



MEDICAID AND CHIP: A TUTORIAL ON COVERAGE FOR CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS (CYSHCN)

Public Insurance Programs and
Children and Youth With Special
Health Care Needs

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INTRODUCTION



DEVELOPMENT AND PURPOSE OF THIS TUTORIAL

The Catalyst Center is the National Center for Health Insurance and Financing for Children and Youth with Special Health Care Needs (CYSHCN). We are funded to provide technical assistance to state Title V programs and other stakeholders who are working to promote universal, continuous, and affordable health care coverage for all CYSHCN. Title 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.

We have created this tutorial to help Title V directors, staff, partners, and others serving CYSHCN increase their knowledge of how the Medicaid and Children's Health Insurance (CHIP) programs work. A more in-depth understanding of program components and policies can help Title V staff build more effective partnerships with their state Medicaid and CHIP programs.

WHY THIS TUTORIAL?

State Title V and Medicaid programs play special roles in the coverage and financing of care for children and youth with special health care needs (CYSHCN).

Title V of the Social Security Act mandates facilitating the development of community-based systems of care for CYSHCN and their families through the state block grant program.¹ In addition to paying directly for services, Title V programs are expected to develop broad systems of care for CYSHCN.

Programs such as Title V that are funded through block grants may provide direct care, but often focus on providing wraparound and population-based services and assuring the capacity for maternal and child health care.



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 CYSHCN.
- **Identify** specific opportunities to partner with the Medicaid and CHIP programs in their own state.

1. *Olmstead v. L.C.* (98-536) 527 U.S. 581 (1999). <https://www.law.cornell.edu/supct/html/98-536.ZS.html>

While Title V programs may provide specific services, Medicaid is an important source of health insurance coverage for CYSHCN. According to the 2020–2021 National Survey of Children’s Health, almost half of CYSHCN ages 0–17 depend on Medicaid or the Children’s Health Insurance Program (CHIP) for some or all of their health care coverage.²

Several federal statutes and regulations require collaboration between Title V and the Medicaid and CHIP programs.³ Collaboration promotes both the development of and access to a robust system of care and services for CYSHCN. Natural points of connection and opportunities for collaboration between Title V and the Medicaid and CHIP programs include the following:

- Providing gap-filling services to publicly insured CYSHCN.
- Identifying Medicaid- and CHIP-eligible CYSHCN and facilitating enrollment.
- Engaging in capacity-building activities that ensure quality health care services are available to CYSHCN at the state and local level.⁴

Even with these areas of overlap, communication and collaboration between these important programs serving CYSHCN 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.

Throughout this tutorial, we refer to “children and youth with special health care needs.” While the screener used by the National Survey of Children’s Health refers to “children with special health care needs,” this

population includes people ages 0–17. We choose to add the word “youth” to be consistent with the inclusion of adolescents up to age 17.

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 CYSHCN through communication and collaboration with Medicaid and CHIP staff.

The tutorial starts in Section 1 with an overview of how definitions of CYSHCN may vary by agency or program. This is followed by 11 additional sections that address major topic areas and recommendations for steps Title V programs can take to build successful partnerships with public insurance programs.

PARTNERSHIPS IN YOUR STATE

Each of the 11 topic areas (Sections 2–12) describes a component of the Medicaid and CHIP programs and includes 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 and CHIP programs in each of these areas.

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 so that readers can check their content knowledge. Each topic concludes with a set of inquiries that provides direction for readers to find out more specific information about Medicaid and CHIP in their state.

2. Child and Adolescent Health Measurement Initiative. 2020–2021 National Survey of Children’s Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved 12/5/21 from <https://www.childhealthdata.org/browse/survey/results?q=9364&r=1&g=1000>

3. Including 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) https://www.ssa.gov/OP_Home/ssact/title19/1902.htm.

4. Lu, M. C., Lauver, C. B., Dykton, C., Kogan, M. D., Lawler, M. H., Raskin-Ramos, L., Watters, K., & Wilson, L. A. (2015). Transformation of the Title V Maternal and Child Health Services Block Grant. *Maternal and Child Health Journal*, 19(5), 927–931. <https://doi.org/10.1007/s10995-015-1736-8>

This document is part of Medicaid and CHIP: A Tutorial on Coverage for Children and Youth with Special Health Care Needs (CYSHCN). The document is available in its entirety at <https://ciswh.org/resources/Medicaid-CHIP-tutorial>

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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 Medicaid and the Children's Health Insurance Program (CHIP) work and their importance to children and youth with special health care needs (CYSHCN), let's take a moment to consider what the term "CYSHCN" may mean to different people. We will begin with the federal Maternal and Child Health Bureau (MCHB) definition, and then compare this definition with 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 CYSHCN, but it's worth reviewing in the context of the discussion to come. MCHB defines CYSHCN 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."*¹

This inclusive definition describes a lot of kids: approximately 19% of the U.S. child population, according to the National Survey of Children's Health.² It guides the work of many stakeholders in serving CYSHCN as a population and in improving the system of care for them. The Catalyst Center uses this definition in its work and in this tutorial. However, the MCHB definition is not necessarily the one 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.

For example, the MCHB definition is not necessarily used to determine eligibility for Title V programs or services.³ Most Title V programs that pay for health care services have more restrictive eligibility criteria, limiting services to children with specific conditions, at certain income



The federal Maternal and Child Health Bureau definition describes CYSHCN 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."

We use this definition in the 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.

1. McPherson, 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. <https://doi.org/10.1542/peds.102.1.137>

2. Child and Adolescent Health Measurement Initiative. 2020-2021 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved 1/31/22 from <https://www.childhealthdata.org/browse/survey/results?q=9314&r=1>

3. HRSA Maternal and Child Health Bureau. Title V Federal-State Partnership and state-specific block grants. <https://mchb.hrsa.gov/programs-impact/title-v-maternal-child-health-mch-block-grant>

levels, or both. To some extent, this is a holdover from the historical origins of Title V. It also stems from the fact that Title V is a block grant program, not an entitlement program, and its funding is capped. As a result, there are limits to what services can be delivered through Title V programs and to whom.

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

Medicaid Definition

CYSHCN who receive Medicaid benefits are enrolled through different “eligibility categories,” which do not correspond directly with the MCHB definition of CYSHCN. Currently there are four major pathways to Medicaid eligibility for children. These pathways 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

Any CYSHCN in a very low-income family (below 138% of the federal poverty level) will be eligible for Medicaid based on income criteria, not because they are a child with special needs. This is important because when a child qualifies for Medicaid by 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 to identify CYSHCN⁴ at the point of enrollment into Medicaid and CHIP programs to make sure they receive appropriate services and referrals. This practice, however, is not widespread.

Disability Criteria

Disability is another important pathway to Medicaid eligibility. The eligibility criteria for disability are narrow 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. The strict income limit for SSI means that many children who meet the functional disability criteria are not eligible for Medicaid because their families’ income exceeds the Medicaid eligibility limit. Additionally, most CYSHCN



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.

4. Bethell, C. D., Blumberg, S. J., Stein, R. E., Strickland, B., Robertson, J., & Newacheck, P. W. (2015). Taking stock of the CSHCN screener: a review of common questions and current reflections. *Academic pediatrics*, 15(2), 165-176. <https://doi.org/10.1016/j.acap.2014.10.003>

have disabilities or conditions that are not severe enough to meet the SSI definition. States have a few other options to offer eligibility to children with disabilities, such as having medical expenses that meet a state-specified medically needy income level.⁵ In general, however, individuals must meet the SSI definition of disability even if income criteria are different.

Eligibility for Institutional Levels of Care

Some CYSHCN from higher-income families may be eligible for Medicaid if their disability is such that they qualify for an institutional level of care. Children who qualify for Medicaid through this pathway may be enrolled in home- and community-based service waiver programs for individuals who have specific health concerns, such as developmental disabilities or traumatic brain injury, or who are medically fragile.

These children may instead be enrolled in Medicaid under the Tax Equity and Fiscal Responsibility Act (TEFRA)⁶ state plan option, (sometimes known as a Katie Beckett program) for children who qualify for an institutional level of care. However, the type, availability, and size of home and community-based waiver and TEFRA 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 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 having special health care needs.

For additional details about definitions of CYSHCN and how states operationalize these definitions, please see our resource [*The Role of State Medicaid and Title V Program Definitions of Children and Youth with Special Health Care Needs in the Provision of Services and Supports*](#).



Both Title V and Medicaid provide vital services to CYSHCN, but they may be thinking about different groups of children at different times.

5. Medicaid and CHIP Payment and Access Commission (MACPAC) (2017). People with disabilities. Retrieved from www.macpac.gov/subtopic/people-with-disabilities/

6. In 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).

This document is part of Medicaid and CHIP: A Tutorial on Coverage for Children and Youth with Special Health Care Needs (CYSHCN). The document is available in its entirety at <https://ciswh.org/resources/Medicaid-CHIP-tutorial>

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SECTION 2

THE BASICS:

What are Medicaid and CHIP?



Many children and youth with special health care needs (CYSHCN) are enrolled in one of two publicly funded health care coverage programs:

- Medicaid, established under Title XIX of the Social Security Act, or
- 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 two programs are administered separately, or both together and separately for different populations. This is described in more detail below.

Both Medicaid and CHIP are funded jointly by the states and the federal government. Together these two programs provide health care coverage to almost 35% of all children in the United States.¹ More than 45% of CYSHCN are covered by Medicaid or CHIP.²

To participate in Medicaid and CHIP, each state submits a "state plan" for each program to the Centers for Medicare and Medicaid Services (CMS), the federal agency that oversees Medicaid and CHIP. The state plan describes these programs in detail. CMS must approve the state plan or any changes to an already approved state plan. For example, if a state 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.³

MEDICAID

Medicaid is a public insurance program that is financed by both state and federal funds. It is an entitlement program for both the individual and the state. This means that, if an individual is eligible for Medicaid in the state in which they live, they must receive the



WHAT'S IN A MEDICAID STATE PLAN?

By completing this tutorial, participants will learn about:

- How the Medicaid program is administered.
- Specific Medicaid eligibility criteria.
- Scope, duration and amount of covered services.
- Quality control.
- Provider payments.
- Programs in their own state.

1. Child and Adolescent Health Measurement Initiative. 2020–2021 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved 1/31/22 from <https://www.childhealthdata.org/browse/survey/results?q=9314&r=1>

2. Child and Adolescent Health Measurement Initiative. 2020–2021 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved 1/31/22 from <https://www.childhealthdata.org/browse/survey/results?q=9314&r=1>

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

coverage allowed under the state's plan, and the state must receive corresponding federal matching dollars.

As a result, if a state's Medicaid enrollment rises or if health costs rise, the state is entitled to additional federal matching dollars that correspond to the increase in enrollment or costs. Moreover, a state cannot limit the number of people it will cover under its Medicaid program if the state experiences a budget shortfall.

Note that this is different from the [block grant funding mechanism](#) in Title V. Under Title V, services are paid for from a fixed annual sum decided by Congress and matched by the state. Individual state allocations from the federal government are determined by a formula based on the proportion of low-income children in the state compared with the number of low-income children in the U.S. as a whole. Thus, unlike Medicaid, state Title V programs cannot obtain additional federal funds even if their funds are insufficient to meet the demand for services.

Medicaid coverage is 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 low-income people aged 65 and over.⁴ Income guidelines vary by state and are usually expressed as a percent of the federal poverty level (FPL). Below are three charts of the 2022 FPL guidelines for your reference.



If an individual is eligible for Medicaid in the state in which they live, they must receive the coverage allowed under the state's plan, and the state must receive corresponding federal matching dollars.

4. People ages 65 and over and people with disabilities who have very low income may be enrolled in Medicaid and Medicare at the same time. Medicare is the first payer, with Medicaid covering those services that Medicare does not. Those with both Medicaid and Medicare are usually referred to as "dually eligible."

THE BASICS: What are Medicaid and CHIP?

