BOSTON UNIVERSITY

Leverage Opportunities + Speak the Medicaid Language: A **Workbook** for Title V

Boston University School of Social Work
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CATALYST CENTER

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Executive Summary

As the National Resource Center for Financing and Coverage of Care for CYSHCN, the Catalyst Center seeks to support states in identifying and pursuing opportunities to improve the system of services for CYSHCN. This system is complex and involves many individuals, institutions, and other interested parties, including CYSHCN, their families, providers, schools, payers, and public health.

This resource focuses on Medicaid as an important element of the system of services, as it is the single largest payor for CYSHCN and provides a robust benefits package for children. The workbook includes didactic sections that describe elements of the Medicaid program, as well as questions to guide users through the process of mapping the Medicaid system in their own state.

The purpose of this resource is to increase Title V program staff knowledge about topics related to financing and the system of services for CYSHCN, especially Medicaid; increase Title V staff ability to describe their role in financing and the system of services for CYSHCN; and facilitate the identification of financing-related strategic priorities for state Title V programs.

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Introduction to the Workbook for Title V

01

Welcome to **The Workbook**. This document was created by the Catalyst Center, the National Center for Health Insurance Coverage and Financing for Children and Youth with Special Health Care Needs (CYSHCN), in partnership with a team of advisors who provided essential guidance.

The purpose of this resource is threefold:

- To increase Title V program staff knowledge about topics related to financing and the system of services for CYSHCN, especially Medicaid.
- To increase Title V staff ability to describe their role in financing and the system of services for CYSHCN.
- To facilitate the identification of financing-related strategic priorities for state Title V programs and specific levers and concrete steps to address those priorities.

This introduction will provide an overview of how to use this workbook, preview the layout of the content chapters, and describe key skills and frameworks that will support you in addressing some of the questions you will encounter later in the workbook.

CHAPTER CONTENTS

WHO THIS CHAPTER IS FOR:

- The primary audience for this chapter is state Title V program leaders and staff.
- We encourage you to collaborate and engage with colleagues in other departments within Title V or other state agencies who play a role in financing the system of services for CYSHCN. State Title V partners can help identify, prioritize, and achieve goals and objectives.

WHY THIS CHAPTER MATTERS:

- This chapter lays a foundation for the rest of this workbook. Understanding the overarching aim of this resource and how it works can help you keep the big picture in mind and decide what sections may be most useful for you.

WHAT YOU WILL LEARN:

- The overall purpose for this workbook
- How to use this resource to increase your knowledge of financing and coverage for CYSHCN
- How to use this workbook to inform Title V strategic planning efforts and shape program goals

1. FINANCING AND THE SYSTEM OF SERVICES FOR CYSHCN

The system of financing and delivery of services for children and youth with special health care needs (CYSHCN) is complex, and involves public and private payors, state agencies, community-based organizations, providers, and families and children. Nationally, less than 15% of families raising CYSHCN report that their child receives care in a well-functioning system.[1] A poorly functioning system of services and absent or inadequate health insurance prevents CYSHCN from receiving coordinated services, results in family financial hardship, hinders access to essential providers, contributes to inequities, and limits opportunities for family/professional partnerships.[2]

The recently published *MCHB Blueprint for Change: A National Framework for a System of Services for Children and Youth with Special Health Care Needs* describes four goals that financing a system of services for CYSHCN should achieve:[3]

- "Families should be able to have care that does not present a financial burden but is also continuously available. In addition, families should have sufficient choice of services and administrative burdens should be low."

[1] In the National Survey of Children's Health (NSCH) methodology, this indicator is a composite measure. Per NSCH: "There are five age-relevant core measures for children age 0–11 years, and six age-relevant core measures for children age 12–17 years. Those five measures for children age 0-11 years include: the family feels like a partner in their child's care, child has a medical home, child receives medical and dental preventive care, child has adequate insurance, and child has no unmet need or barriers to access services. For adolescents age 12–17 years, preparation for transition to adult healthcare is included in addition to the five measures for younger children." Source: Child and Adolescent Health Measurement Initiative. (n.d.). *Indicator 4.17: Children received care in a well-functioning system*. https://www.childhealthdata.org/browse/survey/results?q=8670&r=1&g=921

[2] Adapted from: Comeau, M., Bachman, S., & Kantner Doherty, J. (2019). *Critical Elements for Financing the System of Care for CYSHCN: An Infographic Series*. https://ciswh.org/resources/critical-elements-for-financing-the-system-of-care-for-cyshcn-an-infographic-series/

[3] Schiff, J., Manning, L., VanLandeghem, K., Langer, C. S., Schutze, M., & Comeau, M. (2022). Financing Care for CYSHCN in the Next Decade: Reducing Burden, Advancing Equity, and Transforming Systems. *Pediatrics*, *149*(Supplement 7). https://doi.org/10.1542/peds.2021-056150I

- "[Financing] systems should be oriented to address racial inequities and social risks that impact health and wellbeing. These systems should provide resources and mechanisms to strengthen communities and support families. When possible, services should be embedded in communities so they will be culturally appropriate."
- "[Service] models should reward the value provided to families and CYSHCN through new patient- and family-centered models of care that improve outcomes. These improved value-based models should also rejuvenate provider systems dedicated to the service of CYSHCN, whether they are primary care, community-based services, or integrators of care."
- "[To] be effective in achieving these goals, measurement systems will need to be revamped to integrate data and improve actionable feedback. Such measurement systems need to be flexible and improved continuously."

State Title V leaders are well positioned to work toward these goals due to their skills in systems thinking, deep understanding of the needs of CYSHCN and their families, relationships with a wide variety of state agencies and community organizations, and their ability to leverage statutory requirements that mandate collaboration between state Title V programs and Medicaid agencies. For many Title V programs, financing may include using funds from their own programs or leveraging other funding sources to reduce the number of CYSHCN without health insurance or to pay for services directly.

MCHB Definition of Population Health: "A population health strategy for [CYSHCN] intends to improve the health and well-being of an entire group or subgroup. These strategies occur at the policy or systems level and are measurable over time. They are designed to improve health equity and often focus on social and environmental factors."

See **Appendix I** of the MCHB Title V Block Grant Guidance for more information about population health and CYSHCN.

States have also begun, in alignment with guidance from the Maternal and Child Health Bureau, to take a population health approach when developing strategies to improve the health of CYSHCN.[4] When it comes to financing, a population health approach may include strategies that draw on Title V Block Grant funds as well as those that leverage other funding streams to increase system capacity, or remove access barriers for families. For example, state Title V CYSHCN programs may implement pilot programs that deliver services to CYSHCN. Collaboration with state partners to braid funding can create opportunities to sustain and spread such pilot programs. States may also fund staff members who are trained in Health Insurance Marketplace navigation. Investing in staff expertise can help ensure that CYSHCN have the coverage that they are eligible for and are able to fully utilize coverage benefits. These investments help reduce the need for gap-filling funding from Title V CYSHCN programs.[5]

[4] United States Health Resources and Services Administration, M. and C. H. B. (n.d.-b). *Title V Maternal and Child Health Services Block Grant to States Program: Appendix of Supporting Documents*. https://mchb.tvisdata.hrsa.gov/Admin/FileUpload/DownloadContent?fileName=BlockGrantGuidanceAppendix.pdf&isForDownload=False

[5] The Catalyst Center. (n.d.). *Benefits Counseling*. https://ciswh.org/project/the-catalyst-center/financing-strategy/benefits-counseling/

A note on terminology: Throughout this workbook, we refer to children and youth with special health care needs (CYSHCN). Other entities may use the term children with special health care needs (CSHCN). In instances where CSHCN includes an age range that would be considered youth, we use CYSHCN. If the acronym is not inclusive of youth, we will indicate this.

Collaborations across sectors are required to accomplish the goals described in the *Blueprint for Change*. This workbook focuses particularly on increasing Title V staff knowledge about Medicaid, providing tools to support Title V staff in articulating their program's role in financing and their value to Medicaid as a partner, and guiding Title V staff through a process of identifying opportunities and next steps to advance collaboration with their Medicaid counterparts.

As the largest single payor for services for CYSHCN, Medicaid plays a crucial role in the system of services for CYSHCN. Collaborations between Title V CYSHCN programs and state Medicaid agencies can improve financing the system of services for CYSHCN. For example, states have strengthened Title V-Medicaid Managed Care collaborations to improve care for CYSHCN, established mechanisms for Medicaid reimbursement for care coordination administered by Title V programs, and implemented initiatives to advance racial equity in both Title V and Medicaid programs. These collaborations serve to advance the other three domains outlined in the *Blueprint for Change*, as described in greater depth in the next section.

