require medical technology to maintain their physical health. Institutional level of care under TEFRA/Katie Beckett includes intermediate care facilities for children with intellectual disabilities. Thus, the TEFRA/Katie Beckett option provides a way for children with a variety of physical, mental, behavioral, and developmental health conditions to qualify for Medicaid coverage, when family income exceeds the state's Medicaid income eligibility limits for children.

The TEFRA/Katie Beckett option provides a way for children with a variety of physical and mental, behavioral, and developmental health conditions to qualify for Medicaid coverage, when family income exceeds the state's Medicaid income eligibility limits for children.

⁸³O'Keefe, J., Saucier, P., Jackson, B., Cooper, R., McKenny, E., Crisp, S., & Moseley, C. (2010). Understanding Medicaid home and community services: A Primer. U.S. Department of Health and Human Services. Retrieved from <http://aspe.hhs.gov/understanding-medicaid-home-and-community-services-primer-2010-edition>

⁸⁴Semansky, R.M. & Koyanagi, C. (2004). The TEFRA Medicaid eligibility option for children with severe disabilities: A national study. *The Journal of Behavioral Health Services and Research*, 31(3), 334-342.

⁸⁵Musumeci, M. (2011). Modernizing Medicaid eligibility criteria for children with significant disabilities: Moving from a disabling to an enabling paradigm. *American Journal of Law & Medicine*, 37, (1), 81-127.

TEFRA/KATIE BECKETT OPTION

TEFRA/Katie Beckett and HCBS Waivers

As of 2015, 19 states have adopted TEFRA and two states have adopted TEFRA “look alike” programs⁸⁶ to serve children who meet the above eligibility criteria. Additionally, some states have home- and community-based services (HCBS) waivers known as Katie Beckett waivers (see “Waivers” in Section 4: Pathways to Coverage for more information on waivers in general and HCBS waivers, specifically). Though both HCBS waivers and the TEFRA/Katie Beckett option may carry Katie Beckett’s name⁸⁷, they are distinct programs that are different state options and that provide different benefits to families. The TEFRA/Katie Beckett option is a state plan amendment (SPA), which means that states that have chosen this option have received approval from CMS to make changes to their Medicaid program’s income eligibility criteria for children with disabilities.⁸⁸ States with HCBS waivers have gotten permission to make more significant changes, including benefits, target population, and income eligibility. Because the TEFRA/Katie Beckett option is a SPA and not a HCBS waiver, states do not have to prove that their program is cost-neutral and they cannot maintain a waiting list; all children who qualify for Medicaid through the TEFRA/Katie Beckett option based on the eligibility criteria described above receive the benefit.⁸⁹

The table on the next page compares the TEFRA/Katie Beckett option and HCBS waivers:

⁸⁶O’Malley Watts, M., Cornachione, E., and Musumeci, M. Medicaid Financial Eligibility for Seniors and People with Disabilities in 2015. (March 2016). The Kaiser Commission on Medicaid and the Uninsured. Available at <http://files.kff.org/attachment/report-medicare-financial-eligibility-for-seniors-and-people-with-disabilities-in-2015>

⁸⁷See section 2: The Basics: What are Medicaid and CHIP for more information on state plans and SPAs.

⁸⁸For more information on the difference between the TEFRA state plan option and HCBS waivers, please see Catalyst Center. (2015). [Expanding access to Medicaid coverage: The TEFRA option and children with disabilities.](#)

⁸⁹Smith, G., O’Keefe, J., Carpenter, L., Doty, P., Gavin, K., Burwell, B., Williams, L. (2000). Understanding Medicaid home and community services: A Primer. Retrieved from <https://aspe.hhs.gov/basic-report/understanding-medicare-home-and-community-services-primer>

⁹⁰Families USA. (2012). State plan amendments and waivers: How states can change their Medicaid programs. Washington, DC: Mahan, D. <http://familiesusa.org/product/state-plan-amendments-and-waivers-how-states-can-change-their-medicare-programs>