2021 Federal Poverty Guidelines (Annual Income) 48 Contiguous States and D.C.						
Family size	100%	138%	185%	200%	300%	400%
1	\$13,590	\$18,754	\$25,142	\$27,180	\$40,770	\$54,360
2	\$18,310	\$25,268	\$33,874	\$36,620	\$54,930	\$73,240
3	\$23,030	\$31,781	\$42,606	\$46,060	\$69,090	\$92,120
4	\$27,750	\$38,295	\$51,338	\$55,500	\$83,250	\$111,000
5	\$32,470	\$44,809	\$60,070	\$64,940	\$97,410	\$129,880

2021 Federal Poverty Guidelines (Annual Income) Alaska						
Family size	100%	138%	185%	200%	300%	400%
1	\$16,090	\$22,204	\$29,767	\$32,180	\$48,270	\$64,360
2	\$21,770	\$30,043	\$40,275	\$43,540	\$65,310	\$87,080
3	\$27,450	\$37,881	\$50,783	\$54,900	\$82,350	\$109,800
4	\$33,130	\$45,719	\$61,291	\$66,260	\$99,390	\$132,520
5	\$38,810	\$53,558	\$71,799	\$77,620	\$116,430	\$155,240

2021 Federal Poverty Guidelines (Annual Income) Hawaii						
Family size	100%	138%	185%	200%	300%	400%
1	\$14,820	\$20,452	\$27,417	\$29,640	\$44,460	\$59,280
2	\$20,040	\$27,655	\$37,074	\$40,080	\$60,120	\$80,160
3	\$25,260	\$34,859	\$46,731	\$50,520	\$75,780	\$101,040
4	\$30,480	\$42,062	\$56,388	\$60,960	\$91,440	\$121,920
5	\$35,700	\$49,266	\$66,045	\$71,400	\$107,100	\$142,800

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

The Federal Medical Assistance Percentage (FMAP), also referred to as the “federal match,” is the share of Medicaid funding provided to a state by the federal government. The federal match rate ranges from 50% to 76%, and depends on states’ per capita incomes, 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.

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 administrative 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.⁵ The Affordable Care Act (ACA) sets more uniform standards for eligibility, enrollment, and other aspects of the Medicaid program, although states still have a great deal of discretion in many areas.

While there is no overall cap on the federal dollars available for a state Medicaid program, matching funds available for waiver programs that specifically target a particular service or population may be capped (see Section 3). Only certain kinds of waiver programs are subject to an enrollment cap. (See Sections 4, 5, and 11 for more information about Medicaid waivers).

THE CHILDREN'S HEALTH INSURANCE PROGRAM

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 but is below the CHIP limit.

Like Medicaid, CHIP is a state-federal partnership that is state-administered, with each state setting 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% of the federal poverty level.^{6,7}

CHIP is different from Medicaid in important ways. Unlike Medicaid, the federal dollars available to states for CHIP are capped. Also, states have greater flexibility in how they structure their CHIP programs than they do for Medicaid.

For example, states may implement CHIP programs as Medicaid expansion programs, which follow Medicaid rules; they can implement separate CHIP programs, which have more flexibility; or they can do both.

5. Medicaid and CHIP Payment and Access Commission (2020, March 17). Report to Congress on Medicaid and CHIP. Retrieved August 2, 2017 from <https://www.macpac.gov/wp-content/uploads/2017/03/March-2017-Report-to-Congress-on-Medicaid-and-CHIP.pdf>

6. Currently, 14 states (New York, Iowa, New Jersey, Washington, DC, Connecticut, New Hampshire, Maryland, Pennsylvania, Illinois, Alabama, Washington, Hawaii, 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; 26 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. Kaiser Family Foundation. Medicaid and CHIP Income Eligibility Limits for Children as a Percent of the Federal Poverty Level, January 2022. Retrieved 1/13/22 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/>

7. January 2020 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.



TEST YOUR KNOWLEDGE

- 1. What portion of CYSHCN are enrolled in Medicaid or CHIP?**
 - a. About 20%
 - b. About 33%
 - c. About 45%
 - d. About 70%
- 2. True or False: Children in CHIP have household income that is lower than children enrolled in Medicaid.**
- 3. True or False: If a state Medicaid program is running short on funds, 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?** (See <https://www.medicaid.gov/chip/downloads/chip-map.pdf>)
- 2. In your state, what portion of CYSHCN are enrolled in Medicaid or CHIP? How does your state compare nationally?** (Visit <https://chartbook.ciswh.org/statedata>, select your state, and view the “Factors Influencing Health Insurance Coverage” for this data)

ANSWER KEY

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.

This document is part of Medicaid and CHIP: A Tutorial on Coverage for Children and Youth with Special Health Care Needs (CYSHCN). The document is available in its entirety at <https://ciswh.org/resources/Medicaid-CHIP-tutorial>

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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; they are legally required to coordinate with one another, and each aims to improve the health of the populations they are responsible for. In every state, Medicaid must:

- Have a coordination agreement with the state Title V agency that specifies the responsibilities of each agency;
- Reimburse the state Title V agency for covered services provided to Medicaid beneficiaries.¹

In addition, the Early Periodic Screening, Diagnosis, and Treatment program (EPSDT) is a key child-health component of Medicaid. It is a mandatory benefit in almost every state² for children under 21 years of age who are enrolled in Medicaid.³ EPSDT requires that children:

- Are connected to care.
- Are periodically screened to identify their needs.
- Receive services to address those needs.

Children's identified needs must be addressed even if the required service is not listed in the state's federally approved Medicaid plan, so long as the treatment is determined to be medically necessary for the child.⁴



Medicaid and Title V programs need each other; they are legally required to coordinate with one another, and each aims to improve the health of the populations they are responsible for.

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 agency for covered services provided to Medicaid beneficiaries.

1. The 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) (https://www.ssa.gov/OP_Home/ssact/title19/1902.htm) (regarding Medicaid). See also 42 Code of Federal Regulations Section 431.615 (<https://www.govinfo.gov/app/details/CFR-2009-title42-vol4/CFR-2009-title42-vol4-sec431-615>).

2. Technically, 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.

3. Medicaid and CHIP Payment and Access Commission (MACPAC). (June 2017). *Report to Congress on Medicaid and CHIP*. <https://www.macpac.gov/publication/june-2017-report-to-congress-on-medicaid-and-chip/>

4. Most 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. <https://www.govinfo.gov/app/details/CFR-2019-title42-vol4/CFR-2019-title42-vol4-sec441-56> Learn more at <https://www.medicaid.gov/medicaid/benefits/epsdt/index.html>

Although states have more flexibility in administering CHIP programs than Medicaid, they must describe in the state's CHIP plan how they will coordinate with Title V and other health-related programs.⁵

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

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

THE VALUE OF MEDICAID, CHIP, AND TITLE V PARTNERSHIPS

Two important functions of Title V programs are to promote coordinated care and to facilitate community-based services for children and youth with special health care needs (CYSHCN) and their families, whether or not the children are covered by Medicaid or the Children's Health Insurance Program (CHIP). Because over 45% of CYSHCN nationally depend on Medicaid or CHIP for some or all of their health care coverage, partnering with Title V programs is essential to improving their care and coverage.⁶

Title V programs can help Medicaid and CHIP use their purchasing power to improve the delivery of care for CYSHCN. While Title V is funded at a lower level than either Medicaid and CHIP, the requirement that states target 30% of Title V block grant funds to CYSHCN allows states to use funds in strategic ways to address needs that are not met by Medicaid or CHIP.

5. Federal regulations require that states describe in their 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). <https://www.govinfo.gov/app/details/CFR-2005-title42-vol3/CFR-2005-title42-vol3-sec457-80>

6. Child and Adolescent Health Measurement Initiative. 2020–2021 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved 1/31/22 from <https://www.childhealthdata.org/browse/survey/results?q=9314&r=1>



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 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.⁷ Title V programs can provide important clinical expertise and data to inform how Medicaid and CHIP serve CYSHCN. For example, Title V programs can use data from the National Survey of Children’s Health to educate themselves and Medicaid program staff about who CYSHCN are in their state, and what kinds of health care services they receive or need. 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.

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 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 program with limited funding, whereas in most states, Medicaid is an entitlement program whose funding is not limited to 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 pay only for services that are not available through Medicaid. Similarly, coordination agreements between CHIP programs and Title V programs should specify that Title V assists only with services that are not covered for enrollees of the state’s CHIP program.

Learn strategies for strengthening Title V and Medicaid Partnerships on the Catalyst Center’s State Strategies page, <https://ciswh.org/projects/the-catalyst-center/financing-strategies/>

7. NC-PFCMH, NASHP, and the Catalyst Center. 2017. Supporting Title V and Medicaid Collaboration in Pediatric Medical Home Implementation. https://youtu.be/R_k_XHSqIIE



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 CYSHCN because

- a. Title V programs can help shape Medicaid and CHIP policies that affect CYSHCN.
- b. Title V programs can bring parents with CYSHCN 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 Memorandum of Understanding (MOU) or interagency agreement between Title V and Medicaid? State MOUs are available here:

<https://mchb.tvisdata.hrsa.gov/Home/IAAMOU>

2. How does Title V assist Medicaid in coordinating EPSDT services?

ANSWER KEY

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

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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 their eligibility determined promptly. Parents, caretaker relatives, or guardians may apply for children or youth in their households as well as for themselves. 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 have the opportunity to appeal if they disagree 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:

- Whether the person falls within a category of people who are covered by Medicaid or CHIP.
- 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 incomes below a certain level who are in specific eligibility groups (primarily children and youth, their parents, people receiving Supplemental Security Income [SSI] due to disability, and people over age 65). States then have the option to extend eligibility to people with higher income levels and to other groups of individuals.

States are currently required to provide Medicaid to children and youth aged from birth through 18 who live in households with incomes below 138% of the federal poverty level (FPL).¹ States have the option of extending Medicaid to children and youth who live in

1. The language of the Affordable Care Act (ACA) set the income eligibility limit for the Medicaid expansion population at 133% of the FPL, but then instructs states to disregard a standard 5% of income in calculating eligibility. Throughout the tutorial, we use 138% of the FPL to account for the 5% Modified Adjusted Gross Income (MAGI) disregard. Patient Protection and Affordable Care Act, Pub. L. No. 111-148, §2001(a); Health Care and Education Reconciliation Act, Pub. L. No. 111-152, §1004(e). <https://www.govinfo.gov/app/details/PLAW-111publ152>



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

- Whether the person falls within a category of people who are covered by Medicaid or CHIP.
- 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.

households with higher income levels. All states also participate in the CHIP program (described below), which provides coverage for uninsured children and youth living in households with income levels too high to qualify for Medicaid. Through Medicaid alone or both Medicaid and CHIP, all but two states provide coverage to children and youth living in households with incomes up to at least 200% of the FPL.²

Major Optional Coverage Groups

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

- Children and youth 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 49 states and the District of Columbia.³ For more about TEFRA, please see Section 11.
- Children and youth who meet the SSI disability criteria, live in households with income below 300% of the FPL, and whose families pay a premium to “buy in” to Medicaid.
- Parents with children or youth aged 18 or under in households with income above the level for which Medicaid coverage is federally required.⁴
- Medically needy persons whose income is above the Medicaid eligibility threshold but who “spend down” by incurring significant out-of-pocket medical expenses that reduce their income until they reach a state-specified income eligibility level.⁵

WAIVERS

States may cover other groups of people by requesting a waiver from the Centers for Medicare and Medicaid Services (CMS). The request asks for permission to waive certain requirements of the Social Security Act. States can also request 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. These are:

- **1115 Research and Demonstration waivers** to demonstrate innovations in service delivery. States may use a 1115 waiver to cover people who do not fit into a Medicaid category—for example, adults without dependent children at home.
- **1915(b) waivers** that forgo freedom of choice of providers. This type of waiver is most commonly used to implement a mandatory managed care program.
- **1915(c) waivers** to provide Home and Community-Based Services (HCBS) to people living at home who would otherwise be eligible only if they resided in an institution. For example, many states operate HCBS waivers for adults and children or youth 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.

2. In addition, 35 states and the District of Columbia cover pregnant women with incomes at or above 200% of the FPL. Kaiser Family Foundation (2020 March). *Medicaid and CHIP Eligibility, Enrollment, and Cost Sharing Policies as of January 2020: Findings from a 50-State Survey*. Retrieved May 11, 2021, from <https://www.kff.org/medicaid/report/medicaid-and-chip-eligibility-enrollment-and-cost-sharing-policies-as-of-january-2020-findings-from-a-50-state-survey/>

3. Musumeci, M., Chidambaram, P., & O'Malley Watts, M. (2019 June 14) *Medicaid Financial Eligibility for Seniors and People with Disabilities: Findings from a 50-State Survey*. The Kaiser Commission on Medicaid and the Uninsured. Retrieved May 11, 2021, from <https://www.kff.org/report-section/medicaid-financial-eligibility-for-seniors-and-people-with-disabilities-findings-from-a-50-state-survey-appendix-tables/>

4. States are required to provide Medicaid to parents who would have met the 1996 Aid to Families with Dependent Children (AFDC) eligibility requirements in their state. This income level varies by state, but is very low; the median is 28% of the FPL. States have the option to cover parents with incomes above that level. Kaiser Family Foundation, (2011). *Federal Core Requirements and State Options in Medicaid: Current Policies and Key Issues*, Figure 1. The Kaiser Commission on Medicaid and the Uninsured. Retrieved May 11, 2021, from <https://www.kff.org/health-reform/fact-sheet/federal-core-requirements-and-state-options-in/>

5. Centers for Medicare & Medicaid Services. (n.d.). Eligibility. Retrieved May 11, 2021, from <https://www.medicare.gov/medicaid/eligibility/index.html>

Other waivers that include certain groups of children and youth with special health care needs (CYSHCN) include autism waivers, waivers for children and youth who are medically fragile or technology dependent, and waivers for individuals with traumatic brain injuries (see <https://ciswh.org/project/the-catalyst-center/financing-strategy/medicaid-waivers/>).