2. WORKBOOK FRAMEWORKS AND TOOLS

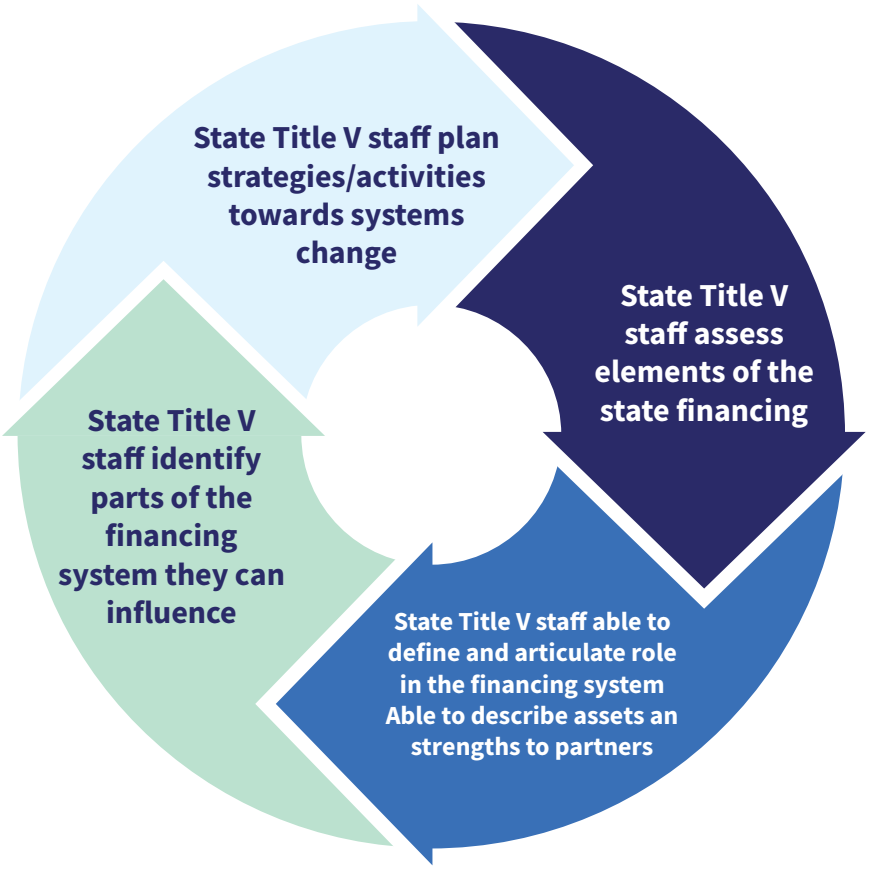
The Catalyst Center designed this workbook to increase Title V staff knowledge about financing and the system of services for CYSHCN, support strategic planning efforts, and increase Title V staff ability to describe their role in financing and the system of services for CYSHCN. This multi-part purpose can also be stated as stages in a cycle (see Figure 1 below):

- State Title V staff assess elements of the state financing system
- State Title V staff are able to define and articulate their role in the financing system; State Title V staff are able to describe their assets and strengths to partners
- State Title V staff identify parts of the financing system they can influence
- State Title V staff plan strategies/activities towards systems change

This workbook is designed to increase Title V capacity by providing education, guiding systems assessment, and increasing confidence to facilitate the steps in the cycle to the right.

Two frameworks informed the development of this workbook: the MCHB *Blueprint for Change* and the 10 Essential Public Health Services. We describe them in detail below, and the frameworks are reflected in the activities, reflection questions, and prompts found throughout the content chapters.

Figure 1. Workbook Objectives



Blueprint for Change

In addition to financing of services, the *Blueprint for Change* describes three other domains that are essential for the system of services for CYSHCN: health equity, quality of life and well-being, and access to services. The *Blueprint for Change* describes guiding principles for each of the four critical areas discretely, but these guiding principles also illustrate how financing is a key element woven throughout. The table below highlights selected principles from the *Blueprint for Change* that relate to financing.

Critical Area 1: Health Equity
Principle 2: Sectors, systems, and programs that fund, deliver, and monitor services and supports for CYSHCN are designed and implemented to reduce health disparities and improve health outcomes for all CYSHCN.
Critical Area 2: Family and Child Well-Being and Quality of Life
Principle 2e: Health systems evaluate and link payment models to quality of life for all children and youth.
Critical Area 3: Access to Services
Principle 1d: Public health programs connect and collaborate with stakeholders in the private sector to invest in and advance the system for CYSHCN and families.

Conversely, principles related to the Critical Area of Financing of Services reinforce the vision articulated within the other critical areas. In addition to explicitly naming racial inequity in multiple principles, the Financing of Services principles describe specific elements of an adequately funded system that enables *all* CYSHCN and their families to receive care that meets their needs and is delivered in a culturally competent manner. Such a system would ensure that CYSHCN are able to access services they need regardless of functional ability, income, type of insurance coverage, or where they live.

10 Essential Public Health Services

The 10 Essential Public Health Services is an established framework describing the core roles of public health entities. It was developed and released by the Centers for Disease Control and Prevention (CDC) in 1994. An update to the framework occurred in 2020, led by Public Health National Center for Innovations and the deBeaumont Foundation. A key change in the framework was to include equity as a core outcome for all of the essential services.

The essential public health services fall in three overall categories: assessment, policy development, and assurance (please see Figure 2, below, for a graphic representation of the 10 Essential Public Health Services).

Assessment

1. Assess and monitor population health status, factors that influence health, and community needs and assets
2. Investigate, diagnose, and address health problems and hazards affecting the population

Policy Development

3. Communicate effectively to inform and educate people about health, factors that influence it, and how to improve it
4. Strengthen, support, and mobilize communities and partnerships to improve health
5. Create, champion, and implement policies, plans, and laws that impact health
6. Utilize legal and regulatory actions designed to improve and protect the public's health

Assurance

7. Assure an effective system that enables equitable access to the individual services and care needed to be healthy
8. Build and support a diverse and skilled public health workforce
9. Improve and innovate public health functions through ongoing evaluation, research, and continuous quality improvement
10. Build and maintain a strong organizational structure for public health

Figure 2. The 10 Essential Public Health Services

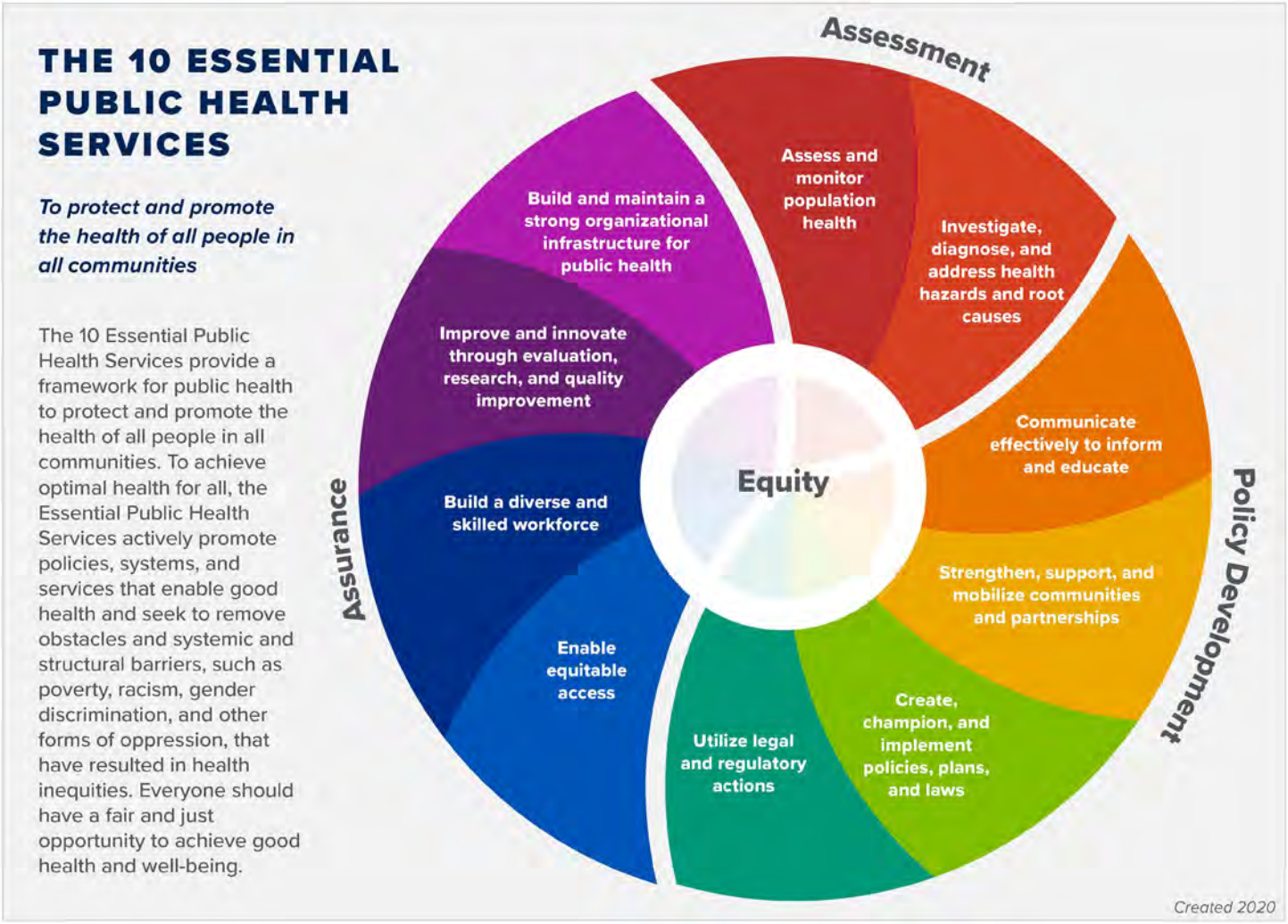


Image source: Centers for Disease Control and Prevention. (2020). 10 Essential Public Health Services. https://www.cdc.gov/publichealthgateway/publichealthservices/essentialhealthservices.html

At the end of each chapter in this workbook, you will find a series of questions informed by the 10 Essential Public Health Services framework. These questions are designed to help you identify connections between information presented about Medicaid and CYSHCN and the role that Title V as a public health entity plays in the system of services for CYSHCN. The final chapter in this workbook includes activities designed to bring together what you have learned throughout the workbook and help you to develop a plan for change based on this knowledge.