⁹¹Ghandour, R. M., Comeau, M., Tobias, C., Dworetzky, B., Hamershock, R., Honberg, L., Mann, M. Y., & Bachman, S. S. (2015). Assuring adequate health insurance for children with special health care needs: Progress from 2001 to 2009-2010. *Academic Pediatrics*, Jul-Aug; 15(4):451-60

TEFRA/KATIE BECKETT OPTION

	TEFRA/Katie Beckett State Plan Option	HCBS Waivers
Who qualifies?	<p><i>Children, birth to age 18 who:</i></p> <ul style="list-style-type: none"> • Meet their state's definition of institutional level of care; • Have medical needs that can safely be provided outside of an institution • Receive care in the community that does not exceed the cost of institutional care^{84,89} 	<p><i>Children (and others as defined by age, diagnosis, or other criteria established by the state) who:</i></p> <ul style="list-style-type: none"> • Meet their state's definition of institutional level of care; • Have medical needs that can safely be provided outside of an institution • Receive care in the community that does not exceed the cost of institutional care^{84,89}
What authority do states use to offer these programs?	<p><i>State plan option (a.k.a. state plan amendment or SPA):</i></p> <ul style="list-style-type: none"> • Allows states to change their individualized state plan, which outlines the way their Medicaid program operates. States may use this to add optional services or change eligibility requirements • States must still follow federal Medicaid rules (i.e., a state cannot use a state plan option to cut mandated services) • All services in the state plan option must be available to all children who qualify for Medicaid in the state • No waiting lists allowed^{90,91} 	<p><i>Home- and community-based service waivers:</i></p> <ul style="list-style-type: none"> • Allow states to request that certain Medicaid guidelines be waived. States can use this to provide additional services not usually covered by Medicaid to help individuals remain in the community • With federal approval, states do not have to comply with federal Medicaid rules (i.e., Medicaid regulations are "waived" to make an exception) • Services can be provided to specific groups (e.g., based on diagnosis, or age) • Waiting lists allowed^{90,91}

This document is part of *Public Insurance Programs and Children with Special Health Care Needs: A Tutorial on the Basics of Medicaid and the Children's Health Insurance Program (CHIP)*, available in its entirety at <http://cahpp.org/resources/Medicaid-CHIP-tutorial>

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The Catalyst Center, the National Center for Health Insurance and Financing for Children and Youth with Special Health Care Needs, is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number U41MC13618, \$473,000. This information or content and conclusions are those of the Catalyst Center staff and should not be construed as the official position or policy of nor should any endorsements be inferred by HRSA, HHS, or the U.S. Government. LCDR Leticia Manning, MPH, MCHB/HRSA Project Officer.

TEFRA/KATIE BECKETT OPTION

Test your knowledge

1. True or False: TEFRA/Katie Beckett is a waiver program, so states can maintain waiting lists for enrollment.
2. Which of the following is **incorrect** about state TEFRA/Katie Beckett programs?
 - a. TEFRA/Katie Beckett allows children who qualify to receive care in the community.
 - b. TEFRA/Katie Beckett institutional level of care criteria are the same in every state.
 - c. Family income is not a factor in determining eligibility for TEFRA/Katie Beckett programs.
 - d. All of the above.
3. True or False: The TEFRA/Katie Beckett option covers services not usually provided by Medicaid.



Find Out in Your State

1. Does your state have a TEFRA/Katie Beckett state plan option? If so, how many children with disabilities are enrolled in Medicaid through this pathway to coverage?
2. What are your state's criteria for determining an institutional level of care?