All waiver programs must demonstrate that they cost the federal government no more than the projected cost 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 who can be served under the waiver. To guarantee cost neutrality, states often cap the number of people who can be 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.⁶

CHIP ELIGIBILITY

The CHIP program provides coverage for uninsured children and youth under age 19 whose income is above the Medicaid eligibility limit, up to a limit established by the state and capped by the federal government. CHIP income eligibility limits range from 175% of the FPL in North Dakota to 405% of the FPL in New York.

Medicaid Eligibility and the Affordable Care Act

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 and youth, from birth through age 18, with family incomes below 138% of the FPL. In states where Medicaid eligibility for children ages 6 to 18 was limited to 100% of the FPL, children enrolled in CHIP were shifted to Medicaid. This improved their benefits (see Section 5). The

“maintenance of effort” (MOE) provision of the Affordable Care Act (ACA), prohibited states from reducing Medicaid or CHIP eligibility limits below those in effect when the ACA was enacted on March 23, 2010 through 2019. In 2018, the Helping Ensure Access for Little Ones, Toddlers, and Hopeful Youth by Keeping Insurance Delivery Stable Act (HEALTHY KIDS Act) and the Advancing Chronic Care, Extenders, and Social Services Act (ACCESS Act) extended this MOE through 2023 and 2027 respectively.⁷

Where Are the Opportunities for Title V Programs?

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 CYSHCN 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 CYSHCN who are Medicaid eligible (particularly under categories such as TEFRA/Katie Beckett 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 interagency agreement (IAA) with the Medicaid and CHIP programs the type of outreach to families of potentially eligible CYSHCN 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 to track eligibility and enrollment trends, create opportunities for cross referrals to Title V, and identify children and youth who may benefit from care coordination or care planning.

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

7. Center for Medicare & Medicaid Services. (October 5, 2018). Key provisions of legislation extending federal funding for the Children’s Health Insurance Program. Retrieved January 26, 2022 from <https://www.medicaid.gov/federal-policy-guidance/downloads/sho18010.pdf>



TEST YOUR KNOWLEDGE

- 1. As of 2014, states must provide Medicaid to children age 0-18 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. 1915(c) 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 interagency agreement between Title V and Medicaid include?**
- 3. What waivers does your state Medicaid program currently have in place that serve CYSHCN? How many CYSHCN are served under these waivers? Is there a waiting list to enroll in these waivers?**

ANSWER KEY

1. b 2. d 3. True. Children living at home with disabilities severe enough to qualify them for care in an institutional setting are eligible in 49 states and D.C. through waiver programs and the TEFRA state plan option.

This document is part of Medicaid and CHIP: A Tutorial on Coverage for Children and Youth with Special Health Care Needs (CYSHCN). The document is available in its entirety at <https://ciswh.org/resources/Medicaid-CHIP-tutorial>

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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.¹ If a service is covered under a state's Medicaid plan, it must be covered everywhere in the state unless the state obtains a federal waiver that exempts them from the usual "statewideness" requirement.

MANDATORY AND OPTIONAL BENEFITS

Medicaid includes both mandatory benefits that states are required to cover under federal law and optional benefits that states may choose to cover for adults.

Among the many optional Medicaid services are:

- Prescription drugs
- Occupational, speech, and physical therapies
- Optometry
- Targeted case management (see [Case Management/Care Coordination](#));
- Skilled nursing facilities for children and youth under age 21
- Rehabilitative services
- Personal care services
- Dental services
- Hospice services
- Inpatient psychiatric services for children and youth under age 21
- Medical and remedial care from other licensed providers, including psychologists.



MANDATORY MEDICAID BENEFITS

Mandatory Medicaid benefits include:

- Inpatient and outpatient hospital services
- Physician services
- Early Periodic Screening, Diagnosis, and Treatment (EPSDT) for children (including screening, diagnosis, and any services needed to treat identified conditions, even if those services would otherwise be optional)
- 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

1. 42 CFR § 440.1-185.

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.”

COPAYMENTS AND DEDUCTIBLES

Medicaid is prohibited from imposing copayments, deductibles, co-insurance, or other fees (“cost sharing”) on services for children and youth whose family income is less than 150% of the federal poverty level (FPL). States and managed care organizations have also been prohibited from imposing anything more than nominal cost sharing on adults receiving Medicaid.²

EARLY PERIODIC SCREENING, DIAGNOSIS, AND TREATMENT

The Early Periodic Screening, Diagnosis, and Treatment (EPSDT) program is a key benefit for children and youth who receive Medicaid coverage. It requires that states provide screening, diagnosis, and treatment to prevent, ameliorate, or treat conditions and to promote development. Identified needs must be treated even if the service would not normally be covered by the state’s Medicaid plan. Thus, for children covered by the Medicaid program, any medically necessary service must be provided.

This does not mean, however, 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 or youth 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 rather than a medical one.

In short, while the EPSDT program provides comprehensive coverage for children, this coverage is limited by the requirements that the services be deemed medically necessary and be delivered by qualified providers.³



EPSDT

The Early Periodic Screening, Diagnosis, and Treatment program requires that states provide children with screening, diagnosis, and treatment to prevent, ameliorate, or treat conditions and to promote development. Identified needs must be treated even if the service would not normally be covered by the state’s Medicaid plan.

2. 42 CFR § 447.56. <https://www.govinfo.gov/app/details/CFR-2021-title42-vol4/CFR-2021-title42-vol4-sec440-1>

3. See 42 CFR §440-441 for descriptions of covered services. <https://www.govinfo.gov/app/details/CFR-2000-title42-vol3/CFR-2000-title42-vol3-part440>, <https://www.govinfo.gov/app/details/CFR-2000-title42-vol3/CFR-2000-title42-vol3-part441>.

CARE COORDINATION/CASE MANAGEMENT

Title V programs often fund care coordination services for children and youth with special health care needs (CYSHCN). 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 and youth gain access to needed medical, social, educational, and other services.

HCBS waiver programs are required to include case management as a covered service. This 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 HCBS might exceed the cost of institutional care.

Managed care and primary care case management programs vary widely in both their interpretation and implementation of case management. For example, targeted case management services (TCM) may be provided for specific groups of children and youth with complex needs, such as those in out-of-home placement, with developmental disabilities, or 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.⁴

EPSDT will cover services such as information and referral, arranging for screenings, and arranging assessment and follow-up care. Sometimes Medicaid programs use EPSDT or TCM funding mechanisms to contract with Title V programs to deliver care coordination services to CYSHCN and receive federal Medicaid matching dollars.

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

4. The regulatory definition of TCM is found at 42 CFR §440.169(b). <https://www.govinfo.gov/app/details/CFR-2009-title42-vol4/CFR-2009-title42-vol4-sec440-169>

HOME AND COMMUNITY-BASED SERVICES

Some children, youth, and adults with serious disabilities receive Medicaid services through a Home and Community-Based Services (HCBS) waiver or an HCBS option without a waiver. These programs assist children, youth, or adults with severe disabilities to live at home and avoid institutionalization. They 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 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 been provided only 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) without going through the waiver process.⁵ Because a state may cap the number of participants under a waiver, but not under a SPA, the choice of a waiver or a SPA will affect the number of people who are able to receive these benefits.

PREMIUM ASSISTANCE PROGRAMS

Finally, many Medicaid and CHIP programs have premium assistance programs. In these programs, if a parent has access to private health insurance for the child or youth through their employer, the state may pay for the parent to purchase this private coverage. The state may do this when it is less expensive to pay the employee's share of the private insurance premium than

to pay directly for the child's or youth's care. The child or youth 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.⁶

CHILDREN'S HEALTH INSURANCE PROGRAM BENEFITS

States with Children's Health Insurance Program (CHIP) programs that are expansions of the state's Medicaid program and are 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. A state's CHIP benefit package must meet one of the following criteria:

- Benchmark coverage: CHIP coverage is "substantially equal" to that provided through one of three options: the Federal Employee Health Benefit Program, the state employee plan, or coverage offered by the health maintenance organization plan with the largest commercial enrollment in the state.
- Benchmark-equivalent coverage: CHIP coverage that has an "aggregate actuarial value" that is "actuarially equivalent" to the coverage under one of the three benchmark plans.
- Coverage approved by the Secretary of the U.S. Department of Health and Human Services.
- Comprehensive state-based coverage that existed when CHIP was enacted (only in Florida, New York, and Pennsylvania).⁷

5. Social Security Act §1915 [42 USC 1396n] (i). https://www.ssa.gov/OP_Home/ssact/title19/1915.htm

6. Thirty-eight states have premium assistance programs. U.S. Department of Labor, Employee Benefits Security Administration. (2020 July 31). Premium assistance under Medicaid and the Children's Health Insurance Program (CHIP). OMB Control Number 1210-0137 (expires 1/31/2023). Retrieved May 11, 2021, from <https://www.dol.gov/sites/dolgov/files/EBSA/laws-and-regulations/laws/chipra/model-notice.pdf>

7. Benefits. Medicaid.gov. Accessed at <https://www.medicaid.gov/chip/benefits/index.html>

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 more restricted than physical health services.

Separately administered CHIP programs are less likely to cover some of the services most needed by CYSHCN that are covered under Medicaid's EPSDT benefit.

Finally, more cost sharing, such as premiums and copayments, may be imposed on CHIP families than on those enrolled in Medicaid; however, total cost sharing may not exceed 5% of the family's income.

THE AFFORDABLE CARE ACT (ACA) AND COVERED SERVICES FOR CYSHCN

In 2014, EPSDT became available to more children and youth in 20 states⁸ because the Affordable Care Act (ACA) required states to raise Medicaid eligibility for children and youth ages 6 to 19 from 100% to 138% of

the FPL, shifting children from CHIP to Medicaid.⁹ Other coverage changes required by the ACA 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 Medicaid programs on how to help parents of enrollees understand the EPSDT benefits that will be available to their children.
- Work with Medicaid and other state policymakers to develop Medicaid buy-in programs or waiver programs to enhance benefits for CYSHCN 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.

8. The 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, January). *The Affordable Care Act and Children with Special Health Care Needs: An Analysis and Steps for State Policymakers*, p. 25. National Academy for State Health Policy. Retrieved May 11, 2021, from <https://ciswh.org/resources/the-affordable-care-act-and-children-with-special-health-care-needs-an-analysis-and-steps-for-state-policymakers/>

9. The ACA language sets the eligibility limit at 133% of the federal poverty level 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). <https://www.govinfo.gov/content/pkg/PLAW-111publ152/html/PLAW-111publ152.htm>



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. Medicaid is prohibited from imposing copayments, deductibles, coinsurance, or other fees (“cost sharing”) on services for children and youth whose family income is less than what percentage of the federal poverty level (FPL)?

- a. 100%
- b. 150%
- c. 200%



FIND OUT IN YOUR STATE

- 1. Does your state have a home health SPA and/or a HCBS waiver?**
- 2. How is care coordination funded for CYSHCN in your state? Is CHIP administered separately from Medicaid?**
- 3. Does Medicaid or CHIP in your state have a premium assistance program?**
- 4. What “optional benefits” are covered by your state Medicaid Plan?**

ANSWER KEY

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

This document is part of Medicaid and CHIP: A Tutorial on Coverage for Children and Youth with Special Health Care Needs (CYSHCN). The document is available in its entirety at <https://ciswh.org/resources/Medicaid-CHIP-tutorial>

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SECTION 6

FINANCING:

How Do Medicaid and CHIP Dollars Flow?