3. WHAT YOU CAN EXPECT FROM WORKBOOK CHAPTERS

This workbook includes chapters on several key Medicaid topics, namely: a Medicaid overview, Medicaid Managed Care, the Early, Periodic, Screening Diagnostic and Treatment (EPSDT) benefit, and Home- and Community-Based Services Waivers and the TEFRA State Plan Option. Each chapter includes an introductory section, formatted like the one above, summarizing who the chapter is for, why it matters, and what you can expect to learn. It is not necessary to complete each chapter, nor each question within the chapters, but we certainly encourage you to do so! Review the chapter introductions to determine which sections will be most useful for you to complete.

Within each chapter, we present clear, concise content describing Medicaid policy and how these policies are operationalized. Most chapter sections also include at least one set of questions for you to respond to using information from your state. You may know the answer to some of these questions based on your experience. Others may be unfamiliar. Instructions for where you may find the answers are included where applicable.

KEY TO RECURRING INTERACTIVE ELEMENTS

Question boxes in green ask you to enter discrete, objective answers, while blue boxes invite reflection and present an opportunity to synthesize what you have learned from answering the green box questions. These reflections and observations can help serve as a reference when you begin the strategic planning process in the final chapter of the workbook.

Examples of question boxes:

Visit the HRSA MCHB website to answer the following questions. https://mchb.tvisdata.hrsa.gov/Financial/FundingByServiceLevel *Note: scroll past Regions to get to the list of states.*	
Total Title V spending in your state for direct services:	*(dollar amount, percent)*
Total Title V spending in your state for enabling services:	*(dollar amount, percent)*
Total Title V spending in your state for public health services and systems for the most recent fiscal year:	*(dollar amount, percent)*

Reflection Questions:	
Based on your knowledge, do you think that the distribution of Title V spending for CYSHCN is similarly proportional to Title V spending in general in your state, or does spending for CYSHCN fall more in a different section of the pyramid?	
Do a quick brainstorm. Based on what you know off the top of your head, what are some priority needs for CYSHCN in your state that could be addressed using a population health approach? What could such an approach look like?	

Call-out boxes throughout the chapters highlight specific state examples that apply key concepts, opportunities for Title V to conduct systems surveillance areas of particular concern related to equity, and tips for finding information.

Public health surveillance enables public health agencies to understand disease burden or distribution of health outcomes in a population. Here, we use the term “systems surveillance” as a way to talk about monitoring how well public health systems, in particular the system of services for CYSHCN, functions. Identifying trends in the ability to access care, rates of insurance coverage, adequacy, and continuity, or in how many families report needing care coordination can indicate opportunities to improve the system overall. Refer to the Appendix for a complete list of data indicators that appear in this workbook. Tracking data on these and other indicators is a role that reflects elements of the 10 Public Health Essential Services under Assessment and Assurance, and it can be extremely useful in CQI efforts to improve the system of services for CYSHCN and their families.

4. WORKBOOK CONTENT AND TITLE V TOPICS

The work of Title V intersects with Medicaid in many ways. The table below lists topics that may be of interest to state Title V programs, and identifies sections of this workbook that are particularly relevant to that topic. If you are already doing work in any of these areas or considering work related to these topics, accessing the related section may help inform your strategic planning.

Topic	Related Workbook Section

Behavioral/ Mental Health	• Chapter 2: Overview of the State Medicaid Program
	  ○ Section 5: Medicaid Eligibility
	  ▪ "Children with mental health conditions are more likely to have other chronic health conditions… than children without mental health conditions."6
	  ▪ No matter how a child qualifies for Medicaid, they are entitled to Medicaid's robust benefits, including coverage for behavioral health care.
	  ○ Section 7: State Plan Options under Medicaid
	  ▪ While all of these options have potential to increase the number of children eligible for Medicaid, and therefore increase their access to mental health services, Reimbursement for Expanded School-Based Health Services represents an opportunity to ensure sustainable financing for school-based mental health services in particular.
	• Chapter 3: Medicaid Managed Care
	  ○ States use different approaches to provide behavioral health services in Medicaid. State Medicaid agencies can contract with Managed Care Organizations to provide both physical and behavioral health services. After you learn about Medicaid Managed Care in Chapter 3, check out this fact sheet from the National Academy for State Health Policy to learn more about managed care and behavioral health.
	• Chapter 4: EPSDT
	  ○ The EPSDT benefit requires that medically necessary services, including behavioral health services, be covered regardless of whether they are included in the Medicaid State Plan. Understanding EPSDT will help you consider ways to leverage this benefit to promote access to behavioral health services.
	• Chapter 5: TEFRA and HCBS Waivers
	  ○ States can design an HCBS waiver specifically for children with behavioral needs such as Serious Emotional Disturbance (SED). As you learn about all of the HCBS waiver programs in your state, this resource from the Medicaid and CHIP Payment and Access Commission (MACPAC) may also be useful.

Care Coordination	• Chapter 2: Overview of the State Medicaid Program
	  ○ Section 7: State Plan Options Under Medicaid
	  ▪ States may use multiple state plan options to implement Health Homes, a model of care that provides a system of comprehensive care coordination to Medicaid beneficiaries who have chronic conditions.
	• Chapter 5: Pathways to Medicaid Coverage for Children who Require an Institutional Level of Care: TEFRA/Katie Beckett and Home- and Community-Based Services Waivers
	  ○ Section 4: 1915(c) Home- and Community-Based Services Waivers
	  ▪ Under 1915(c) Home- and Community-Based Services Waivers, states may provide services such as Care Coordination to specific populations.

[6] National Academy for State Health Policy. (July 2017). Providing behavioral health treatment for children through Medicaid delivery systems. https://www.nashp.org/wp-content/uploads/2018/07/Behavioral-Health-Fact-Sheet-w-links.pdf

Topic	Related Workbook Section
Care Coordination (*continued*)	• Once you have read the chapters and are familiar with EPSDT, Medicaid Managed Care, and Waiver Programs, read this brief about how states have used Medicaid delivery systems to reimburse for Title V-administered care coordination.
Developmental Screening	• Chapter 4: EPSDT ○ Screening is a key component of the Medicaid EPSDT benefit for children—it's the "S"!
Medical Home	• Chapter 3: Medicaid Managed Care (MMC) ○ Principles of the Patient-Family-Centered Medical Home can be promoted throughout the Medicaid Managed Care procurement process. Medical Home elements, for example, can be integrated Medicaid managed care contracts to ensure that providers in the MMC are implementing Medical Home models in their practices.
Health Equity	• Inequities in health are perpetuated by systems of oppression including racism, poverty, ableism, and others.[7] Public health can promote equity by supporting and implementing "policies, systems, and overall community conditions that enable optimal health for all."[8] ○ Throughout this workbook, you will find "Focus on Equity" call-out boxes in yellow, which highlight opportunities to apply an equity lens to your work. • Chapter 1: Introduction ○ Section 1: Financing and the System of Services for CYSHCN ■ This section includes an examination of how financing intersects with the Critical Areas of MCHB's *Blueprint for Change*, one of which is Health Equity.
Health Care Transition	• Chapter 3: Medicaid Managed Care (MMC) ■ Core principles and elements of health care transition (HCT) can be promoted throughout the Medicaid Managed Care procurement process. The Six Core Elements of HCT,[9] for example, can be integrated Medicaid managed care contracts to ensure that providers in the MMC are implementing them in their practices. MMC contracts can also specify that data be collected to measure youth experience with HCT.
Children with Medical Complexity (CMC)	• This workbook in general focuses on children and youth with special health care needs (CYSHCN). Some state work may focus on children with medical complexity (CMC), a sub-group of CYSHCN. • Chapter 2: Overview of the State Medicaid Program ○ Section 7: State Plan Options Under Medicaid ■ A new state plan option enacted through the ACE Kids Act of 2017 allows states to establish health homes specifically for CMC. • Chapter 5: Pathways to Medicaid Coverage for Children who Require an Institutional Level of Care: TEFRA/Katie Beckett and Home- and Community-Based Services Waivers • This chapter describes options that states have to create a pathway to Medicaid coverage for children who require an institutional level of care.

[7] Centers for Disease Control and Prevention. (2021, March 18). *10 Essential Public Health Services*. https://www.cdc.gov/publichealthgateway/publichealthservices/essentialhealthservices.html

[8] Ibid.

[9] Got Transition. (n.d.). *Six Core Elements of Health Care Transition*. https://www.gottransition.org/six-core-elements/.

5. RESOURCES

Each chapter of the workbook will include links to resources specific to the content in that chapter. Some resources that may be generally helpful to you throughout are included below.

- National Standards for Systems of Care for CYSHCN. The Association of Maternal and Child Health Programs & the National Academy for State Health Policy. https://cyshcnstandards.amchp.org/app-national-standards
    - The National Academy for State Health Policy created a map, How States Use the National Standards for CYSHCN in their Health Care Systems, describing how different states are using the National Standards in their Medicaid and Title V programs. You can access this resource here.
- Glossary. The Catalyst Center. https://ciswh.org/projects/the-catalyst-center/glossary/
    - Includes key terms in financing and coverage for CYSHCN
- State Data Chartbook. The Catalyst Center. https://ciswh.org/projects/the-catalyst-center/state-data-chartbook/
    - The State Data Chartbook is a selective list of health indicators for all 50 states as well as Puerto Rico and the District of Columbia (DC). Drawing from a range of trusted sources and updated regularly, it provides data in areas that include demographics, economics, child health services, insurance availability, and factors impacting coverage for Children and Youth with Special Health Care Needs (CYSHCN). This information can be compared state-by-state or against the national average.
- Financing Strategies. The Catalyst Center. https://ciswh.org/projects/the-catalyst-center/financing-strategies/
    - This page links to examples of the innovative strategies states are using to improve and finance care for CYSHCN.