1. False 2. b 3. False

Section 12

EARLY AND PERIODIC SCREENING, DIAGNOSTIC, AND TREATMENT (EPSDT)



EPSDT: A Brief History

Congress established the Medicaid program as Title XIX of the Social Security Act in 1965 to provide medical care to children living in poverty who had no other options for paying for health services. In most states, children with disabilities who receive Supplemental Security Income (SSI) are also eligible for Medicaid. (For more background about Medicaid, [see Section 2 – The Basics: What are Medicaid and CHIP?](#)) Medicaid is an important source of coverage for all children, especially children with special health care needs (CSHCN). Almost 50% of CSHCN rely on publicly funded health care coverage.⁹² In 1967, Medicaid was amended to include the EPSDT benefit because many military draftees and children in Head Start were first being diagnosed with disabilities or chronic conditions that could have been prevented or identified earlier with regular health screenings (the Early and Periodic part of EPSDT).⁹³ EPSDT is the first entitlement to child health services in the United States. Reconciliation Act of 1989 (OBRA '89) expanded EPSDT to ensure that children with mental and developmental disabilities in all states receive coverage of the services to which they are entitled under the benefit.⁹⁴

What is EPSDT?

As discussed in [Section 5](#) (Covered Services), every Medicaid program must provide the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit. This federally mandated benefit ensures that all children younger than 21 years old who are enrolled in Medicaid receive preventive screenings and comprehensive health services in the amount, scope, and duration they need to develop and thrive.

In 1967, Medicaid was amended to include the EPSDT benefit because many military draftees and children in Head Start were first being diagnosed with disabilities or chronic conditions that could have been prevented or identified earlier with regular health screenings (the Early and Periodic part of EPSDT).⁹³ EPSDT is the first entitlement to child health services in the United States.

⁹²National Survey of Children's Health. NS-CH 2016. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved September 13, 2017 <http://www.childhealthdata.org/browse/survey/results?q=4562&r=1&g=638>. A Catalyst Center calculation based on preliminary NS-CH data. The calculation was performed using the population estimate of CSHCN with public insurance (n=5,739,375) and the population estimate of CSHCN with public and private insurance (n=1,049,865), divided by the estimate of the total CSHCN population (n=13,901,999).

⁹³The Commonwealth Fund. (2005). EPSDT: An overview. Washington, DC: The Commonwealth Fund. <http://www.commonwealthfund.org/publications/data-briefs/2005/sep/epsdt--an-overview>

⁹⁴Retrieved from <https://www.medicaid.gov/medicaid/benefits/list-of-benefits/index.html>.

EPSDT provides all medically necessary services, even if that service is not included in the state's Medicaid plan.⁹⁵ The Medicaid Act does not include a definition of medical necessity.⁹⁶ The definition varies by state,⁹⁷ but in general, medically necessary services are those that:

- Improve health or lessen the impact of a condition
- Prevent a condition
- Cure or restore health

Each state has a Medicaid state plan, which specifies the mandatory (required by federal law) and optional (services that states have decided to cover, beyond what is required by federal law) covered benefits. [Note: Adults 21 and over do not receive EPSDT. For example, dental benefits are covered for children as part of EPSDT, but are an optional service for adults. Many states do not include adult dental benefits in their Medicaid state plans.]

Regardless of how a child qualifies for Medicaid (e.g., income, disability), once eligible, the child is entitled to EPSDT and all medically necessary services are covered until he or she turns 21 years old. When the Children's Health Insurance Program (CHIP) was created in 1997, it gave states the option to add EPSDT as an optional benefit for children enrolled in CHIP. In states where children's Medicaid is expanded with CHIP funds, all children must receive EPSDT.

Because EPSDT requires state Medicaid programs to cover any service that is deemed medically necessary, each child gets the care he or she needs, whether or not the services are in the Medicaid state plan.⁹⁸ The comprehensive and individualized nature of EPSDT is particularly important for children with special health care needs (CSHCN), who, by definition, require more health care services than other children due to their complex conditions and need for specialized health care services.

Covered Services

EPSDT requires that Medicaid-eligible children receive regular, periodic screenings at age-appropriate intervals. States are required to cover certain mandatory⁹⁹ benefits in their Medicaid state plan. States may also cover optional services for adults, as well as any additional services that are deemed medically necessary for a child, even if that service is not included in the state plan. Medicaid must provide physical, mental, developmental, dental, hearing, vision, and other tests to screen for and identify potential health problems, perform follow-up diagnostic tests to rule out or confirm a health risk or diagnosis, and treat, control, correct, or reduce the identified health problems.