In 2019, Medicaid spending accounted for 16% of total U.S. health care spending.¹ Medicaid expenditures nationally amounted to over \$613 billion in that fiscal year, while expenditures on the Children's Health Insurance Program (CHIP) amounted to over \$19 billion.² Medicaid usually consumes the largest or second-largest share of state budgets, ranging from a high of 27% in Missouri to lows of 7% and 6% in West Virginia and Hawaii, respectively.³

MEDICAID'S STATE AND FEDERAL FUNDING

The federal government provides funds for at least half of what states pay to purchase health care services under their Medicaid programs. The federal contribution to Medicaid is called the Federal Medical Assistance Percentage, better known as FMAP or the "federal match." In FY 2022 the FMAP ranged from 56.20% to 84.51% for medical services.⁴ Under this funding formula, states with lower per capita incomes receive higher FMAP rates than states with higher per capita incomes. A state with a 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, described above). These administrative dollars can be spent to conduct outreach and provide education for families of children and youth with special health care needs (CYSHCN).

Efforts to improve enrollment, such as translating the application and Medicaid benefit materials into other languages, developing web-based application systems, and providing consumer assistance



The Medicaid and CHIP programs account for over 16% of total U.S. health care spending. Medicaid expenditures nationally amounted to over \$613 billion in fiscal year 2019, while CHIP expenditures amounted to over \$19 billion.

1. Centers for Medicare & Medicaid Services. (2020, December 16). National Health Expenditures Fact Sheet. Retrieved May 11, 2021, from <https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/NationalHealthExpendData/NHE-Fact-Sheet>

2. Centers for Medicare & Medicaid Services. (2020, December 16). Table 19. National Health Expenditures by Type of Expenditure and Program: Calendar Year 2019. Retrieved May 11, 2021, from <https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/NationalHealthExpendData/NationalHealthAccountsHistorical>

3. Kaiser Family Foundation. (n.d.). State Health Facts. Distribution of State Expenditures (in millions), SFY [State Fiscal Year] 2018. Retrieved May 11, 2021 from <https://www.kff.org/other/state-indicator/distribution-of-state-spending/?dataView=1¤tTimeframe=0&sortModel=%7B%22colId%22:%22Medicaid%22,%22sort%22:%22desc%22%7D>

4. Kaiser Family Foundation. (n.d.). State Health Facts. Federal Medical Assistance Percentage (FMAP) for Medicaid and Multiplier, FY 2022. Retrieved May 11, 2021, from <https://www.kff.org/medicaid/state-indicator/federal-matching-rate-and-multiplier/?currentTimeframe=0&sortModel=%7B%22colId%22:%22FMAP%20Percentage%22,%22sort%22:%22desc%22%7D>

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.

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. Interagency agreements between Medicaid and Title V programs may include consumer assistance activities and Medicaid payment for these activities.²⁰

While federal matching dollars are crucial, states still make a large financial contribution to the Medicaid program. In FY 2021 the state share ranged from approximately \$238 million in Wyoming to \$38 billion in California.⁵ 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 2019, look at the table on the Kaiser Family Foundation State Health Facts website at 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.⁶ Medicaid spending tends to rise in tough economic times. When unemployment rises and employers cut back on insurance coverage, more people become eligible to enroll in Medicaid or CHIP, leading to increased expenditures on those programs. States may be hard-pressed to cover these costs, especially with shrinking revenues and budget cuts. 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

When Medicaid eligibility was expanded in 2014, the federal share of Medicaid spending for newly eligible individuals was 100%. This lasted through 2016, when the federal matching rate for those newly eligible began to phase down annually from 100% to 90% by 2020.⁷



During tough economic times, more families tend to become eligible for Medicaid, just when states are under increased budget pressure due to declining revenue.

5. Kaiser Family Foundation. (n.d.). State Health Facts. Federal and State Share of Medicaid Spending, FY 2019. Retrieved May 11, 2021, from <http://www.kff.org/medicaid/state-indicator/federalstate-share-of-spending>

6. Medicaid and CHIP Payment and Access Commission (MACPAC). (2011, March). *Report to the Congress on Medicaid and CHIP March 2011*, Figure 1-1. Retrieved May 8, 2021, from <https://www.macpac.gov/publication/report-to-the-congress-on-medicare-and-chip-311/>

7. Medicaid and CHIP Payment and Access Commission (MACPAC). (n.d.). *State and Federal Spending Under the ACA*. Retrieved May 11 2021, from <https://www.macpac.gov/subtopic/state-and-federal-spending-under-the-aca/>

CHIP FUNDING

Unlike Medicaid, federal CHIP funds are capped and are allotted for 2 years based on a formula that changes annually. Regardless of program design, states' CHIP spending is reimbursed by the federal government at a matching rate higher than that for Medicaid.^{8,9} The Medicare Access and CHIP Reauthorization Act of 2015 (MACRA, P.L. 114-10) extended federal CHIP funding for 2 years through FY 2017. The HEALTHY KIDS Act, passed by Congress in 2017, extended funding for CHIP through FY 2023; the Bipartisan Budget Act of 2018 later extended this through FY 2027.¹⁰ In FY 2021, the CHIP-enhanced FMAP (E-FMAP) ranges from 65% to 84.43%.¹¹

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 CYSHCN in Medicaid or CHIP.
- Examine 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.

8. For the enhanced federal match rate for CHIP by fiscal year and state, see <https://www.kff.org/other/state-indicator/enhanced-federal-matching-rate-chip/?currentTimeframe=0>

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

10. Medicaid and CHIP Payment and Access Commission. (n.d.). CHIP Financing. Retrieved May 11, 2021, from <https://www.macpac.gov/subtopic/financing/>

11. Medicaid and CHIP Payment and Access Commission. (n.d.). EXHIBIT 6. Federal medical assistance percentages (FMAPs) and enhanced FMAPs (E-FMAPs) by state. [data set]. Retrieved May 11, 2021, from <https://www.macpac.gov/publication/federal-medical-assistance-percentages-fmaps-and-enhanced-fmaps-e-fmaps-by-state-selected-periods/>



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 charge 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?**

ANSWER KEY

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

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SECTION 7

SERVICE DELIVERY MODELS: How Do States Deliver Health Care Services to Children and Youth Enrolled in Medicaid and CHIP?



Most states deliver Medicaid and CHIP health services by:

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

MANAGED CARE

As of July 2020, Medicaid beneficiaries in 40 states and the District of Columbia received care through prepaid capitated MCOs.¹ In these models, the MCO is paid a set amount 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.” In contrast with the fee-for-service payment system, in which 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.

MCOs offer several potential opportunities to improve the delivery of care for children and youth with special health care needs (CYSHCN). 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 in multi-specialty clinics.

In addition, capitation payments reduce the financial incentive to deliver as many services as possible, regardless of utility or cost, that is prevalent in the fee-for-service payment system. If MCOs can control service utilization and costs, they retain the saved dollars.



Most states deliver **Medicaid and CHIP health services** by:

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

1. Kaiser Family Foundation. (2018). State Health Facts. Total Medicaid MCOs. Retrieved May 11, 2021, from <http://www.kff.org/medicaid/state-indicator/total-medicaid-mcos/>

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.
- Encourage the use of generic drugs.

The use of such techniques to manage health care utilization is rapidly evolving in both managed care and traditional fee-for-service programs. Because of the concern that MCOs will limit service use to control costs, federal regulations establish certain standards and safeguards in managed care. These standards include:

- The adequacy of the MCO's provider network to serve their enrollee population,
- 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 wrongfully denied a service.

In addition, states can require MCOs to meet specific quality benchmarks or implement special programs or services as part of the managed care contract.

MANAGED CARE AND CYSHCN

States vary as to which groups of Medicaid beneficiaries they require to enroll in a managed care plan. In some states, enrollment in a Medicaid managed care program is mandatory; in others it is voluntary. Within a state, enrollment in managed care may be mandatory for some groups but voluntary for others.

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

Prior to 1997, if a state wanted to mandate enrollment in a Medicaid managed care program, it needed to seek a 1915(b) "freedom of choice" waiver from the federal government because it would be restricting the enrollee's choice of providers. This changed with the enactment of the Balanced Budget Act (BBA) of 1997, which allowed states to mandate Medicaid managed care enrollment through their Medicaid state plan rather than by seeking a waiver.

Many CYSHCN were excluded from this new rule, such as children and youth receiving Supplemental Security Income (SSI) benefits, those receiving foster care or adoption subsidies, institutionalized children and youth, and children and youth recognized as having special needs under the Maternal and Child Health Title V Block Grant Program.²

States are still required to obtain a federal waiver to mandate the enrollment of these groups of CYSHCN in Medicaid managed care programs. They also require a waiver to make managed care enrollment mandatory for disabled SSI recipients.

Nevertheless, because about 45% of CYSHCN are covered by Medicaid or the Children's Health Insurance Program (CHIP), many children enrolled in Medicaid managed care plans may still have special health care needs.³

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 either on a fee-for-service basis or through a different managed care plan. Often,

2. Kaiser Family Foundation. (1997, September 29). *Comparison of the Medicaid Provisions in the Balanced Budget Act of 1997 (P.L. 105-33) with Prior Law*. Retrieved May 11, 2021, from <https://www.kff.org/medicaid/report/comparison-of-the-medicaid-provisions-in-the/>

3. Child and Adolescent Health Measurement Initiative. 2020-2021 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved 1/31/22 from <https://www.childhealthdata.org/browse/survey/results?q=9314&r=1>

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 schools—are carved out of the managed care plan.

The contract between a state and an MCO 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 (HBCS).

Capitation rates paid to MCOs must be “actuarially sound,” meaning that they have been developed by professional actuaries and are 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, 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 chronic illnesses such as CYSHCN. By definition, CYSHCN use more health care services than children typically do, and are consequently more costly to cover.⁴

For example, if a child with special health care needs is enrolled in a managed care plan in which the capitation rate is set at the average cost of care for all children in the plan, they will likely cost more than the average child. MCOs may therefore have an incentive to discourage CYSHCN from enrolling in their plans because it is likely that caring for CYSHCN will cost more than caring for the average child. This is known as “selection bias,” which may occur 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 occur 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 CYSHCN, plans will find it easier to finance the comprehensive care that CYSHCN 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:



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.

4. McPherson, M., Arango, P., Fox, H., Lauver, C., McManus, M., Newacheck, P. W., Perrin, J. M., Shonkoff, J. P., & Strickland, B. (1998). A new definition of children with special health care needs. *Pediatrics*, 102(1 Pt 1), 137-140. <https://doi.org/10.1542/peds.102.1.137>

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

These are some of the issues that should be addressed in the contract between a Medicaid program and an 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. Because it is often during the RFP and contract development process that decisions on these questions are initially made, this is a good time for Title V programs to bring their expertise and judgment to some of these decisions. Please see the Catalyst Center brief ["Strengthening Title V-Medicaid Managed Care Collaborations to Improve Care for CYSHCN"](#) for more information.

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 the beneficiary's care.

Typically, in PCCM, the primary care provider refers patients to specialty services, and these referrals may be required for the beneficiary to access specialty care. Health care providers are paid on a fee-for-service basis each time they deliver a service. In addition, the primary care provider is paid an additional fee for managing the beneficiary's care.⁵ This fee is usually a set amount such as \$2 or \$5 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 CYSHCN. 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 and youth have complex health care needs.

THE AFFORDABLE CARE ACT AND SERVICE DELIVERY

The Affordable Care Act (ACA) offers several opportunities to change the way care is delivered for CYSHCN to ensure that financial incentives are aligned with the delivery of high-quality care rather than with a high volume of care. These opportunities 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.
- Funding to create incentives for healthy behaviors.

See Section 9 for more details about these opportunities.

5. Hanlon, C. (2011, January 24). *Improving the Lives of Young Children: Opportunities for Care Coordination and Case Management for Children Receiving Services for Developmental Delay*. Urban Institute. Retrieved March 3, 2021, from <https://www.urban.org/research/publication/improving-lives-young-children>

WHERE ARE THE OPPORTUNITIES FOR TITLE V PROGRAMS?