02

Overview of the Medicaid Program

02

Person completing this chapter: _____

Role: _____

Date: _____

Additional Collaborative Partners for this chapter: _____

_____

_____

CHAPTER CONTENTS

WHO THIS CHAPTER IS FOR:

- The primary audience for this chapter is state Title V program leaders and staff.
- If applicable, we encourage you to collaborate with colleagues in other departments within Title V or other state agencies who serve children and families that are enrolled in Medicaid.
- If you have direct contact with families about insurance coverage, you may find this chapter particularly helpful.

WHY THIS CHAPTER MATTERS:

- Medicaid is a critical source of health care coverage for children and youth with special health care needs (CYSHCN). In fact, it is the single largest payer in the U.S. for children, including CYSHCN
- State Title V programs are statutorily required to collaborate with Medicaid in different ways. Being equipped with knowledge of the state Medicaid program will allow Title V staff to engage as well-informed partners, identify opportunities for partnership, and draw on their expertise to provide tailored input to Medicaid partners

WHAT YOU WILL LEARN:

- State-Federal financing of Medicaid
- How states can change their Medicaid programs
- Medicaid Eligibility
- Medicaid Benefits
- State Options under Medicaid

Throughout this tool, we invite you to reflect on and assess Title V's role in the administration and implementation of the state Medicaid program; this chapter offers questions to help you identify potential roles for Title V related to Medicaid. As with each chapter in this tool, it is not necessary to complete every single question for the tool be useful to you.

If you would like support, the Catalyst Center is here to help. Reach out to us at cyshcn@bu.edu.

1. INTRODUCTION

The objective of the Medicaid program is to provide health coverage to low-income individuals to ensure they can access the health care services they need.[10] Medicaid is a critical source of health care coverage in the United States. It is the primary source of health insurance coverage for low-income individuals, and the largest single payer of health care services for children, including children and youth with special health care needs (CYSHCN). Medicaid is a state-federal partnership program. It is funded and implemented by both states and the federal government. In general, Medicaid accounts for a little over half of federal funds that flow into states.[11]

FOR YOUR INFORMATION:

Medicaid.gov is a great general resource where you can view your state's State Plan Amendments (SPAs) and waivers.

We encourage you to locate your state Medicaid website. You should be able to find it through a google search (type [state name] and Medicaid). Bookmark this site for easy access, and explore all of the information it contains.

FOCUS ON EQUITY:

Public insurance is intimately linked in its purpose with equity. Children in marginalized groups, whether by disability, language, income, or race/ethnicity, are more often covered by public insurance compared to other populations.

Medicaid was established as a program to support the health of the most vulnerable populations in the U.S., including children, pregnant people, seniors, and people with disabilities. Public insurance covers approximately 55% of Black, 49% of Hispanic, 28% of Asian, 23% of White, and 32% of other children nationwide.[12] It also covers the vast majority of children in the poorest households in the country (incomes below 200% of the federal poverty level).[13] Fifty-six percent of children living in families for whom English is not the primary language are covered by public insurance compared to 31% of children living in households where English is the first language.[14] CYSHCN with more complex health needs are more often covered by public insurance compared to CYSHCN with less complex health needs and non-CYSHCN (49%, 35%, and 32%, respectively).[15]

[10] Social Security Act, 42 U.S.C. § 1901 (1935). https://www.ssa.gov/OP_Home/ssact/title19/1901.htm, cited in Solomon, J., & Schubel, J. (2017, August 29). *Medicaid Waivers Should Further Program Objectives, Not Impose Barriers to Coverage and Care*. Center on Budget and Policy Priorities. https://www.cbpp.org/research/health/medicaid-waivers-should-further-program-objectives-not-impose-barriers-to-coverage#_ftn2

[11] National Association of State Budget Officers. (2020). *2020 State Expenditure Report Fiscal Years 2018-2020*. https://higherlogicdownload.s3.amazonaws.com/NASBO/9d2d2db1-c943-4f1b-b750-0fca152d64c2/UploadedImages/SER%20Archive/2020_State_Expenditure_Report_S.pdf

[12] Child and Adolescent Health Measurement Initiative. 2019-2020 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 from https://www.childhealthdata.org/browse/survey/results?q=8595&g=914&r=1

[13] Child and Adolescent Health Measurement Initiative. 2019-2020 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 from https://www.childhealthdata.org/browse/survey/results?q=8595&r=1&g=900

[14] Child and Adolescent Health Measurement Initiative. 2019-2020 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 from https://www.childhealthdata.org/browse/survey/results?q=8595&r=1&g=917

[15] Child and Adolescent Health Measurement Initiative. 2019-2020 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 from https://www.childhealthdata.org/browse/survey/results?q=8595&r=1&g=922

The Federal System and Medicaid

Medicaid was established in 1965 in Title XIX of the Social Security Act, which also established Medicare. It was originally designed to increase access to health care for low-income individuals.

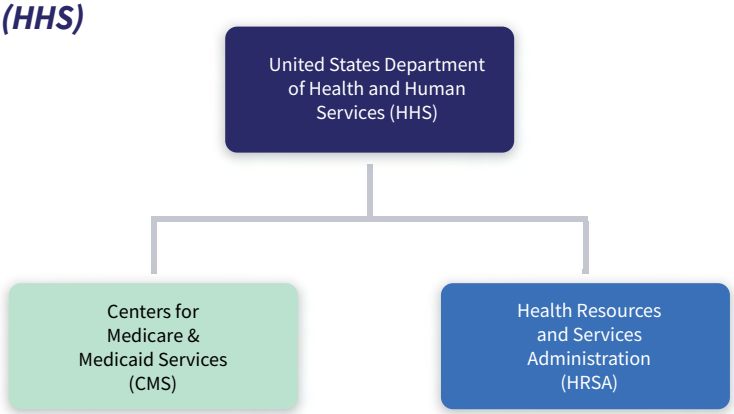
Table 1. Roles of the Federal and State Government in Medicaid

	Federal Government	State Government
Administration	Oversees state programs, provides guidance and parameters for state Medicaid programs	Direct administration and implementation of Medicaid program
Financing	Federal Medicaid Assistance Percentage (FMAP)-federal share of costs	State share of costs
	Guaranteed federal funding with no cap	Limits on source of state funds16
Program Rules and Regulations	Federal statute establishes minimum standards on eligibility, benefits, and access	Establishes optional eligibility for groups Determines which optional benefits/services are included in the Medicaid state plan
	Guaranteed enrollment for some groups	System to deliver care (e.g., fee-for-service, managed care)
	Limits on cost sharing for services for children17*	Cost Sharing allowed for certain programs18
	Specific managed care rules	Sets provider rates

**Note: See the Medicaid Benefits Section for more information on cost sharing in Medicaid.*

The Centers for Medicare & Medicaid Services (CMS) administers the Medicaid program at the Federal level. It is housed within the Department of Health and Human Services. In terms of organizational structure, CMS is led by the CMS administrator, who is appointed by the President. CMS approves state plans, amendments and waivers (see Section 4) writes rules for Medicaid and CHIP, and issues guidance to state Medicaid agencies that interprets CMS rule-making and federal legislation.

Image 1. Partial Organizational chart for the United States Department of Health and Human Services (HHS)



[16] Additional information is available at: United States Government Accountability Office. (2020). *Medicaid: CMS Needs More Information on States' Financing and Payment Arrangements to Improve Oversight*. https://www.gao.gov/products/gao-21-98

[17] Please see the following for additional information: Centers for Medicare & Medicaid Services. (n.d.-b). *Cost Sharing*. https://www.medicaid.gov/medicaid/cost-sharing/index.html; and Centers for Medicare & Medicaid Services. (n.d.-g). *Out-of-Pocket Cost Exemptions*. https://www.medicaid.gov/medicaid/cost-sharing/out-pocket-cost-exemptions/index.html

[18] Medicaid and CHIP Payment Access Commission. (n.d.-a). *Cost sharing and premiums*. https://www.macpac.gov/subtopic/cost-sharing-and-premiums/#:~:text=The%20total%20amount%20of%20premiums,family's%20monthly%20or%20quarterly%20income.&text=Up%20to%20%2420%20per%20month,under%20a%20medically%20needy%20pathway

Congress also shapes Medicaid through legislation that amends the Social Security Act. For example, the Affordable Care Act, among other things, created the option for states to expand Medicaid eligibility to nearly all low-income adults under age 65. More recently, the Families First Coronavirus Response Act established an enhanced federal matching rate for states that met specific eligibility and enrollment requirements during the course of the COVID-19 public health emergency.

The roles of the federal legislative and executive branches in Medicaid are summarized in the graphic below.

THE CHILDREN'S HEALTH INSURANCE PROGRAM

Established in 1997 specifically to address uninsurance among children, the Children's Health Insurance Program (CHIP), is a separate public payer in addition to Medicaid. Please see Section 7 of this chapter for more information about CHIP.

Federal Legislative Branch

Congress enacts legislation that authorizes programs.

Examples include:
- Title V of the Social Security Act
- Title XIX of the Social Security Act (Medicaid)
- Title XXI of the Social Security Act (CHIP)

Federal Executive Branch

Legislation gives the **Centers for Medicare and Medicaid Services** the authority to write rules for Medicaid and CHIP that are open for public comment.