⁹⁵Center for Medicare and Medicaid Services. (2014). EPSDT – A Guide for States: Coverage in the Medicaid Benefit for Children and Adolescents. Washington, DC: U.S. Department of Health and Human Services. https://www.medicaid.gov/medicaid/benefits/downloads/epsdt_coverage_guide.pdf

⁹⁶NHelp. (2004). Q & A: Defining Medical Necessity. Retrieved Feb. 29, 2016 from http://www.healthlaw.org/about/staff/mara-youdelman/all-publications/qa-defining-medical-necessity#.VtRTs_krJaQ

⁹⁷Medical Necessity, retrieved on March 22, 2016 from <http://www.nashp.org/medical-necessity/>

⁹⁸The Commonwealth Fund. (2005). EPSDT: An overview. Washington, DC: The Commonwealth Fund. <http://www.commonwealthfund.org/publications/data-briefs/2005/sep/epsdt--an-overview>

⁹⁹Medicaid.gov - Benefits. Retrieved August 16, 2016 from <https://www.medicaid.gov/medicaid/benefits/list-of-benefits/index.html>

Early	Assess and identify problems as early as possible
Periodic	Check children's health status at regular, periodic, age-appropriate intervals
Screening	Provide physical, mental, developmental, dental, hearing, vision, and other screening tests to detect potential problems
Diagnosis (aka Diagnostic)	Perform diagnostic tests to follow up (rule out or confirm) when screening identifies a risk or potential problem
Treatment	Control, correct or reduce health problems found

The table below provides examples of mandatory benefits states must provide and optional benefits they can choose to provide.¹⁰⁰ As noted above, if a service is deemed medically necessary for a child, the state must provide it under the EPSDT benefit, even if it is not included in the state plan.

Mandatory Medicaid Services	Optional Medicaid Services
EPSDT	Prescribed drugs
Physician services	Clinic services
Inpatient hospital services	Physical & occupational therapy and related services
Outpatient hospital services	Speech, hearing, and language services
Family planning services and supplies	Respiratory care
Nurse midwife and certified pediatric nurse practitioner services	Dental services
Laboratory and X-ray services	Prosthetic devices
Home health services	Private duty nursing services
Services at federally qualified health centers & rural health clinics	Services in an intermediate care facility serving individuals and inpatient psychiatric services for individuals under age 21
Transportation	Case management

¹⁰⁰Medicaid.gov - Benefits. Retrieved August 16, 2017 from <https://www.medicaid.gov/medicaid/benefits/list-of-benefits/index.html>

EPSDT and Autism Services

Historically, there has been wide variation in how states provide Medicaid services to children with autism. Some states did not cover applied behavioral analysis (ABA), stating it was not an evidence-based treatment. Other states did provide ABA, but only through home- and community-based waivers, which limited the number of children who could receive services and often included other restrictions such as age and household income. In July 2014, the Centers for Medicare and Medicaid Services (CMS) issued a [Clarification of Medicaid Coverage of Services to Children with Autism](#).¹⁰¹ This document noted that ABA was one of several treatments for improving the physical and mental development of children with autism spectrum disorders. In addition, the document noted that if the services are deemed medically necessary, states must cover them under EPSDT, even if it is not included in the state plan.

EPSDT and Youth in Transition

Children enrolled in Medicaid are entitled to the EPSDT benefit until they turn 21. However, states are only required to provide Medicaid to eligible children until age 19, unless they qualify for Medicaid because they are first eligible for SSI when they turn 18, or unless the state has implemented the ACA Medicaid expansion for adults.