It is critical to bring the expertise of Title V programs to help shape Medicaid policies that affect the delivery of care to CYSHCN. Assessing and addressing the gaps in services for CYSHCN 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 CYSHCN. For example, Title V programs can:

- Help Medicaid programs develop contracts with managed care plans and help set and monitor standards for managed care networks.⁶
- Participate in building the medical home model and improving preventive and developmental care in pediatric primary care practices.⁷
- Help design and administer “health home” options, whether under the ACA (§2703) or other legislation for children with certain chronic conditions.⁸ The Advancing Care for Exceptional Kids (ACE Kids) Act, enacted by Congress in 2019, gives states the option of providing coordinated care for children with complex medical conditions through a health home.⁹ For more information, please see the issue brief “[Improving Care Coordination for Children with Medical Complexity: Exploring Medicaid Health Home State Options](#).”
- Play a role in linking pediatric primary care providers who provide EPSDT screenings with referral resources for diagnosis and treatment, as well as in assuring that community and educational programs that screen children and youth link back to their health care providers.¹⁰
- Based on historically strong relationships with providers of CYSHCN services, ensure that managed care provider networks include critically important service providers.



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 CYSHCN.

6. MCH Digital Library. State MCH-Medicaid Coordination. Title V and Title XIX Interagency Agreements. Accessed at <https://www.mchlibrary.org/IAA/>

7. NC-PFCMH, NASHP, and the Catalyst Center. 2017. Supporting Title V and Medicaid Collaboration in Pediatric Medical Home Implementation. https://youtu.be/R_k_XHSq1IE

8. Centers for Medicare and Medicaid Services. (n.d.) Health Home Information Resource Center. Retrieved May 11, 2021, from <https://www.medicaid.gov/resources-for-states/medicaid-state-technical-assistance/health-home-information-resource-center/index.html>

9. Advancing Care for Exceptional Kids Act (ACE Kids Act) of 2019 (H.R. 1226). <https://www.congress.gov/bill/116th-congress/house-bill/1226>

10. Centers for Medicare and Medicaid Services. (n.d.) The State Medicaid Manual. Chapter 5: Early and Periodic Screening. Retrieved May 11, 2021, from <https://www.cms.gov/media/325446>



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 CYSHCN through managed care organizations, fee for service, PCCM or more than one of these service delivery options?**
- 2. If MCO's are enrolling CYSHCN, 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 CYSHCN?**
- 4. Has your state considered or implemented the health home option under the ACA (Section 2703) for children with chronic conditions?**

ANSWER KEY

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

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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 a reasonable cost. Both programs offer opportunities for collaboration with Title V programs around quality improvement for children and youth with special health care needs (CYSHCN).

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). This annual report provides basic information about the number of children and youth (by age and Medicaid eligibility category) who receive medical and dental screens and the number referred for diagnostic or treatment services. (More information about EPSDT is available at <https://www.medicaid.gov/medicaid/benefits/early-and-periodic-screening-diagnostic-and-treatment/index.html>.)

The federal benchmark for EPSDT participation rates—calculated as the percentage of enrolled children and youth who are eligible for child and adolescent screenings who receive initial or periodic screening—is 80%.¹ These data are important for determining whether children and youth are routinely screened and receive appropriate follow-up.

For CHIP, each state must list in its CHIP state plan the quality measures it will use and its data collection methodology, and must report on these measures annually to the U.S. Department of Health and Human Services (HHS).² States must report data on access to primary and specialty services, access to networks of care, and care coordination, using quality care and satisfaction measures



States with **Medicaid managed care programs** that contract with managed care organizations (MCOs) must include provisions in the MCO contracts that require assessment of the quality and appropriateness of the care and services furnished by the MCOs.

1. Centers for Medicare & Medicaid Services. The State Medicaid Manual. Chapter 5, Early and Periodic Screening. Retrieved May 12, 2021, from <https://www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/Paper-Based-Manuals-Items/CMS021927>. States must file CMS Form 416, in which states report the number of individuals eligible for EPSDT, the state periodicity schedule for childhood screenings, total screens received, and other data. The form may be downloaded at <https://www.cms.gov/Medicare/CMS-Forms/CMS-Forms/CMS-Forms-Items/CMS1184680>. The Bright Futures/American Academy of Pediatrics Periodicity Schedule lays out the recommended screenings each child should receive and at what stage of development each screening should occur (e.g., infancy, early childhood, middle childhood, adolescence). Learn more at <https://www.aap.org/periodicityschedule>

2. Social Security Act, §2107. https://www.ssa.gov/OP_Home/ssact/title21/2107.htm

from the Agency for Health Care Research and Quality's Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey.³

QUALITY ASSESSMENT REQUIREMENTS FOR MANAGED CARE

In addition, states with Medicaid managed care programs that contract with managed care organizations (MCOs) must include provisions in MCO contracts that require assessment of the quality and appropriateness of the care and services furnished by the MCOs. One such procedure is the requirement to evaluate care provided to children, youth, and adults with special health care needs. When an MCO is paid on a per-member-per-month (PMPM) basis for each enrollee, both Medicaid and CHIP are required to contract with an independent External Quality Review Organization (EQRO) to evaluate the quality, timeliness, and access to care provided by the MCO.¹

One of the ways that EQROs evaluate quality of care is through Performance Improvement Projects (PIPs).² To complete a PIP, states follow a structured process to identify an issue, collect data about it, and make improvements. State expenditures for these activities are eligible for enhanced federal matching funds. States can choose their own PIP topics; several states have focused PIPs on issues relevant to CYSHCN, such as measuring and improving coordination between mental health and medical providers (Utah) and coordinating care with community-based services (Oregon).

CHILDREN'S HEALTH CARE QUALITY MEASURES

The Children's Health Insurance Program Reauthorization Act of 2009 (CHIPRA) required the federal government to develop a set of quality measures of child health care for voluntary use by states in both Medicaid and CHIP. In 2009, HHS published a set of 24 initial core measures encompassing both physical and mental health. The Centers for Medicare & Medicaid Services releases an updated set of core measures annually.³ The 2023-2024 core set includes quality measures in six domains:

- Primary care access and preventive care
- Maternal and perinatal health
- Care of acute and chronic conditions
- Behavioral health care
- Dental and oral health services
- Experience of care



Under a 2018 federal law, state reporting of the Child Core Set of measures is mandatory starting in federal fiscal year 2024.

3. Social Security Act, §2108(e)(4). https://www.ssa.gov/OP_Home/ssact/title21/2108.htm

Current core measures include:

- Screening for developmental delays,
- Immunizations,
- Weight assessment,
- Nutritional and physical activity counseling,
- Preventive dental care,
- Emergency department visits, and
- Follow-up care after a hospitalization for mental illness.

The full core set of measures can be found at <https://www.medicaid.gov/medicaid/quality-of-care/downloads/2023-child-core-set.pdf>. Section 50102(b) of the Bipartisan Budget Act of 2018 makes state reporting of the Core Set of Children's Health Care Quality measures mandatory starting in fiscal year (FY) 2024.

CHIPRA requires CHIP programs to report annually on consumer satisfaction measures. Many states use the CAHPS Child Medicaid Survey to measure consumer satisfaction. Since December 31, 2013, all CHIP programs have been required to submit CAHPS data. Medicaid reporting of CAHPS data is voluntary.⁴ CAHPS has a set of questions for assessing satisfaction with care for children and youth with chronic conditions that includes a five-item screener to identify them.⁵

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 health quality data for children and youth across all programs and potentially for all children and youth.
- Monitor the screening ratios tracked by Medicaid programs and collaborate with their state Medicaid program on strategies to reach the 80% screening benchmark.
- Analyze service utilization data for CYSHCN enrolled in Medicaid and CHIP to better inform care delivery and contracting.
- Work with their states' Medicaid and CHIP programs or MCOs to train primary care providers in caring for CYSHCN. For example, Georgetown University's Bright Futures program worked with both Medicaid and Title V programs to train primary care health professionals; Connecticut's Title V and Medicaid programs worked with the Yale Center for CYSHCN to train pediatric residents in the care of children and youth with chronic illness and disabilities. See more examples of how Title V and Medicaid programs are working together to ensure children and youth receive EPSDT at <https://ciswh.org/project/the-catalyst-center/financing-strategy/epsdt/>.
- Collaborate with Medicaid programs on how the state's targeted case management and EPSDT services are structured in order to improve care coordination for CYSHCN.
- Collaborate with their Medicaid and CHIP counterparts to develop PIPs on quality measures that particularly affect CYSHCN.

4. Centers for Medicare & Medicaid Services (CMS). (2011, Feb. 14). *CHIPRA Quality Measures*. [Letter to State Health Officials from Cindy Mann: SHO # 11-001 CHIPRA #20]. Retrieved May 12, 2021, from <https://www.medicaid.gov/Federal-Policy-Guidance/downloads/SHO-13-002.pdf>

5. Agency for Health Care Research and Quality. CAHPS Item Set for Children with Chronic Conditions. Retrieved May 12, 2021, from <https://cahps.ahrq.gov/surveys-guidance/item-sets/children-chronic/index.html>



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?**

 ANSWER KEY

1. b 2. a 3. d

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CHANGES TO MEDICAID AND THE CHILDREN'S HEALTH INSURANCE PROGRAM UNDER THE AFFORDABLE CARE ACT



ELIGIBILITY FOR MEDICAID AND THE CHILDREN'S HEALTH INSURANCE PROGRAM

Medicaid eligibility changes in the Affordable Care Act (ACA) are best understood in the context of the goal for health care reform: that, after 2014, nearly everyone would have either public or private health coverage. At that time, a single system for screening individuals and families for eligibility, enrolling them 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 went into effect in 2014.

- Medicaid programs could cover people with income below 138% of the federal poverty level (FPL).¹
- Children and youth who had been enrolled in the Children's Health Insurance Program (CHIP) and whose family income was below 138% of the 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 (see Section 5).
- Young people who were in foster care when they turned 18 became eligible to maintain their Medicaid benefits until age 26. The aim of this extended eligibility is to help ease the transition from foster care to adulthood, including access to higher education and employment, by guaranteeing continued health care coverage.²

Finally, states were given a 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 and youth was barred from enrolling in CHIP. Under the ACA, if a state can demonstrate that it has maintained

1. The ACA language 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, §2001(a); Health Care and Education Reconciliation Act, Pub. L. No. 111-152 §1004(e). <https://www.govinfo.gov/content/pkg/PLAW-111publ152/html/PLAW-111publ152.htm>

2. Wilson-Simmons, R., Dworsky, A., Tongue, D., & Hulbutta, M. (2016). *Fostering Health: The Affordable Care Act, Medicaid, and Youth Transitioning from Foster Care*. New York: National Center for Children in Poverty, Columbia University Mailman School of Public Health. Retrieved May 12, 2021, from https://www.nccp.org/wp-content/uploads/2016/10/text_1165.pdf

its own contribution toward family coverage but that 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 includes a “maintenance of effort” (MOE) provision that prohibits states from reducing Medicaid or CHIP eligibility limits below those that were in effect when the ACA was enacted on March 23, 2010. MOE was required for adults until 2014 and for children and youth under age 19 through September 30, 2019.³

Under the ACA, people whose incomes exceed the limit for Medicaid or CHIP eligibility and who do not have access to employer-sponsored insurance can purchase private coverage through a health insurance marketplace (also known as an exchange). Marketplace enrollees are eligible for federal help with the cost of coverage if their income is below 400% of the FPL. Anyone who applies through the marketplace and is found to be eligible for Medicaid or CHIP 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.⁴ In 2014, states began determining Medicaid or CHIP eligibility 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” (which affects whose income counts in the eligibility calculation) and the deductions from income that applicants can take when calculating eligibility.

The shift to MAGI in calculating eligibility for Medicaid and CHIP aligns with the calculation used to determine eligibility for premium subsidies in the ACA-created health insurance marketplaces. This makes any transition between Medicaid, CHIP, and the marketplaces—all of which are income-sensitive—easier for both consumers and coverage administrators.

With a consistent definition of income used to calculate eligibility for Medicaid, CHIP, and marketplace insurance plans, a single application can be used to determine eligibility for any of these programs.

The change in calculating eligibility for Medicaid did not affect many people who have special health care needs, including:

- Children, youth, 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; and
- Children and youth who qualify for Medicaid under the TEFRA/Katie Beckett option (see Section 11) or because they are in foster care.⁵

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

- Establish a system of enrollment and enrollment renewals via a website as well as by phone or in person.
- Coordinate the determination of Medicaid or CHIP eligibility along with the determination of eligibility for tax credits to purchase private insurance in the marketplaces.
- Conduct outreach to vulnerable populations, including families with CSHCN, to encourage enrollment in Medicaid and CHIP.
- Permit hospitals to make “presumptive eligibility” determinations for Medicaid, to be verified later by the state Medicaid program.