Rules cover:
- Program implementation
- Oversight and monitoring
- Reporting outcomes

Federal Executive Branch

Centers for Medicaid and CHIP Services publishes guidance on these rules and regulations.

Guidance covers:
- Letters to state officials
- FAQs
- Information bulletins

The State Medicaid Program

As mentioned above in Table 1, within the parameters set by CMS, states have a great deal of flexibility in the design and implementation of their individual Medicaid programs. The legislative and executive branches of government at the state level impact Medicaid policies in a structure similar to the federal level.

The roles of the state legislative and executive branches in Medicaid are summarized in the graphic below.

State Legislative Branch

State Legislature enacts legislation that can impact the state's Medicaid and CHIP programs.

State Executive Branch

State Medicaid Agency creates the state's Medicaid and CHIP plans in accordance with federal and state legislation and regulations.

State Executive Branch

State Executive Branch uses their authority (given through the state Constitution or statute) to implement the Medicaid and CHIP program through:
- Development of administrative rules
- Collaboration with other state agencies such as Title V and foster care
- Contracting with Medicaid Managed Care Organizations
- Reporting to state government and CMS

State Executive Branch

State Medicaid Agency or Contracted Entity writes and maintains policies and procedures.

These include:
- Manual of operations
- Handbooks for beneficiaries
- Manuals for providers

Public Health Essential Services—Policy Development #4	Locate the organizational chart for your state Medicaid plan (tip: type "[state name] Medicaid organizational chart" in Google or your internet browser	*Link to state Medicaid organizational chart:*
	What do you notice about your state's Medicaid organization?	
	Who on the chart does Title V interact with?	
	Who could Title V interact with?	

BLOCK GRANT TIP:

Consider attaching the organizational charts you find to your state Block Grant Application (see pages 18 and 19 of the MCHB Title V Block Grant Guidance).

2. THE FEDERAL MEDICAL ASSISTANCE PERCENTAGE (FMAP)[19]

Medicaid programs are funded jointly by the state and federal government. The federal government pays states a percentage of Medicaid program expenditures. This percentage is called the Federal Medical Assistance Percentage, or FMAP. The FMAP is a statutory formula that is updated at the federal level each year. The FMAP for a state is calculated based on the state's per capita income. By law, the FMAP for a state cannot be lower than 50%. States with lower per capita income will have a higher FMAP (i.e., receive more funds from the federal government for Medicaid). The FMAP can vary for certain eligibility groups of individuals; for example, the FMAP for Medicaid expansion adults is 90% (the federal government contributes 90% of the cost of their care). The FMAP can also vary for certain services. For example, the FMAP for administrative costs is generally 50%, but the FMAP for building infrastructure (e.g., data systems) can be up to 90%.[20]

What is the FMAP for your state? Tip: You can find a list of FMAP rates here	
How does the FMAP in your state compare to two other states in your HRSA MCHB Region?	
HRSA Region:	
State 1:	
State 2:	

[19] For additional information, see: United States Office of the Assistant Secretary for Planning and Evaluation. (n.d.). *Federal Medical Assistance Percentages or Federal Financial Participation in State Assistance Expenditures (FMAP)*. https://aspe.hhs.gov/federal-medical-assistance-percentages-or-federal-financial-participation-state-assistance

[20] Medicaid and CHIP Payment Access Commission. (n.d.-b). *Matching rates*. https://www.macpac.gov/subtopic/matching-rates/

3. THE STATE MEDICAID PROGRAM

As previously mentioned, states have a large amount of flexibility in the design and implementation of their Medicaid programs.

The Medicaid state plan describes what services are covered for all Medicaid enrollees. Within the state plan, mandated benefits are those required by federal law in a state Medicaid plan—EPSDT is an example of such a benefit (see Chapter 4 for more on the child health benefit in Medicaid). Optional benefits are services that state Medicaid programs can choose to cover, but are not required by federal law.

Section 1902 of the Social Security Act outlines the federal requirements for the state plan. A few important requirements[21] are:

- 1902(a) (10) (B)—Comparability: A Medicaid-covered benefit generally must be provided in the same amount, duration, and scope to all enrollees.
- 1902(a) (23)—Freedom of choice: All beneficiaries must be permitted to choose a health care provider from among any of those participating in Medicaid.
- 1902(a) (1)—Statewideness: Statute dictates that a state Medicaid program cannot exclude enrollees or providers because of where they live or work in the state.

4. HOW DO STATES MAKE CHANGES TO THEIR MEDICAID PROGRAM?

State Medicaid agencies have two primary mechanisms for making changes to their Medicaid programs: state plan amendments (SPAs) and waivers. States design and implement their Medicaid programs under the framework of federal Medicaid laws and regulations; consequently many changes at the state level must be approved by CMS. Table 2. outlines the major characteristics and differences between SPAs and waivers.

Table 2. State Plan Amendments and Waivers

State Plan Amendment	Waiver
Can apply to any part of the state Medicaid plan	Only applies to Medicaid benefits
No cost neutrality requirement	Cost neutrality required
Permanent (does not expire)	Time-limited and must be renewed with CMS regularly
No waiting lists for services allowed	Waiting lists for services are allowed
Changes apply state-wide to all Medicaid beneficiaries	Changes do not need to apply to the entire state or all Medicaid beneficiaries

[21] Social Security Act, 42 U.S.C. § 1902 (1935). https://www.ssa.gov/OP_Home/ssact/title19/1902.htm

State Plan Amendment (SPA)

The state plan for Medicaid is an agreement between the state and the federal government that describes how the state designed and will administer its Medicaid program. The state plan also functions as an assurance that the state will adhere to federal rules and claim federal funds (FMAP) for its program activities. The state plan describes who is eligible for Medicaid coverage, what optional services the state will pay for, and how much providers will be reimbursed.

When a state would like to make a change to its Medicaid program and policies, it will submit a state plan amendment to CMS for review and approval.[22] States must submit a SPA even if the change in the program is permitted by federal laws and rules.

Waivers

Medicaid waivers are state requests to CMS to ask for permission to "waive" certain requirements of the Social Security Act. Requests can be made to waive other federal rules such as statewide availability of services, freedom of choice of providers, and universal access to all benefits.

STATE SPOTLIGHT:

In September 2022, CMS approved Oregon's 2022–2027 1115 Waiver. In addition to maintaining existing provisions, this waiver includes several important new provisions. These include:

- Continuous eligibility for children up to age six
- Continuous two-year eligibility for children and adults age six and older
- Expanding the EPSDT benefit to youth with special health care needs through age 26

These provisions will ensure continuous access to health coverage and care for all young children and for CYSHCN through adolescence and into young adulthood.

Source: https://www.oregon.gov/oha/HSD/Medicaid-Policy/Documents/2022-2027-Waiver-Policy-Summary.pdf?utm_medium=email&utm_source=govdelivery

There are many different types of waivers that states can submit to CMS. Two main types of significance to CYSHCN are 1115 demonstration waivers and 1915(c) Home-and Community-Based Services waivers.

Section 1115 of the Social Security Act gives the Secretary of Health and Human Services the authority to approve experimental, pilot, or demonstration projects that assist in promoting the objectives of the Medicaid program. In general, section 1115 waivers are approved for five years initially and states can request further five-year authorizations.

Broadly, Home- and Community-Based Services waivers are used to provide services to disabled individuals outside of an institution. States have implemented HCBS waivers that allow a family's income to be disregarded when considering a child's eligibility for Medicaid coverage and access to additional services. The topic of HCBS waivers is covered in detail in Chapter 5.

[22] To access state plan amendments since 2000, see: Centers for Medicare & Medicaid Services. (n.d.-f). *Medicaid State Plan Amendments*. https://www.medicaid.gov/medicaid/medicaid-state-plan-amendments/index.html

5. PATHWAYS TO MEDICAID COVERAGE

Children and youth with special health care needs may be eligible for Medicaid coverage via several different pathways.

• *Path one: By Income, not health status*

States establish income eligibility criteria either as a dollar threshold or as a percentage of the Federal Poverty Level (FPL). States have flexibility in establishing income-based eligibility, as long as it is not lower than the Federal limit of 138% FPL. The Federal Poverty Level (FPL) is updated every year and it is adjusted to account for inflation.

FOCUS ON EQUITY:

A 2020 Urban Institute report (Urban) stated that after more than 10 years of decline, the rate of uninsurance among children stalled and then started to increase. The authors reported that in 2018, the share of uninsured children eligible for public insurance but not enrolled was over 57%. Are the Medicaid outreach and enrollment efforts in your state equitable? How could they be more equitable?

BLOCK GRANT TIP:

Consider including the information from the table below in the "Overview of the State" section of your state Block Grant Application.

Under federal statute, Title V is required to help Medicaid with outreach and enrollment activities for Medicaid eligible people. Please see Section 8 in this chapter for more information about Title V and Medicaid partnership.

Complete the rows below with the income eligibility level for children under age 21 in your state Medicaid program.

Start at https://www.benefits.gov/categories/Healthcare%20and%20Medical%20Assistance

Filter for your state and select "Medicaid and Medicare" under the Subcategory drop down menu. You will see a list of Federal benefit programs in your state. Select your state's Medicaid program. From there, if available, use the household size drop down to complete the table below. If not, follow the link on the page to the website for your state's Medicaid program to complete the table. Insert the dollar amount followed by the %FPL this dollar amount represents.