A separate provision of the ACA allows parents to continue to cover their young adult children on their health plans until age 26.¹⁰² Nineteen and 20-year-olds who do not have the option to be covered under their parents' health plans may qualify for Medicaid if they live in a state that expanded Medicaid and their income is less than 138% of the federal poverty level (FPL).¹⁰³ Some states, rather than expanding Medicaid, have approval from CMS to use Medicaid funds to enroll individuals in private health plans in the new Marketplaces (also known as Exchanges) created by the ACA. As these plans do not provide EPSDT, 19- and 20-year-olds with Marketplace coverage will receive EPSDT through wrap around Medicaid coverage.¹⁰⁴ [Note: Massachusetts expanded Medicaid for adults, and in an effort to ensure 19- and 20-year olds receive EPSDT, Massachusetts raised the income eligibility limit for this age group to 150% FPL. If income exceeds 150% FPL, the young adult can retain Medicaid and the EPSDT benefit by buying-in to the Medicaid program.¹⁰⁵]

¹⁰¹Clarification of Medicaid Coverage of Services to Children with Autism, retrieved March 22, 2016 from <https://www.medicaid.gov/Federal-Policy-Guidance/Downloads/CIB-07-07-14.pdf>

¹⁰²Young Adults and the Affordable Care Act https://www.cms.gov/CCIIO/Resources/Files/adult_child_fact_sheet.html

¹⁰³The language of the Affordable Care Act (ACA) set the Medicaid income eligibility limit for the Medicaid expansion population at 133% of the Federal Poverty Level (FPL), but then instructs states to disregard a standard 5% of income in calculating eligibility. Throughout the Tutorial, we use 138% of FPL to account for the 5% Modified Adjusted Gross Income (MAGI) disregard. Affordable Care Act, Section 2001(a); Health Care and Education Reconciliation Act, Pub. L. No. 111-152 Section 1004(e).

In addition to covering a broad array of health care services, EPSDT requires Medicaid programs to provide parent education regarding the EPSDT benefit. Unlike in private insurance, under EPSDT, Medicaid not only has to cover services, but also has to tell parents about the EPSDT benefit and help them access services that are covered under it, such as:

- Transportation
- Assistance with scheduling appointments
- Other assistance in accessing covered services
- Assistance in securing uncovered services, particularly those offered by state Women, Infants, and Children (WIC) and Title V programs

EPSDT and Youth Aging Out of Foster Care

The Affordable Care Act (ACA) includes a provision to extend Medicaid to children who have aged out of the foster care system until they turn 26, regardless of income. However, these young adults only receive the EPSDT benefit until they turn 21.¹⁰⁶ In addition, states do not have to extend Medicaid to youth who aged out of foster care in one state and moved to another.

EPSDT and Managed Care

Managed Care is one of the service delivery models you learned about in [Section 7](#) (Service Delivery Models: How Do States Deliver Health Care Services to Children Enrolled in Medicaid and CHIP?) of this tutorial. As of March 2017, 38 states and the District of Columbia were contracting with Managed Care Organizations (MCOs) to manage, provide or arrange for care to be provided, and coordinate the care of Medicaid enrollees.¹⁰⁷ Children enrolled in Medicaid managed care are entitled to the EPSDT benefit. EPSDT services may be provided directly by the MCO. The Medicaid agency provides any supplemental services that are not included in the MCO contract.

EPSDT and Title V

Interagency coordination is a statutory requirement for both Medicaid and Title V programs; EPSDT law requires that Medicaid reimburse Title V providers for services they deliver and the Social Security Act requires that Title V programs assist with coordination of EPSDT.¹⁰⁸ Additionally, Title V programs are required to help identify Medicaid-eligible children and they can access EPSDT funds by providing services to Medicaid-enrolled children with whom they interact.

Each state has an Interagency Agreement, which outlines the way that their Title V and Medicaid programs partner to provide medically necessary services to children enrolled in Medicaid under the EPSDT benefit.

States have flexibility with respect to the details of this relationship and can be creative in how they partner to ensure that all children, and CSHCN specifically, enrolled in Medicaid receive the EPSDT services they need to develop and thrive.