3. Center for Medicaid, CHIP and Survey & Certification. (2011). Maintenance of Effort. Retrieved May 12, 2021, from <https://www.medicaid.gov/federal-policy-guidance/downloads/smd11001.pdf>

4. The ACA language sets the eligibility limit at 133% of the FPL in 2014, but then instructs states to disregard an amount of income that brings the household to 138% of the FPL. Affordable Care Act, §2001(a); Health Care and Education Reconciliation Act, Pub. L. No. 111-152 §1004(e). <https://www.govinfo.gov/content/pkg/PLAW-111publ152/html/PLAW-111publ152.htm>

5. National Health Law Program (NHeLP). (n.d.). *NHeLP Analysis of the Health Care Reform Law: PPACA and the Reconciliation Act, Part II: Role of Public Programs*, p.

9. Retrieved May 12, 2021, from <https://healthlaw.org/resource/nhelp-analysis-of-the-affordable-care-act-and-the-reconciliation-act/>

- Permit Medicaid and CHIP eligibility for children and youth to be decided by public “express lane” agencies—i.e., agencies that use household income to determine eligibility for other federal programs such as the Women, Infants, and Children nutrition program; subsidized housing; and school lunch programs.⁶

COVERED SERVICES FOR CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS

Under the ACA, states are encouraged or required to adjust benefits in numerous ways. Significantly, EPSDT became available to more children and youth in 20 states in 2014⁷ because Medicaid eligibility for children and adolescents ages 6 to 19 increased in those states to 138% of the FPL, shifting many children and youth from CHIP to Medicaid.⁸ The remaining states already covered these children and youth under Medicaid.

Depending on the benefits covered by their state’s CHIP program, children and adolescents ages 6 to 19 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 and youth who are enrolled in Medicaid or CHIP may elect to receive hospice care without having to forgo potentially curative care. (For more information about concurrent care, see the Catalyst Center’s ACA fact sheet, available at <https://ciswh.org/resources/affordable-care-act-fact-sheets-families/>).

FINANCING CHANGES

As described above, many more people became eligible for Medicaid in 2014. The federal government financed health coverage for newly eligible people at 100% through 2016, after which the federal matching rate began to phase down annually from 100% to 90% in 2020.

Unlike Medicaid, federal funds for the CHIP program are capped, with the capped amount based on a state’s recent CHIP spending and growth. States have two years to spend their allotted funds. Regardless of program design, the federal government reimburses states’ CHIP spending at a matching rate higher than that for Medicaid.^{9,10}

In 2018, the HEALTHY KIDS Act extended federal CHIP funding through fiscal year (FY) 2023; later that year, the Bipartisan Budget Act of 2018 funded CHIP through 2027.¹¹

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; and
- Creating “health homes” for people with certain chronic health conditions. As explained below, health homes are similar to medical homes.

6. Children’s Health Insurance Program Reauthorization Act of 2009, P.L. 111-3, §203, codified in 42 U.S.C. §1396a(e)(13) and §1397gg(e)(1)(B) <https://www.govinfo.gov/app/details/PLAW-111publ3>

7. The 20 states were 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., & Justice, D. (2011). *The Affordable Care Act and Children with Special Health Care Needs: An Analysis and Steps for State Policymakers*, p. 25. Retrieved May 12, 2021, from <https://ciswh.org/resources/the-affordable-care-act-and-children-with-special-health-care-needs-an-analysis-and-steps-for-state-policymakers/>

8. The ACA language 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 §2001(a); Health Care and Education Reconciliation Act, Pub. L. No. 111-152 §1004(e). <https://www.govinfo.gov/content/pkg/PLAW-111publ152/html/PLAW-111publ152.htm>

9. For the enhanced CHIP federal match rate in FY 2021 by state, see <https://www.macpac.gov/publication/federal-medical-assistance-percentages-fmaps-and-enhanced-fmaps-e-fmaps-by-state-selected-periods/>

10. For the Medicaid federal match rate in FY 2021 by state, see <https://www.macpac.gov/publication/federal-medical-assistance-percentages-fmaps-and-enhanced-fmaps-e-fmaps-by-state-selected-periods/>

11. Medicaid and CHIP Payment and Access Commission (MACPAC). (n.d.) CHIP financing. Retrieved May 129, 2021, from <https://www.macpac.gov/subtopic/financing/>

SERVICE DELIVERY

Health reform offers state Title V programs opportunities to realign health care delivery for children and youth with special health care needs (CYSHCN), 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 children, youth, and adults with chronic conditions to better integrate physical and mental health, coordinate care, and promote efficiencies.¹²
- Health homes, as established in section 2703 of ACA, 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 through a contract either with a managed care organization or 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 who have serious and persistent mental health conditions or two or more of the following: a mental health condition, substance use disorder, asthma, diabetes, or heart disease, or who are overweight. With approval from CMS, states may specify additional conditions, such as autism and pediatric asthma.¹³
- The ACA also contains language to implement state-level demonstration projects for pediatric accountable care organizations (ACOs). ACOs are provider organizations that aim to align financial incentives with better health outcomes for patients. For example, a hospital might partner 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.¹⁴
- Many state Medicaid programs have applied for newly available grants designed to create incentives for healthy behaviors and prevent chronic diseases.¹⁵ From 2011 to 2015, 10 states received grants as part of the Medicaid Incentives for the Prevention of Chronic Diseases Model. A list of participating states and the final evaluation report are available at <https://innovation.cms.gov/innovation-models/mipcd>.

12. Affordable Care Act, §2703, *State option to provide health homes for enrollees with chronic conditions*. See also Center for Medicaid, CHIP and Survey & Certification. (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 May 12, 2021, from <https://www.medicaid.gov/Federal-Policy-Guidance/downloads/SMD10024.pdf>

13. See Center for Medicaid, CHIP and Survey & Certification. (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 May 12, 2021, from <https://www.medicaid.gov/Federal-Policy-Guidance/downloads/SMD10024.pdf>

14. NC-PFCMH, NASHP, and the Catalyst Center. 2017. Supporting Title V and Medicaid Collaboration in Pediatric Medical Home Implementation. https://youtu.be/R_k_XHSqIIE

15. See Centers for Medicare & Medicaid Services, *Medicaid Incentives for Prevention of Chronic Diseases Program*, at <https://innovation.cms.gov/initiatives/mipcd/>



TEST YOUR KNOWLEDGE

1. **Starting in 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. **CHIP is different from Medicaid because:**
 - a. CHIP enrolls children and Medicaid does not
 - b. The amount of money a state receives for CHIP is capped, but Medicaid funds are not capped
 - c. The federal matching rate (FMAP) is lower for CHIP than for Medicaid
 - d. CHIP is only for children age 0 to 5, while Medicaid serves all ages
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?**
3. **What is the FMAP for Medicaid and CHIP in your state?**

ANSWER KEY

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

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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.¹ Conversely, to develop effective partnerships, Medicaid and CHIP staff may need comparable education about Title V programs. With a shared understanding, partners can identify the potential benefits of collaboration for both the programs and the children and youth they 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. Read on for some suggestions.

BASICS TO KNOW ABOUT YOUR STATE'S MEDICAID PROGRAM

- What are the income eligibility criteria for children and youth in your state's Medicaid and CHIP programs? Are there many eligible children and youth who could be enrolled, but are not? To what extent are their parents eligible for coverage?
- Does your state offer a TEFRA/Katie Beckett option for children and youth with severe disabilities? If so, how does the state Medicaid program determine eligibility for this option? (For more about TEFRA, see Section 11.)
- Does either the state Medicaid or CHIP program fund care coordination for children and youth with special health care needs (CYSHCN)? If yes, how is it funded (through a medical home, a managed care organization [MCO], a Home and Community-Based Services waiver targeted case management, a Title V contract)?
- How does the state Medicaid program track the delivery of services required by the Early Periodic Screening, Diagnosis, and Treatment (EPSDT) program? When a need for these services is identified, does a mechanism exist to track referrals and follow-up care?



Suggestions for developing and improving upon partnerships will depend on the relationships and systems that exist in each state.

- Learn the specifics of your state's Medicaid program
- Develop or expand key contacts
- Work with agency contacts to identify targeted "doable" improvement projects for CYSHCN
- Create effective formal or informal cross-agency committees or work groups
- Engage patients and families

1. See the Catalyst Center's interactive worksheets for Title V program staff, family leaders, and other stakeholders at <https://ciswh.org/resources/title-v-medicicaidchip-interactive-worksheets/>. Each worksheet includes resources for finding and inserting state-specific information to help demonstrate the importance of Title V, Medicaid, and CHIP for CYSHCN.

- What cooperative agreements already exist between Title V and the state Medicaid program? Do these agreements need amending or updating?
- What quality data do the state Medicaid program, MCOs, external quality review organizations, and primary care case management programs collect?

Suggestions for developing and improving upon partnerships will depend on the relationships and systems that exist in each state. Starting points include:

- Learn the specifics of your state's Medicaid program
- Develop or expand key contacts
- Work with agency contacts to identify targeted "doable" improvement projects for CYSHCN
- Create effective formal or informal cross-agency committees or work groups
- Engage patients and families

Answers to many of the above questions can be obtained from the sources listed in the Appendix.



DEVELOP OR EXPAND KEY CONTACTS

- Who in the state Medicaid program or within your state's MCOs works on quality measurement and implements the quality measures required by the Children's Health Insurance Plan Reauthorization Act of 2009? What are the challenges of collecting and using these quality measurement data?
- Who is in charge of eligibility and enrollment in the state Medicaid and CHIP programs? How is the state implementing Medicaid and CHIP benefits and the eligibility provisions of health reform?
- Who are the "go-to" people for obtaining Medicaid and CHIP program data?
- How is your program involved in working with primary care and other providers to improve care for CYSHCN?
- Could the Title V model of employing parents of CYSHCN work in your state's Medicaid and CHIP programs?
- Who is providing leadership in your state to improve the quality of care for CYSHCN?



WORK WITH PROGRAM CONTACTS TO IDENTIFY TARGETED “DOABLE” IMPROVEMENT PROJECTS FOR CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS

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

CREATE EFFECTIVE FORMAL OR INFORMAL CROSS-AGENCY COMMITTEES OR WORK GROUPS

- Is a working group or committee addressing issues relevant to CYSHCN, or to all children and youth, or to all people with chronic conditions or disabilities, including CYSHCN?
- Is the Medicaid program considering implementing Health Homes? 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

- Which agency or program is the designated Family-to-Family Health Information Center in your state?

A LAST WORD

Title V programs can assist Medicaid and CHIP agencies to fulfill their responsibilities, and at the same time ensure that CYSHCN receive the services they need.

NEED is the operative word here. Keep the following four things in mind when working with state Medicaid and CHIP programs:

N NEEDS
Keep the needs of CYSHCN in mind when designing, evaluating, and improving managed care and other service-delivery contracts.

E ENROLLMENT
Assure that CYSHCN are properly enrolled and receiving appropriate services.

E EFFICIENCIES
Develop the most efficient financing mechanisms for services.

D DATA
Help to analyze and respond to outcome data in order to improve the quality of care.

This document is part of Medicaid and CHIP: A Tutorial on Coverage for Children and Youth with Special Health Care Needs (CYSHCN). The document is available in its entirety at <https://ciswh.org/resources/Medicaid-CHIP-tutorial>

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PATHWAYS TO MEDICAID FOR CHILDREN AND YOUTH WITH DISABILITIES:

The TEFRA State Plan Option and Home and Community-Based Services Waivers



For most people, low income is the primary pathway to Medicaid coverage. This means that the eligibility of children and youth (including that of children and youth with disabilities) for this important public benefit is based on their family's income. However, the Centers for Medicare & 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. Two of these pathways to Medicaid eligibility for children and youth with disabilities are the so-called TEFRA state plan option (sometimes referred to as the Katie Beckett option)¹ and Home and Community-Based Service (HCBS) waivers.

When a child or youth 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.² However, if the child or youth is cared for at home and in the community, Medicaid eligibility is based on his or her family's income. Prior to 1981, a family that could not afford to cover the medical expenses of a child or youth with disabilities, but did not financially qualify for Medicaid, had to place their child or youth in an institutional setting, become impoverished so as to qualify for Medicaid, or relinquish custody of the child.

The Katie Beckett option created an exception to the Medicaid income-qualification rules that allowed families, regardless of income, to obtain Medicaid coverage to care for a child with disabilities at home. Congress then expanded this waiver by creating a new state plan option under Section 134 of the Tax Equity and Fiscal Responsibility Act (TEFRA) of 1982. This option allows children and youth with disabilities who require an institutional level of care, but whose families have incomes that are traditionally too high to qualify for Medicaid, to receive comprehensive services



TEFRA refers to a provision of the **Tax Equity and Fiscal Responsibility Act (TEFRA)** of 1982 that created a state plan option 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.