	Annual Income (%FPL)
A household of 2	
A household of 4	
A household of 6	

• *Path Two: By Income and Functional Disability*

Individuals who are eligible for Supplemental Security Income (SSI) are eligible for Medicaid in most states.[23] Eligibility for SSI is based on income and meeting the Social Security Administration's definition of disability.[24] In many states where individuals who receive SSI are eligible for Medicaid, the Social Security Administration is permitted to enroll SSI recipients in Medicaid and sends a notice informing recipients that they are enrolled in Medicaid with the SSI award letter. In a few states, Medicaid eligibility is not aligned with eligibility for SSI. These states are known as "209(b) states."[25] This comes from Section 209(b) of the Social Security Amendments of 1972, which allows states to use more restrictive criteria (based on income and assets, disability, or both) than SSI for Medicaid eligibility.[26]

Is your state a 209(b) state? *Tip: You can find out here.*	
If yes, what is the criteria in your state for Medicaid? How is it different from the criteria for SSI?	

States can choose to include individuals with higher incomes, who have high health-related expenses through what are known as "Medicaid Buy-in" programs. The Family Opportunity Act (FOA) established such an option for states related to children with disabilities, and you can read more about it below in the State Option section.

• *Path 3: By Severe Disability (TEFRA state plan option and home- and community-based service waiver programs)*

States may choose to implement programs that allow them to enroll CYSHCN who require an institutional level of care in Medicaid regardless of family income. Each state can establish its own definition,[27] but generally "institutional level of care" means that a child needs a level of care that is typically provided in an institutional setting, such as an intermediate care facility.[28] States implement this pathway to Medicaid through a TEFRA state plan option or Home- and Community-Based Services (HCBS) waivers. See Chapter 5 for more information about this eligibility pathway.

[23] United States Department of Health and Human Services. (n.d.-b). *Supplemental Security Income (SSI) Disability & Medicaid coverage*. https://www.healthcare.gov/people-with-disabilities/ssi-and-medicaid/

[24] United States Department of Health and Human Services. (n.d.-b). *Supplemental Security Income (SSI) Disability & Medicaid coverage*. https://www.healthcare.gov/people-with-disabilities/ssi-and-medicaid/

[25] United States Social Security Administration. (2017). *Program Operations Manual System*. https://secure.ssa.gov/poms.nsf/lnx/0501715010

[26] Centers for Medicare & Medicaid Services. (n.d.-g). *Implementation Guide: Medicaid State Plan Eligibility More Restrictive Requirements than SSI under 1902(f) – 209(b) States*. https://www.medicaid.gov/resources-for-states/downloads/macpro-ig-more-restrictive-requirements-1902f-209bstates.pdf

[27] Catalyst Center. (2015). *Expanding Access to Medicaid Coverage: The TEFRA Option and Children with Disabilities*. https://ciswh.org/wp-content/uploads/2016/02/TEFRA-policy-brief.pdf

[28] Catalyst Center. (2016). *The TEFRA Medicaid State Plan Option and Katie Beckett Waiver for Children – Making it possible to care for children with significant disabilities at home.* https://ciswh.org/wp-content/uploads/2016/07/TEFRA.pdf

• *Path 4: Foster Care*

Children in foster care are eligible for Medicaid regardless of disability status or income level. Notably, these children also meet the HRSA definition of CYSHCN. The ACA (2010) established that children aging out of foster care are eligible for Medicaid in the state where they were in care until age 26.[29]

What are the characteristics of children in foster care in your state?

Tip: Go to the Kids Count Data Center and look at the indicators for your state. Look for the "Out of Home Placement" indicators in the topic "Safety and Risky Behaviors." You may also find data for your state on the website for the state agency responsible for children in foster care. You can find National data on foster care on the Administration for Children and Families website: https://www.acf.hhs.gov/cb/research-data-technology/statistics-research/afcars

Children 0 to 17 in foster care	
Children in foster care by age group	
• Under 1	
• 1 to 5	
• 6 to 10	
• 11 to 15	
• 16 to 20	
Children in foster care by gender	
• Male	
• Female	

Use this space to note other indicators of interest to you.

Anyone in the state has the right to apply for Medicaid or CHIP, and the state Medicaid agency must assess eligibility promptly. If a disability determination is not involved in the application, the state is required to make a decision on the application within 45 days. If a disability determination is involved as part of the application (for example, as when assessing eligibility for an FOA buy-in program), the state is required to complete the determination process within 90 days. All applicants must receive notice in writing of the eligibility decision; all applicants must also be provided the opportunity to appeal the decision if they wish.

[29] Adrienne L. Fernandes-Alcantara, & Evelyne P. Baumrucker. (2018). *Medicaid Coverage for Former Foster Youth up to Age 26*. https://sgp.fas.org/crs/misc/IF11010.pdf

BLOCK GRANT TIP:

Consider including the information from the table below in the Overview of the State and/or the State Action Plan Narrative Overview section of your Block Grant Application.

6. MEDICAID BENEFITS

Federal laws and regulations specify that state Medicaid programs must include certain benefits.[30] One of the most important mandated benefits for CYSHCN is the Early, Periodic Screening, Diagnostic and Treatment (EPSDT) benefit. You can learn more about the EPSDT benefit and its importance for CYSHCN in Chapter 4. State Medicaid programs have a great deal of flexibility regarding other services that they pay for including targeted case management and prescription drugs.

States have the option to charge premiums and to establish cost sharing requirements, including copayments, coinsurance, and deductibles, for Medicaid enrollees. However, certain population groups are exempt from cost sharing, including children under 18, with the exception of children under age 18 who are not covered under a mandatory categorically needy eligibility group or the Family Opportunity Act.[31] Cost sharing is also not allowed for any preventative service provided to children, regardless of their eligibility pathway. States, however, can charge limited premiums for some children enrolled in Medicaid, including medically needy individuals, disabled children eligible under the Family Opportunity Act, and infants with family income at or above 150% FPL.[32]

Locate your state Medicaid plan on the state Medicaid website and review the benefits covered in the state plan. Tip: if your state utilizes managed care within Medicaid, look for the Medicaid fee-for-service plan first. Medicaid Managed Care is the focus on Chapter 3.	*Link to state plan webpage:*
Locate the beneficiary Handbook for your state Medicaid program and review the benefits covered in the program. Note: if your state Medicaid program utilizes managed care models, each Medicaid Managed Care plan will have its own beneficiary/member handbook. Try to first find the beneficiary handbook for the state fee-for-service Medicaid program.	*Link to beneficiary handbook:*

[30] Centers for Medicare & Medicaid Services. (n.d.-e). *Mandatory and Optional Medicaid Benefits*. https://www.medicaid.gov/medicaid/benefits/mandatory-optional-medicaid-benefits/index.html

[31] Centers for Medicare & Medicaid Services. (n.d.-g). *Out-of-Pocket Cost Exemptions*. https://www.medicaid.gov/medicaid/cost-sharing/out-pocket-cost-exemptions/index.html

[32] Centers for Medicare & Medicaid Services. (n.d.-b). *Cost Sharing*. https://www.medicaid.gov/medicaid/cost-sharing/index.html

7. STATE PLAN OPTIONS UNDER MEDICAID

States have a large amount of flexibility in the design and implementation of their Medicaid programs. There are many policies that have been approved at the federal level that are options for states to adopt and include in their Medicaid programs. In order to implement one of these options, a state Medicaid agency writes a State Plan Amendment (SPA) and submits it to CMS for approval. Sometimes, in addition to a SPA, a state will also need to pass legislation in order to fully implement a state plan option. Below are some state plan options that are related to the system of care for CYSHCN.

Medicaid Expansion

The Affordable Care Act of 2010 originally required states to expand Medicaid eligibility to all adults with incomes up to 138% FPL. After this policy was contested in the courts, the policy became optional for states. While the Medicaid expansion policy applies only to adults, research has established a parental "welcome mat" effect in which health coverage among children already eligible for Medicaid or CHIP increases when their parents become eligible as well.[33]

Use this resource from the Kaiser Family Foundation to answer the following questions. https://www.kff.org/medicaid/issue-brief/status-of-state-medicaid-expansion-decisions-interactive-map/

Public Health Essential Services—Policy Development #5	Is your state a Medicaid Expansion state?	
	If not, is there activity in your state towards adopting Medicaid expansion? Describe.	

Family Opportunity Act (FOA)

The FOA was passed as part of the Deficit Reduction Act in 2005. It offers states the opportunity to create a buy-in program to extend Medicaid coverage to children who meet SSI disability criteria, but whose family incomes are too high to be eligible for SSI. Per the legislation, family incomes must still fall below 300% FPL for them to be eligible. Under this state option, state Medicaid programs are allowed to charge premiums to families whose children with disabilities are enrolled in Medicaid through the FOA.

A buy-in program allows both uninsured and underinsured children to be eligible to enroll in Medicaid. Medicaid, especially the EPSDT benefit, can play a crucial role in filling gaps in coverage for CYSHCN covered by commercial insurance. When a child is enrolled in both private coverage and Medicaid, the private insurance is their primary

33 Hudson, J. L., & Moriya, A. S. (2017). Medicaid Expansion For Adults Had Measurable 'Welcome Mat' Effects On Their Children. *Health Affairs*, *39*(9). https://www.healthaffairs.org/doi/10.1377/hlthaff.2017.0347

coverage. Services can be covered under EPSDT after all options under the commercial insurance have been exhausted. Please see the EPSDT chapter for more information on children with a combination of Medicaid and private insurance.

Public Health Essential Services—Policy Development #5 and 6	Does your state have a Medicaid Buy-in Program?	
	Reflection Question:	
	How would the CYSHCN in your state potentially benefit from a FOA buy-in program?	