Some creative ways that Title V and Medicaid programs can form partnerships under EPSDT include:

- Medicaid reimburses Title V for services, such as care coordination, that they provide to Medicaid-enrolled children;
- Quality assurance/improvement;
- In some states, Title V and Medicaid work to streamline their data systems so they can monitor children's insurance status, other needed resources and referrals, and health outcomes ;
- While many Title V programs do not enroll children in public benefit programs, many provide important outreach and enrollment activities to make families aware of Medicaid eligibility and may even screen children for eligibility or refer them to Medicaid;

¹⁰⁴Where Does EPSDT Stand in Post-ACA Medicaid Expansion 1115 Waivers? Retrieved on March 22, 2016 from <http://ccf.georgetown.edu/all/where-does-epsdt-stand-in-post-aca-medicaid-expansion-1115-waivers/>

¹⁰⁵MassHealth: The Basics - Facts and Trends. Retrieved from <http://bluecrossmafoundation.org/publication/updated-masshealth-basics-facts-and-trends>

¹⁰⁶The Affordable Care Act and Youth Aging Out of Foster Care: New Opportunities and Strategies for Action. Retrieved from <http://www.clasp.org/resources-and-publications/publication-1/The-Affordable-Care-Act-and-Youth-Aging-Out-of-Foster-Care.pdf>

¹⁰⁷Kaiser Family Foundation, State Health Facts, Total Medicaid MCOs (March 2017). Retrieved August 15, 2017 from <http://www.kff.org/medicaid/state-indicator/total-medicaid-mcos/>

¹⁰⁸National Center for Education in Maternal and Child Health at Georgetown University. Chapter 2: A Review of Title V and Title XIX Interagency Agreements. Retrieved August 16, 2017 from https://www.ncemch.org/IAA/resources/C_State_MCH_Medicaid_Chapter2.pdf

EPSDT and Title V cont.

- Title V and Medicaid partner to create new billing codes to reimburse for nutritional supplements or streamline the prior approval process;
- And many Title V programs, such as home visiting programs, newborn screening, and early intervention conduct parent education regarding the EPSDT benefit.

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Test your knowledge

1. EPSDT is the child health benefit to all Medicaid enrollees under the age of
 - a. 12
 - b. 19
 - c. 21
 - d. 26
2. True or False: EPSDT only covers all mandatory and optional services in the Medicaid State Plan.
3. True or False: Children enrolled in Medicaid managed care do not receive EPSDT.
4. Name two ways Title V and Medicaid can partner to ensure access to EPSDT for CSHCN.



Find Out in Your State

1. Has your state established a definition for medical necessity that is specific to children?
2. Does your Title V program access EPSDT in providing services to Medicaid enrolled children who interact with Title V?
3. Does your state enroll CSHCN in managed care?

1. C 2. False 3. False 4. Reimbursement for services provided by Title V to Medicaid enrolled children; Data monitoring and sharing; Outreach and enrollment efforts; Care coordination; Consult about medical necessity determinations



SELECTED RESOURCES

Title V and Medicaid/CHIP Collaboration

The following resources are from the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau:

EPSDT & Title V Collaboration to Improve Child Health
<https://mchb.hrsa.gov/maternal-child-health-initiatives/mchb-programs/early-periodic-screening-diagnosis-and-treatment>

Medicaid/CHIP Data for Your State

Catalyst Center State-at-a-glance Chartbook on Coverage and Financing of Care for CYSCHN
<http://chartbook.cahpp.org/>

Federal Medical Assistance Percentage (FMAP) for Medicaid and Multiplier
<http://kff.org/medicaid/state-indicator/federal-matching-rate-and-multiplier/>

Federal and State Share of Medicaid Spending, FY2016
<http://kff.org/medicaid/state-indicator/federalstate-share-of-spending/>

Distribution of Medicaid Enrollees by Enrollment Group, FY2014 - Children
<http://kff.org/medicaid/state-indicator/distribution-of-medicaid-enrollees-by-enrollment-group/>

State Medicaid and CHIP Waiver and Demonstration Programs
<http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Waivers.html>

Children's Medicaid/CHIP Participation Rates, 2013-2015
<http://kff.org/medicaid/state-indicator/medicaidchip-child-participation-rates/>

Medicaid and CHIP Income Eligibility Limits for Children as a Percent of the Federal Poverty Level, January 2016
[http://kff.org/health-reform/state-indicator/medicaid-and-chip-](http://kff.org/health-reform/state-indicator/medicaid-and-chip-income-eligibility-limits-for-children-as-a-percent-of-the-federal-poverty-level/)