1. This 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 on the background of TEFRA and the Katie Beckett provision, please see: Catalyst Center. (2012). The TEFRA Medicaid state plan option and Katie Beckett waiver for children. Retrieved May 12, 2021, from <https://ciswh.org/resources/tefra-medicaid-state-plan-option-katie-beckett-waiver-children/>

2. Medicaid and CHIP Payment and Access Commission (MACPAC). Managed long-term services and supports. Retrieved May 12, 2021, from <https://www.macpac.gov/topics/long-term-services-and-supports/>

at home instead of in an institution. If the child with disabilities has other health insurance (e.g., commercial insurance), that payer is the primary insurer and Medicaid will cover remaining expenses such as deductibles, co-pays, and co-insurance.

One of the most important Medicaid benefits that the TEFRA state plan option provides to children and youth with disabilities is the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) benefit, which requires that all medically necessary services be covered under a state's Medicaid program for children and youth under age 21. (See Section 12.) The TEFRA option, therefore, ensures that not only do more children and youth with special health care needs (CYSHCN) qualify for Medicaid, but also that they are eligible to receive all of the services they need.

TEFRA STATE PLAN OPTION ELIGIBILITY CRITERIA

A child or youth must meet the following eligibility criteria to enroll in Medicaid under the TEFRA state plan option:^{3,4}

- Be under age 18;
- Live in a family whose income exceeds the state's Medicaid eligibility level;
- Meet the state's definition of institutional level of care;
- Have medical care needs that can safely be provided outside of an institutional setting; and
- Have medical, mental, and emotional health needs that are described by the [listing of childhood impairments on the Social Security website](#).

In addition to covering children and youth with medically complex health care needs or who require medical technology to maintain their physical health, the TEFRA state plan option also covers care in intermediate-care facilities for children and youth with intellectual disabilities. It therefore provides a way for children and youth with a variety of physical, mental, behavioral, and developmental health



The TEFRA/Katie Beckett option provides a way for children and youth 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.

3. O'Keefe, J., Saucier, P., Jackson, B., Cooper, R., McKenny, E., Crisp, S., & Moseley, C. (2010). Understanding Medicaid Home and Community Services: A Primer, 2010 Edition. U.S. Department of Health & Human Services. Retrieved April 27, 2021, from <http://aspe.hhs.gov/understanding-medicare-home-and-community-services-primer-2010-edition>

4. Semansky, R.M., & Koyanagi, C. (2004). The TEFRA Medicaid eligibility option for children with severe disabilities: A national study. *Journal of Behavioral Health Services & Research*, 31(3), 334-342. doi: 10.1007/BF02287295

conditions to qualify for Medicaid coverage when their family's income exceeds their state's Medicaid income eligibility limits.

Because each state sets its own criteria for determining what qualifies as an institutional level of care,⁵ eligibility for Medicaid under the TEFRA state plan option may differ from state to state. As of 2018, 20 states have adopted state plan options under TEFRA and two states have adopted TEFRA "look alike" programs⁶ to expand Medicaid to children and youth who meet the above eligibility criteria.

HOME AND COMMUNITY-BASED SERVICE WAIVERS

Another pathway to Medicaid eligibility for children and youth with disabilities is the HCBS waiver, sometimes known as the Katie Beckett waiver. (See Section 4 for more information on waivers in general and HCBS waivers in particular). Though both the HCBS waiver and the TEFRA state plan option may carry Katie Beckett's name, they are distinct programs that provide different advantages to families.

States with HCBS waivers have received permission from CMS to make changes to their state Medicaid programs such as offering additional benefits, targeting specific populations, and changing income eligibility levels. In addition, among other requirements, they must demonstrate that providing services under an HCBS waiver will not cost more than providing these services in an institution.⁷

By contrast, the TEFRA state plan option is implemented through a state plan amendment (SPA; see Section 2 for more information about SPAs). States that have chosen this option have received CMS approval to make changes to their state's Medicaid program's income eligibility criteria for children and youth with disabilities.⁸ These states do not have to prove that their program is cost-neutral and they cannot maintain a waiting list; all children and youth who qualify for Medicaid through the TEFRA state plan option based on the eligibility criteria described above are entitled to enrollment in Medicaid.⁹

The table on the next page compares the two pathways to Medicaid for children and youth with disabilities: the TEFRA state plan option and the HCBS waiver program.

5. Musumeci, 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. doi: [10.1177/009885881103700103](https://doi.org/10.1177/009885881103700103)

6. Musumeci, M., Chidambaram, P., & Watts, M.O. (2019, June 14). Medicaid Financial Eligibility for Seniors and People with Disabilities: Findings from a 50-State Survey. Retrieved May 12, 2021, from <https://www.kff.org/report-section/medicaid-financial-eligibility-for-seniors-and-people-with-disabilities-findings-from-a-50-state-survey-appendix-tables/>

7. Centers for Medicare and Medicaid Services. Home & Community-Based Services 1915(c). Retrieved May 12, 2021, from <https://www.medicare.gov/medicaid/home-community-based-services/home-community-based-services-authorities/home-community-based-services-1915c/index.html>

8. For more about the differences between the TEFRA state plan option and an HCBS waiver, please see: Wilson, K., Dworetzky, B., Comeau, M. (2015). Expanding Access to Medicaid Coverage: The TEFRA Option and Children with Disabilities. Catalyst Center. Retrieved May 12, 2021, from <https://ciswh.org/resources/expanding-access-medicare-coverage-tefra-option-children-disabilities/>

9. Smith, G., O'Keefe, J., Carpenter, L., Doty, P., Gavin, K., Burwell, B., & Williams, L. (2000). Understanding Medicaid Home and Community Services: A Primer. U.S. Department of Health & Human Services. Retrieved May 12, 2021, from <https://aspe.hhs.gov/basic-report/understanding-medicare-home-and-community-services-primer>

PATHWAYS TO MEDICAID FOR CHILDREN AND YOUTH WITH DISABILITIES: The TEFRA State Plan Option and Home and Community-Based Services Waivers

	TEFRA State Plan Option	HCBS Waiver Program
Who qualifies?	Children and youth from birth to age 18 who: • Meet their state’s definition for an institutional level of care • Have medical needs that can safely be provided outside of an institution	Children (and others as defined by age, diagnosis, or other criteria established by the state) who: • Meet their state’s definition for an 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
What authority do states use to offer these programs?	<i>State plan option (a.k.a. state plan amendment or SPA)</i> • With approval from CMS, states may change their individualized state Medicaid plan by adding optional services or changing eligibility requirements. • States must still follow federal Medicaid rules (e.g., a state cannot use a state plan option to cut mandated services). • All services provided under the state plan option, including EPSDT, must be available to all children who qualify for Medicaid in the state • No waiting lists allowed^{10,11}	<i>Home and Community-Based Service waiver</i> • States may request that certain Medicaid guidelines be waived to allow them provide additional services not usually covered by Medicaid to help individuals remain in the community (e.g., home/vehicle modifications). • With federal approval, states do not have to comply with certain federal Medicaid rules (i.e., certain Medicaid regulations are waived). • Services can be provided to specific groups of people (e.g., based on diagnosis or age) • Children and youth under age 21 who are enrolled in Medicaid under an HCBS waiver receive the EPSDT benefit in addition to any unique benefits offered under the waiver program. • Waiting lists allowed

10. Families USA. (2012). State Plan Amendments and Waivers: How States Can Change Their Medicaid Programs. Issue Brief. Retrieved May 12, 2021, from <https://www.sfdph.org/dph/files/CBHSdocs/QM2017/4Families-USA-IssueBrief2012StatePlanAmendmentsWaivers.pdf>

11. Ghandour, 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*, 15(4):451–60. doi: 10.1016/j.acap.2015.02.002



TEST YOUR KNOWLEDGE

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



FIND OUT IN YOUR STATE

- 1. Does your state have a TEFRA 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?**

ANSWER KEY

1. False 2. b 3. False

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EARLY AND PERIODIC SCREENING, DIAGNOSTIC, AND TREATMENT (EPSDT): A Brief History



EARLY PERIODIC SCREENING, DIAGNOSIS, AND TREATMENT: A BRIEF HISTORY

Congress established the Medicaid program as Title XIX of the Social Security Act in 1965 to provide medical care to people living in poverty who had no other options for paying for health services (For more background about Medicaid, see Section 2). Medicaid is an important source of coverage for all children, especially children and youth with special health care needs (CYSHCN). As of 2021, approximately 45% of CYSHCN rely, in whole or part, on publicly funded health care coverage.¹

In 1967, Medicaid was amended to include the Early Periodic Screening, Diagnosis, and Treatment (EPSDT) benefit because many military draftees and children enrolled in the Head Start program were 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).² EPSDT is the only entitlement benefit for child health services in the United States. The Omnibus Budget Reconciliation Act of 1989 (OBRA '89) expanded EPSDT to ensure that children and youth with mental and developmental disabilities in all states receive coverage of the services to which they are entitled under this benefit.”³

WHAT IS EPSDT?

As discussed in Section 5, every Medicaid program must provide the EPSDT benefit to enrolled children and youth under age 21. This federally mandated benefit ensures that all children and youth under age 21 who are enrolled in Medicaid receive preventive screenings and comprehensive health services in the amount, scope, and duration they need to develop and thrive.



Every Medicaid program must provide the **Early and Periodic Screening, Diagnostic, and Treatment (EPSDT)** benefit to enrolled children under age 21. 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.

1. Child and Adolescent Health Measurement Initiative. 2020-2021 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved 1/31/22 from <https://www.childhealthdata.org/browse/survey/results?q=9314&r=1>

2. The Commonwealth Fund. (2005). EPSDT: An overview. Washington, DC: The Commonwealth Fund. https://www.commonwealthfund.org/publications/other-publication/2005/sep/epsdt-overview?redirect_source=/publications/data-briefs/2005/sep/epsdt--an-overview

3. Centers for Medicare & Medicaid Services. Mandatory & Optional Medicaid Benefits. Retrieved April 28, 2021, from <https://www.medicare.gov/medicaid/benefits/list-of-benefits/index.html>

EPSDT provides all medically necessary services, including services that are not otherwise provided under the state's overall Medicaid plan.⁴ Notably, the law establishing EPSDT did not include a specific definition of medical necessity.⁵ Rather, Section 1905 (r)(5) of the Social Security Act requires that the EPSDT benefit cover "Such other necessary health care, diagnostic services, treatment, and other measures described in section 1905(a) to correct or ameliorate defects and physical and mental illnesses and conditions discovered by the screening services, whether or not such services are covered under the state plan."⁶

In the absence of a federal definition of medical necessity, states can adopt their own definition as long as it is not more restrictive than the federal law. Consequently, definitions of medical necessity vary by state Medicaid program.⁷ In general, medically necessary services are those that:

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

Each state has a Medicaid state plan, which specifies the mandatory (required by federal law) and optional (services that the state has decided to cover beyond what is required by federal law) covered benefits.

When the Children's Health Insurance Program (CHIP) was created in 1997, it did not include the EPSDT benefit. However, states can choose to use their CHIP funding to expand Medicaid eligibility to children who qualify for CHIP. In states where children's access to Medicaid is expanded with CHIP funds, all children must receive EPSDT. Regardless of how a child or youth qualifies for Medicaid (e.g., income, disability), once

eligible, they are entitled to EPSDT and all medically necessary services are covered until they reach age 21.

Adults aged 21 and over do not receive EPSDT. For example, dental benefits are covered for children and youth under age 21 as part of EPSDT, but are an optional service for adults. Many states do not include adult dental benefits in their Medicaid state plans.

Because EPSDT requires state Medicaid programs to cover any service that is deemed medically necessary, each child or youth should receive the care they need, whether or not the services are ordinarily provided under the Medicaid state plan.⁸ The comprehensive and individualized nature of EPSDT is particularly important for children and youth with special health care needs (CYSHCN), who by definition require more health care services than other children and youth their age due to their health conditions and need for specialized health care services.

COVERED SERVICES

EPSDT requires that Medicaid-eligible children and youth receive regular, periodic screenings at age-appropriate intervals. States are required to cover certain mandatory benefits in their Medicaid state plan.⁹ 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.