TEFRA

This state plan option is named for the legislation that contains it, the Tax Equity and Fiscal Responsibility Act (TEFRA) of 1982. As described above in the Pathways to Medicaid section, this state plan option allows state Medicaid programs to extend Medicaid eligibility to children who require an "institutional level of care." Being eligible for Medicaid mean that these individuals can receive care in the home and community (Home- and Community-Based Services) instead of being restricted to living in an institution. Family income is disregarded when determining eligibility for Medicaid via this pathway. Read more about TEFRA in Chapter 5.

Health Homes[34]

The state Health Home option was created in Section 2703 of the Affordable Care Act. Health Homes provide a system of comprehensive care coordination to Medicaid beneficiaries who have chronic conditions. Notably, this state option is not specific to children or CYSHCN. Under Section 2703, a state can limit enrollment in health homes

STATE SPOTLIGHT:

"In December 2016, New York launched a pediatric-centered health home model, the Health Homes Serving Children (HHSC) program, through a SPA under Section 2703 of the ACA. The HHSC program is a component of the broader New York State Health Home Program, which provides statewide comprehensive care coordination and case management for Medicaid-enrolled individuals. Eligible individuals have two or more chronic conditions or one single qualifying chronic condition and are assessed by providers as being appropriate for the intense level of care provided by a health home. As of October 2019, approximately 27,000 children and youth were enrolled in the HHSC program."

(Excerpted from Improving Care Coordination for Children with Medical Complexity: Exploring Medicaid Health Home State Options)

[34] For additional information about Health Homes, please see: Centers for Medicare & Medicaid Services. (n.d.-d). *Health Homes*. https://www.medicaid.gov/medicaid/long-term-services-supports/health-homes/index.html and Thompson, V., & Honsberger, K. (2021). Improving Care Coordination for Children with Medical Complexity: Exploring Medicaid Health Home State Options https://ciswh.org/wp-content/uploads/2021/03/Medicaid-Health-Home-State-Options-Brief.pdf

to certain geographic areas, but they are not allowed to exclude Medicaid beneficiaries by age, delivery system (e.g., fee-for-service or managed care), or dual-eligibility status (Medicaid and Medicare). States are allowed to determine health home provider eligibility, and some states use this discretion to design health homes that specifically serve CYSHCN. Examples include children with medical complexity (CMC) served by pediatric specialists, or children with serious mental illness served by behavioral health providers.

Another Health Home option for states was established by the Advancing Care for Exceptional (ACE) Kids Act in 2019. The ACE Kids Act allows states to develop health homes targeted to children with medical complexity starting October 1, 2022. CMS is in the process of releasing guidance to state Medicaid programs and interested parties about this state option.

Public Health Essential Services—Policy Development #5 and 6	Does your state have a Health Home under Section 2703 of the ACA?	
	Reflection Questions:	
	How would the CYSHCN in your state potentially benefit from such a program?	
	Is your state Medicaid agency planning to pursue a Health Home for children with medical complexity (CMC) through the Section 1945A state option?	
	How would the CMC in your state potentially benefit from such a program?	

Reimbursement for Expanded School-based Health Services[35]

In 1997, CMS implemented what was known as the "Free Care Rule", which limited the ability of education systems to bill Medicaid for student health care services. CMS reversed this policy in 2014, creating an opportunity for state education systems to expand reimbursement for school-based health services provided to Medicaid beneficiaries, including CYSHCN.

Public Health Essential Services—Policy Development #5 and 6	*Use this resource to find information about your state: https://docs.google.com/document/d/1u0j1so-se8ohhyl7AcHaaXlGX5l3s0PN2cuIDejXZQw/edit*	
	Has your state taken action to align its Medicaid policy with the reversal of the "Free Care" policy?	
	Reflection Question:	
	How would the CYSHCN in your state potentially benefit from expanding reimbursement for school based health services?	

8. THE CHILDREN'S HEALTH INSURANCE PROGRAM

This workbook focuses on Medicaid. However, the Children's Health Insurance Program (CHIP) is also an important source of coverage for uninsured children and is referenced periodically within this resource. Like Medicaid, CHIP is jointly financed by federal and state dollars, and is administered by each state. CHIP provides health care coverage to uninsured children up to age 19 whose family income is too high for Medicaid, but less than state-specific income eligibility limits.[36] 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 (FPL). In 2019, the median allowed income for eligibility for separate CHIP programs was 255% FPL.[37]

[35] Catalyst Center. (2022). *The Role of Title V Programs in Increasing Access to School-Based Health Services: Opportunities for Bolstering Medicaid Reimbursement*. https://ciswh.org/wp-content/uploads/2022/04/Free-Care-Rule-Explainer.pdf

[36] Centers for Medicare & Medicaid Services. (n.d.-a). *CHIP Eligibility*. https://www.medicaid.gov/chip/eligibility/index.html

[37] Kaiser Family Foundation. (2022, January 1). *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/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D

Within broad federal guidelines, each state determines the design of its program, eligibility groups, benefit packages, reimbursement rates, and administrative and operating procedures. Federal law allows states to choose from three different program designs for their CHIP programs:[38]

1. Separate CHIP—States design their programs within the statutes of the CHIP program.
2. Medicaid Expansion CHIP (also referred to as CHIP-funded Medicaid)—States cover CHIP-eligible children through their Medicaid program.
3. Combination CHIP—States use elements of the separate CHIP and Medicaid expansion models.

Use the website below to find out what CHIP model your state uses. See the section "State Options for Designing the CHIP Program": https://www.medicaid.gov/chip/state-program-information/index.html	
Using the web page below, indicate the upper income limit for CHIP eligibility in your state. There may be different numbers for different ages if your state uses a CHIP-funded Medicaid model. You can find eligibility data here.	

9. TITLE V AND MEDICAID PARTNERSHIP

Statutory Requirements

Interagency coordination is a statutory requirement for both state Title V and Medicaid programs. This collaboration can take different forms in different states, and is described to varying degrees in each state's interagency agreement (sometimes also known as a Memorandum of Understanding (MOU). Title V's expertise working with CYSHCN and their families as a population and its focus on direct, enabling, and public health services are assets for informing the content of effective interagency agreements. Statutory requirements for collaboration as described by the Maternal and Child Health Bureau include:[39]

- "Medicaid reimburses Title V for services Title V provides to Medicaid-enrolled children (statutorily required: 42 CFR 431.615(c)(3) and (4)).
    - *Example: Check out the Catalyst Center issue brief "Medicaid Reimbursement of Title V Care Coordination Services" (available here: https://ciswh.org/wp-content/uploads/2022/06/CareCoordination-brief-6.27.22.pdf) to learn more. The example from Iowa in particular describes how that state leveraged their EPSDT benefit to reimburse for care coordination services.*

[38] Centers for Medicare & Medicaid Services. (n.d.-b). *CHIP State Program Information*. https://www.medicaid.gov/chip/state-program-information/index.html

[39] Items in this list adapted from: Rosenthal, J., Henderson, M., Dolatshahi, J., Hess, C., Tobias, C., Bachman, S., Comeau, M., Dworetzky, B., & Wilson, K. (2017). *Public Insurance Programs and Children with Special Health Care Needs: A Tutorial on the Basics of Medicaid and the Children's Health Insurance Program (CHIP)*. http://ciswh.org/resources/Medicaid-CHIP-tutorial; and United States Health Resources and Services Administration. (n.d.-a). *Early Periodic Screening, Diagnosis, and Treatment*. Retrieved August 2, 2022, from https://mchb.hrsa.gov/programs-impact/programs/early-periodic-screening-diagnosis-treatment

- Assist with coordination of EPSDT to ensure programs are carried out without duplication of effort. (Section 505 [42 U.S.C. 705] (a)(5)(F)(i) and Section 509 [42 U.S.C. 709] (a)(2))
- Assist in coordination with other federal programs, including supplement food programs, related education programs, and other health and developmental disability programs. (Section 505 [42 U.S.C. 705] (a)(5)(F)(iii))
- Provide, directly or through contracts, outreach, and assistance with applications and enrollment of Medicaid-eligible children and pregnant women. (Section 505 [42 U.S.C. 705] (a)(5)(F)(iv))
- Provide a toll-free number for families seeking information about Title V or Medicaid providers or services. (Section 505 [42 U.S.C. 705] (a)(5)(E))
- Projects designed to increase the participation of obstetricians and pediatricians under Title V or Medicaid. (Section 501 [42 U.S.C. 705] (a)(3)(B))
- Share data collection responsibilities, particularly related to services provided for pregnant women and infants eligible for Medicaid or CHIP. (Section 505 [42 U.S.C. 705] (a)(3)(D))"

STATE SPOTLIGHT:

The Title V program in the District of Columbia collaborates with their Medicaid agency to address disparities in access to EPSDT services. As part of a quality improvement initiative, the two agencies collaborated with DC Public Schools to implement a memorandum of understanding that allows for data sharing to identify Medicaid-enrolled students who have not submitted required health forms and for whom related Medicaid claims have not been filed.* Schools then conduct outreach to families to provide information about preventive services available through Medicaid.

Sources: http://ciswh.org/resources/Medicaid-CHIP-tutorial; and United States Health Resources and Services Administration. (n.d.-a). Early Periodic Screening, Diagnosis, and Treatment. Retrieved August 2, 2022, from https://mchb.hrsa.gov/programs-impact/programs/early-periodic-screening-diagnosis-treatment

As described in the introduction, the 10 Essential Public Health Services are a key framework underpinning this workbook. Complete the table below to assess your state Title V program's level of activity related to the state Medicaid program and level of capacity to collaborate with the state Medicaid agency.