[income-eligibility-limits-for-children-as-a-percent-of-the-federal-poverty-level/](http://kff.org/health-reform/state-indicator/medicaid-and-chip-income-eligibility-limits-for-children-as-a-percent-of-the-federal-poverty-level/)

Separate Children's Health Insurance Program (CHIP) Income Eligibility Limits for Children, October 2000 - January 2017
<http://kff.org/medicaid/state-indicator/separate-childrens-health-insurance-program-chip-income-eligibility-limits-for-children/>

All 50 States and D.C. CHIP Fact Sheets, 2016, from the National Academy for State Health Policy
<http://www.nashp.org/childrens-health-insurance-fact-sheets>

The Affordable Care Act (ACA)

The Patient Protection and Affordable Care Act of 2010 (Public Law 111-148).
Full text of the legislation:
<http://docs.house.gov/energycommerce/ppacacon.pdf>

The Affordable Care Act and Children with Special Health Care Needs: An Analysis and Steps for State Policymakers, developed by the National Academy for State Health Policy (NASHP) for the Catalyst Center
<http://cahpp.org/resources/the-affordable-care-act-and-children-with-special-health-care-needs-an-analysis-and-steps-for-state-policymakers/>

The Affordable Care Act: A Side-by-Side Comparison of Major Provisions and the Implications for Children and Youth with Special Health Care Needs, from the Catalyst Center
<http://cahpp.org/wp-content/uploads/2015/04/ACAsidebyside-catalystctr.pdf>

Health Care Transformation section of the Catalyst Center website
<http://cahpp.org/projects/the-catalyst-center/health-care-transformation/>

ACA (cont.)

Association of Maternal and Child Health Programs' National Center for Health Reform Implementation provides assistance to state MCH programs and their key partners (e.g., state Medicaid and CHIP programs, community health centers, local health departments, providers) to optimize the opportunities presented by health reform for women, children including children with special health care needs (CSHCN), and their families.

<http://www.amchp.org/Policy-Advocacy/health-reform/Pages/default.aspx>

Affordable Care Act (ACA). Visit this section of the Medicaid.gov website to read the compilation of the ACA, review the law by section, or learn about specific provisions.

<https://www.medicaid.gov/affordable-care-act/index.html>

InsureKidsNow.gov map. Use this resource to find state-specific information about Medicaid and CHIP programs.

<http://www.insurekidsnow.gov/state/index.html>

The Role of Children's Coverage Programs in a Changing Health Care Landscape: EPSDT, CHIP, and Health Care Reform.

National Academy for State Health Policy. <http://www.nashp.org/publication/childrens-coverage-programs-changing-health-care-landscape>

Medicaid Eligibility Determinations

Medicaid Eligibility Determinations, Applications, and Online Accounts, 2017

<http://kff.org/health-reform/state-indicator/features-of-online-and-telephone-medicaid-applications/>

Streamlined Enrollment & Renewal Practices

State Adoption of Presumptive Eligibility for Eligible Individuals Enrolling in Medicaid/CHIP

<http://kff.org/health-reform/state-indicator/state-adoption-of-presumptive-eligibility-for-eligible-individuals-enrolling-in-medicaid-chip/>

State Adoption of Express Lane Eligibility for Children's Medicaid and CHIP at Enrollment and Renewal

<http://kff.org/health-reform/state-indicator/state-adoption-of-express-lane-eligibility-for-childrens-medicaid-and-chip-at-enrollment-and-renewal/>

State Adoption of 12-Month Continuous Eligibility for Children's Medicaid and CHIP

<http://kff.org/health-reform/state-indicator/state-adoption-of-12-month-continuous-eligibility-for-childrens-medicaid-and-chip/>

State Adoption of Selected ACA Medicaid Eligibility and Renewal Provisions for Aged/Disabled Population

<http://kff.org/other/state-indicator/state-adoption-of-selected-aca-medicaid-eligibility-and-renewal-provisions-for-aged-disabled-population/>

SELECTED RESOURCES

The Maternal and Child Health Bureau-funded National Centers Serving CSHCN



The Catalyst Center at Boston University is dedicated to improving coverage and financing of care for children and youth with special health care needs. They create publications and products, answer technical assistance questions, research innovative state-based financing strategies, guide stakeholders to outside resources, and connect those interested in working together to address complex health care financing issues. See their website for more resources.