The table on the next page provides examples of mandatory benefits that states must provide to all

4. Centers for Medicare & Medicaid Services. (2014). EPSDT—A Guide for States: Coverage in the Medicaid Benefit for Children and Adolescents. Retrieved May 12, 2021, from https://www.medicaid.gov/sites/default/files/2019-12/epsdt_coverage_guide.pdf

5. Perkins, J., & Youdelman, M. (2013). Q & A: Defining Medical Necessity. Retrieved May 12, 2021, from <https://healthlaw.org/resource/q-a-defining-medical-necessity/>

6. Social Security Act, §1905(a)(5). Retrieved May 12, 2021, from https://www.ssa.gov/OP_Home/ssact/title19/1905.htm

7. National Academy for State Health Policy. (2021). State Definitions of Medical Necessity under the Medicaid EPSDT Benefit. Retrieved January 3, 2023, from <https://nashp.org/state-definitions-of-medical-necessity-under-the-medicaid-epsdt-benefit/>

8. The Commonwealth Fund. (2005). EPSDT: An Overview. Retrieved May 12, 2021, from <https://www.commonwealthfund.org/publications/other-publication/2005/sep/epsdt-overview>

9. Centers for Medicare & Medicaid Services. Benefits. Retrieved May 12, 2021, from <https://www.medicaid.gov/medicaid/benefits/index.html>

enrollees and optional benefits that they can choose to provide to adults.¹⁰ As noted above, if a service is deemed medically necessary for a child or youth, the state must provide it under the EPSDT benefit, even if it is not included in the Medicaid state plan.

THE ELEMENTS OF EPSDT

E arly	Assess and identify problems as early as possible
P eriodic	Check children's health status at regular, periodic, age-appropriate intervals
S creening	Provide physical, mental, developmental, dental, hearing, vision, and other screening tests to detect potential problems
D agnosis (aka Diagnostic)	Perform diagnostic tests to follow up (rule out or confirm) when screening identifies a risk or potential problem
T reatment	Control, correct, or reduce health problems found

EPSDT AND PARENT EDUCATION

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

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

EPSDT AND AUTISM SERVICES

Historically, there has been wide variation in how states provide Medicaid services to children and youth with autism. For example, 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 a Home and Community-Based Services waiver program that limited the number of children and youth who could receive the service and often included other restrictions such as age and household income. In July 2014, the Centers for Medicare & Medicaid Services (CMS) issued a

10. Centers for Medicare & Medicaid Services. Benefits. Retrieved May 12, 2021, from <https://www.medicaid.gov/medicaid/benefits/index.html>

Clarification of Medicaid Coverage of Services to Children with Autism.¹¹ This document noted that ABA was one of several evidence-based treatments for improving the physical and mental development of children and youth with autism spectrum disorders and, as such, should be covered under EPSDT for those children and youth for whom it is deemed medically necessary.

EPSDT AND YOUTH IN TRANSITION TO ADULT CARE

Children and youth enrolled in Medicaid are entitled to the EPSDT benefit until they reach age 21. However, states are required to provide Medicaid to eligible children and youth only until they reach age 19, unless

- They qualify for Medicaid because they have enrolled in the Supplemental Security Income (SSI) program upon reaching age 18, or
- The state has implemented the Affordable Care Act (ACA) Medicaid expansion for adults.

A separate provision of the ACA allows parents to continue to cover their young adult children on their private health plans until the children reach age 26.¹² Youth ages 19 and 20 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).¹³

Some states, rather than expanding Medicaid, have approval from CMS to use Medicaid funds to enroll individuals in private health plans in the marketplaces (also known as exchanges) created by the ACA. As these plans do not provide EPSDT, 19- and 20-year-olds with marketplace coverage receive EPSDT through wraparound Medicaid coverage.¹⁴

EPSDT AND YOUTH AGING OUT OF FOSTER CARE

The ACA includes a provision to extend Medicaid to young people who have aged out of the foster care system in their state of residence until they reach age 26, regardless of income. However, these young adults receive the EPSDT benefit only until they reach age 21.¹⁵ Individuals aged 21 to 25 do not receive the EPSDT benefit. In addition, states are allowed, but not required, to extend Medicaid to young adults who have aged out of the foster care system in one state and then moved to another. According to the most recently published data, the following 13 states provide Medicaid coverage to former foster care youth until age 26, regardless of the state in which they were in foster care:

California	New Mexico
Georgia	New York
Kentucky	Pennsylvania
Louisiana	South Dakota
Massachusetts	Wisconsin
Michigan	Virginia
Montana	

11. Centers for Medicare & Medicaid Services. Clarification of Medicaid Coverage of Services to Children with Autism. Retrieved April 28, 2021, from <https://www.medicaid.gov/Federal-Policy-Guidance/Downloads/CIB-07-07-14.pdf>

12. Centers for Medicare & Medicaid Services. Young Adults and the Affordable Care Act: Protecting Young Adults and Eliminating Burdens on Families and Businesses. Retrieved April 28, 2021, from https://www.cms.gov/CCIIO/Resources/Files/adult_child_fact_sheet

13. The Affordable Care Act sets the 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 when calculating eligibility. Throughout this tutorial we use 138% of FPL to account for the 5% Modified Adjusted Gross Income (MAGI) disregard. Affordable Care Act §2001(a); Health Care and Education Reconciliation Act, Pub. L. No. 111-152 §1004(e). <https://www.govinfo.gov/app/details/PLAW-111publ152>

14. Schwartz, S. (2014). Where Does EPSDT Stand in Post-ACA Medicaid Expansion 1115 Waivers? Center for Children and Families, Georgetown University Health Policy Institute. Retrieved May 12, 2021, from <https://ccf.georgetown.edu/2014/01/30/where-does-epsdt-stand-in-post-aca-medicaid-expansion-1115-waivers/>

15. Emam, D., & Golden, O. (2014 April). The Affordable Care Act and Youth Aging Out of Foster Care: New Opportunities and Strategies for Action. State Policy Advocacy and Reform Center. Retrieved May 12, 2021, from <https://firstfocus.org/resources/report/affordable-care-act-youth-aging-out-foster-care>

EPSDT AND MANAGED CARE

Managed care is one of the service delivery models discussed in Section 7 of this tutorial. As of July 2018, 39 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.¹⁶ Children and youth enrolled in Medicaid managed care programs are entitled to the EPSDT benefit. EPSDT services may be provided directly by the MCO. The Medicaid program provides any supplemental services that are not included in the MCO contract.

EPSDT AND TITLE V

Interagency coordination is a statutory requirement for both the Medicaid and Title V programs. The Title V–Medicaid interagency agreement is often known as the Memorandum of Understanding (MOU). Federal law establishing the EPSDT benefit requires that Medicaid reimburse Title V providers for services they deliver to enrollees, while the Social Security Act requires that Title V programs assist with the coordination of EPSDT.¹⁷ Additionally, Title V programs are required to help identify Medicaid-eligible children.

Each state has a Medicaid interagency agreement/MOU, which outlines the way that their Title V and Medicaid programs will partner to provide medically necessary services under the EPSDT benefit to children and youth enrolled in Medicaid.¹⁸

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 youth, and CYSHCN specifically, enrolled in Medicaid receive the EPSDT services they need to develop and thrive.

Some innovative 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 and youth in public benefit programs, others provide important outreach and enrollment activities to make families aware of Medicaid eligibility and may even screen children and youth for eligibility or refer them to Medicaid.
- Title V and Medicaid partner to create new billing codes to reimburse for nutritional supplements or streamline the prior approval process.
- Many Title V programs, such as home visiting, newborn screening, and early intervention programs, conduct parent education about the EPSDT benefit.

16. Kaiser Family Foundation, State Health Facts, Total Medicaid MCOs (July 2018). Retrieved May 12, 2021, from <http://www.kff.org/medicaid/state-indicator/total-medicaid-mcos/>

17. National Center for Education in Maternal and Child Health at Georgetown University. A Review of Title V and Title XIX Interagency Agreements. Chapter 2: Federal Legislation, Regulations, and Policy. Retrieved May 12, 2021, from https://www.ncemch.org/IAA/resources/C_State_MCH_Medicaid_Chapter2.pdf

18. Current State Title V–Medicaid Interagency Agreements/MOUs can be found at: <https://mchb.tvisdata.hrsa.gov/Home/IAAMOU>



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: Children enrolled in Medicaid managed care do not receive EPSDT.**
3. **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 CYSHCN in managed care?**

ANSWER KEY

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

This document is part of Medicaid and CHIP: A Tutorial on Coverage for Children and Youth with Special Health Care Needs (CYSHCN). The document is available in its entirety at <https://ciswh.org/resources/Medicaid-CHIP-tutorial>

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APPENDIX: SELECTED RESOURCES



TITLE V AND MEDICAID/CHIP COLLABORATION

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

EPSTD—Title V MCH Program Interagency Collaboration <https://mchb.hrsa.gov/programs-impact/early-periodic-screening-diagnosis-treatment>

Strategies for Changing State Medicaid Policy to Improve Services to Children with Medical Complexity https://ciswh.org/resources/medicaid_policy_strategies/

Paths to Financial Sustainability for Comprehensive Pediatric Complex Care Programs <https://ciswh.org/resources/paths-sustainability-complex-care/>

MEDICAID/CHIP DATA FOR YOUR STATE

Catalyst Center State-at-a-glance Chartbook on Coverage and Financing of Care for CYSHCN <https://chartbook.ciswh.org/>

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

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

Distribution of Medicaid Enrollees by Enrollment Group <https://www.kff.org/medicaid/state-indicator/distribution-of-medicaid-enrollees-by-enrollment-group/>

State Medicaid and CHIP Waiver and Demonstration Programs <https://www.medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/index.html>

Children's Medicaid/CHIP Participation Rates, <https://www.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, <https://www.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, 2000-2022 <https://www.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 for all years, from the National Academy for State Health Policy <https://nashp.org/all-50-states-and-washington-d-c-chip-fact-sheets-for-all-years/>

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 <https://ciswh.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 <https://ciswh.org/resources/the-affordable-care-act-a-side-by-side-comparison/>

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

Association of Maternal Child Health Programs. Promoting Coverage, Current Initiatives. <https://amchp.org/promoting-coverage-current-initiatives/#tabs1>

Find Coverage for Your Family at InsureKidsNow.gov. Use this resource to find state- specific information about Medicaid and CHIP programs. <https://www.insurekidsnow.gov/coverage/index.html>

MEDICAID ELIGIBILITY DETERMINATIONS

Medicaid Eligibility Determinations, Applications, and Online Accounts, <https://www.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 <https://www.kff.org/health-reform/state-indicator/presumptive-eligibility-in-medicaid-chip/>

State Adoption of 12-Month Continuous Eligibility for Children's Medicaid and CHIP <https://www.kff.org/health-reform/state-indicator/state-adoption-of-12-month-continuous-eligibility-for-childrens-medicaid-and-chip/>

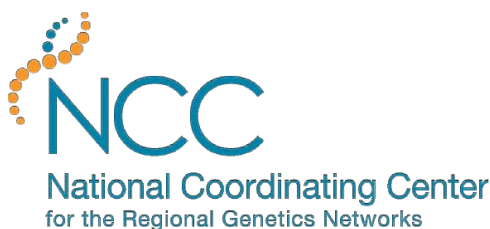
THE MATERNAL AND CHILD HEALTH BUREAU-FUNDED NATIONAL CENTERS SERVING CSHCN



The Advancing Systems of Services for CYSHCN Network was established in 2018. The Network's goal is to improve the health and well-being of children and youth with special health care needs (CYSHCN) and their families by establishing a network of centers that focus on three core health system components: access to the patient/family-centered medical home, transition into adult health care systems, and continuous and adequate health care coverage. As the Network, the [Catalyst Center](#), the [National Resource Center for Patient/Family-Centered Medical Home \(NRC-PFCMH\)](#), and [Got Transition](#) collaborate to support state Title V programs, family leadership organizations, health care providers, and other stakeholders. In addition to the activities of the Network, each national center continues to provide its own technical assistance and training on topics specific to its area of expertise.



Family Voices Leadership in Family and Professional Partnerships (LFPP) 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 engagement at all levels of health care from direct patient care to program design and policymaking. <https://familyvoices.org/lfpp/>



The National Coordinating Center for the Regional Genetics Networks (NCC) works with the seven Regional Genetics Networks and the National Genetics Education and Family Support Center to improve access to genetic services for underserved populations. They develop resources related to education on genetics and genetics policy, workforce development, and raising awareness about public health genetics. <https://nccrcg.org/>

PARTNERSHIP AND COLLABORATION



Leadership in Family and Professional Partnerships

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>