<http://cahpp.org/project/the-catalyst-center/>



Got Transition? Got Transition? is a national resource for health care professionals, families, youth, and state policy makers focusing on a young adult's transition from pediatric to adult health care. This site serves as the basis for an information exchange about health care transition, particularly as pertaining to youth with special health care needs.

<http://gottransition.org/>



The National Center for Family Professional Partnerships (NCFPP), a project of Family Voices, is dedicated to providing leadership in helping families and professionals partner together in decision-making by providing technical assistance to the Family-to-Family Health Information Centers (F2F HICs), Family Voices State Affiliate Organizations and other family leaders in the states and partnering with other stakeholders to improve family/professional partnership opportunities.

<http://www.fv-ncfpp.org/>



The National Center for Medical Home Implementation (NCMHI). Housed at the American Academy of Pediatrics, the overarching goal of the NCMHI is to ensure that all children and youth, including children with special needs, have a medical home where health care services are accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally competent.

<https://medicalhomeinfo.aap.org/Pages/default.aspx>



National Center for Hearing Assessment and Management (NCHAM). NCHAM serves as the National Resource Center for the implementation and improvement of comprehensive and effective Early Hearing Detection and Intervention (EHDI) systems. As a multidisciplinary Center, their goal is to ensure that all infants and toddlers with hearing loss are identified as early as possible and provided with timely and appropriate audiological, educational, and medical intervention.

<http://www.infanthearing.org/>



National Newborn Screening and Genetics Resource Center (NNSGRC) provides information and resources in the area of newborn screening and genetics to benefit health professionals, the public health community, consumers and government officials.

<http://genes-r-us.uthscsa.edu>

SELECTED RESOURCES

Partnership and Collaboration



Family Voices. Family Voices is a national organization with state affiliate organizations (SAOs) dedicated to achieving culturally competent, accessible, affordable family-centered care for children and youth with special health care needs. Veteran family members provide information and support, train other family members for leadership positions on the local, state and federal levels and advocate for policies that promote high-quality, community-based services and supports for CYSHCN.

<http://www.familyvoices.org>



Data Resource Center for Child and Adolescent Health (DRC). The mission of the DRC is to take the voices of parents, gathered through the [National Survey of Children's Health \(NSCH\)](#) and share the results through this free online resource. Easy access to children's health data allows researchers, policymakers, family advocates and consumers to work together to promote a higher quality health care system for children, youth and families.

<http://www.childhealthdata.org>



National Academy for State Health Policy (NASHP) is an independent academy of state health policymakers. They are dedicated to helping states achieve excellence in health policy and practice. NASHP provides a forum for constructive, nonpartisan work across branches and agencies of state government on critical health issues facing states.

<http://www.nashp.org>

State Medical Home Initiatives

Approved Health Home State Plan Amendments on [Medicaid.gov](https://www.medicaid.gov/state-resource-center/medicaid-state-technical-assistance/health-homes-technical-assistance/approved-health-home-state-plan-amendments.html), here you can read the SPAs, ask questions, etc.

NASHP tracks and supports state efforts to advance medical homes for Medicaid and CHIP participants. NASHP's medical home map allows you to click on a state to learn about its efforts:

<http://nashp.org/med-home-map>

NOTES

This document is part of *Public Insurance Programs and Children with Special Health Care Needs: A Tutorial on the Basics of Medicaid and the Children's Health Insurance Program (CHIP)*, available in its entirety at <http://cahpp.org/resources/Medicaid-CHIP-tutorial>

Is this tutorial helpful to you? Please take our survey at <http://bit.ly/2gXLyuy-catalyst-survey>

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NATIONAL ACADEMY
for STATE HEALTH POLICY