The table below is adapted from State Title V Roles in Health Reforms Including the Affordable Care Act: A Title V State Access to Care Assessment Tool*, A product of the National MCH Workforce Development Center.*

1 – Not applicable 2 – No activity/capacity 3 – Low activity/capacity 4 – Moderate activity/capacity 5 – Strong activity/capacity

Essential Public Health Service	**Current Activity and Capacity**	**Comments**
Assess and monitor population health status, factors that influence health, and community needs and assets	Activity ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 Capacity ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5	
Investigate, diagnose, and address health problems and hazards affecting the population	Activity ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 Capacity ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5	
Communicate effectively to inform and educate people about health, factors that influence it, and how to improve it	Activity ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 Capacity ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5	
Strengthen, support, and mobilize communities and partnerships to improve health	Activity ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 Capacity ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5	
Create, champion, and implement policies, plans, and laws that impact health	Activity ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 Capacity ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5	
Utilize legal and regulatory actions designed to improve and protect the public's health	Activity ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 Capacity ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5	
Assure and effective system that enables equitable access to the individual services and care needed to be healthy	Activity ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 Capacity ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5	
Build and support a diverse and skilled public health workforce	Activity ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 Capacity ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5	
Improve and innovate public health functions through ongoing evaluation, research, and continuous quality improvement	Activity ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 Capacity ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5	
Build and maintain a strong organizational structure for public health	Activity ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 Capacity ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5	

10. RESOURCES

- Catalyst Center. Public Insurance Programs and Children with Special Health Care Needs: A Tutorial on the Basics of Medicaid and the Children's Health Insurance Program (CHIP). https://ciswh.org/resources/Medicaid-CHIP-tutorial
- Title XIX of the Social Security Act—ssa.gov, govinfo.gov (tip: search Title XIX Social Security Act)
- Title 42, Chapter IV, Code of Federal Regulations, https://www.ecfr.gov/current/title-42/chapter-IV; https://www.law.cornell.edu/cfr/text/42/chapter-IV
- The Center for Medicaid and CHIP Services (CMCS) within Centers for Medicare and Medicaid Services (CMS). Agency of the U.S. Department of Health and Human Services (HHS). https://www.medicaid.gov/
- Medicaid and CHIP Payment and Access Commission (MACPAC).
  - Annotated Title XIX and Title XXI
  - Reference Guide to Federal Medicaid Laws and Regulations
- Keeping Medicaid's Promise: Strengthening Access to Services for Children and Youth with Special Health Care Needs (2017, Manatt) https://www.manatt.com/insights/white-papers/2019/keeping-medicaids-promise-strengthening-access-to
- Children's Health Insurance Program. Medicaid.gov. https://www.medicaid.gov/chip/index.html
- National Academy of State Health Policy (NASHP). State CHIP Fact Sheets. https://www.nashp.org/all-states-chip-fact-sheets/

03

Medicaid Managed Care

03

Person completing this chapter: _____

Role _____

Date: _____

Additional Individuals and Affiliations Completing this Chapter: _____

_____

_____

CHAPTER CONTENTS

WHO IS THIS CHAPTER FOR?

- The primary audience for this chapter is state Title V program leaders and staff.
- If applicable, we encourage you to collaborate with colleagues in other departments within Title V or other state agencies who may play a larger role in Medicaid Managed Care in your state.

WHY IT MATTERS:

- Most states have some form of Medicaid managed care (MMC) arrangements. Whether or not specific Medicaid Managed Care Organizations (MCOs) are tailored to them, CYSHCN are enrolled in MMC coverage. Understanding MCOs can help Title V CYSHCN staff be prepared to engage with these entities with an eye toward collaboration to improve the system of services for CYSHCN.
- By collaborating with MCOs, Title V CYSHCN programs can help ensure the needs of CYSHCN are met and help develop innovative practices to improve the system of services, health, and quality of life for CYSHCN and their families.

WHAT YOU WILL LEARN:

- An overview of Medicaid Managed Care (MMC)
- The process of selecting and contracting with Medicaid managed care organizations
- State requirements related to MMC quality and how to find state reported quality data

1. INTRODUCTION

Medicaid managed care is a common mechanism for financing health care services for CYSHCN. In fact, 47 states use some form of Medicaid managed care (MMC) to serve children and youth with special health care needs (CYSHCN).[40]

Managed care is a health care delivery system organized to manage cost, utilization, and quality. Medicaid managed care (MMC) programs deliver physical and behavioral health benefits along with additional services through contractual arrangements between state Medicaid programs and managed care organizations (MCOs) through a set per member per month (PMPM) payment for services.[41] The structure of state Medicaid managed care models varies by state.

When state Medicaid programs design their managed care delivery systems, they must determine which Medicaid beneficiaries will be enrolled in managed care. In the past, many states exempted CYSHCN from enrollment in MMC because of the complex health needs and number of specialized services often required by CYSHCN. More

[40] Honsberger, K., & VanLandeghem, K. (2017). *State Medicaid Managed Care Enrollment and Design for Children and Youth with Special Health Care Needs: A 50 State Review of Medicaid Managed Care Contracts*. https://www.nashp.org/wp-content/uploads/2017/09/50-State-Scan-Issue-Brief.pdf

[41] Ibid.

recently, however, state Medicaid agencies have begun enrolling CYSHCN into MMC with the aims of enhancing care coordination, controlling health care costs, and improving health care quality and outcomes.[42]

Title V and Medicaid often refer to CYSHCN differently. In state Medicaid agencies, for example, children and youth in certain Medicaid eligibility groups are considered CYSHCN. These groups may include those eligible for the Medicaid Aged, Blind, and Disabled (ABD) aid category, those receiving Supplemental Security Income (SSI), those who are in foster care or receiving adoption assistance, indigenous youth, and children enrolled in Home- and Community-based Service 1915(c) waiver programs. Some state Medicaid programs have also designed and implemented MMC programs to exclusively serve specific populations of CYSHCN. For example, nine states have specialized MMC programs for children and youth in foster care, six have MMC programs for children and youth eligible through the ABD Medicaid aid category, and five states have MMC programs for children and youth enrolled in 1915(c) waiver programs. (For additional information about definitions of CYSHCN, check out the Catalyst Center brief 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.)

State Medicaid agencies can make programmatic decisions within their MMC programs to ensure that CYSHCN receive high-quality support. Twenty-nine states include a definition of CYSHCN in their MMC contracts to support identification of CYSHCN and determine eligibility for specific services and supports, such as enhanced assessment and care coordination.[43] Thirty-seven states also include specific MMC contract language regarding quality measures for services provided to CYSHCN.[44]

As with each chapter in this tool, it is not necessary to complete every single question for the tool be useful to you.

If you would like support, the Catalyst Center is here to help. Reach out to us at cyshcn@bu.edu.

2. MEDICAID MANAGED CARE IN YOUR STATE

RESOURCES

To find information in this section, try the following resources:

- Review your state's profile on the Commonwealth Fund's Medicaid Managed Care Database, https://www.commonwealthfund.org/medicaid-managed-care-database#/
- Visit your state's Medicaid agency website and use the site map to navigate to pages that may focus specifically on managed care
- Find information on Medicaid Managed Care for CYSHCN using this NASHP resource, National Academy for State Health Policy. 2020. State Medicaid Managed Care Program Design for Children and Youth with Special Health Care Needs. https://www.nashp.org/state-medicaid-managed-care-program-design-for-children-and-youth-with-special-health-care-needs/
- The Centers for Medicare and Medicaid Services (CMS) publishes reports on Medicaid Managed Care enrollment, https://www.medicaid.gov/medicaid/managed-care/enrollment-report/index.html
- If you get stuck, reach out to the Catalyst Center at cyshcn@bu.edu

[42] Ibid.

[43] Randi, O., & Honsberger, K. (2020). *States Are Increasing Their Use of Medicaid Managed Care for Children and Youth with Special Health Care Needs*. https://www.nashp.org/states-are-increasing-their-use-of-medicaid-managed-care-for-children-and-youth-with-special-health-care-needs/.

[44] Ibid.

Essential Public Health Service #4 & #10

What are the Medicaid Managed Care Organizations (MCO) in your state that serve children, including CYSHCN?

The first row in the table below shows an example of how to complete it.

- *Population Served* refers to whether the MCO serves all children, including CYSHCN, or a specific population of children (e.g., children in foster care)
- *Specific Services* refers to whether the MCO covers specific types of services only (e.g., dental or behavioral health)
- *Geographic Area* refers to the part of the state that the MCO covers (e.g., statewide, specific counties, etc.)
- The Kaiser Family Foundation's State Health Facts page, especially the Medicaid Managed Care Market Tracker, may be a place to start (keep in mind that MCO contracts may have been updated since the date the resource was last revised: https://www.kff.org/state-category/medicaid-chip/

MCO Name	Population Served	Specific Services (if any)	Geographic Area
Kids R Us	*children in foster care*	*N/A*	*State-wide*

State MCO contracts vary in length. For each of the MCOs you listed above, record the start and end of the contract.

TIP: This information will be helpful for the section below on the MMC Procurement Process.

MCO Name	Start of Contract	End of Contract

Who are the MCO staff that the state CYSCHN program has relationships with? What is their contact information?

MCO Name	Staff Name	Job Title	Contact Information	Brief Role Description

For each of the individuals above, assess the relationship with Title V using the scale below:

Staff name:

Relationship:

I just looked up their name today

I can contact this person any time and they will help me

I have a defined collaborative working relationship with this contact

For each contact, consider where you might want the relationship to be, and how you could move it along the continuum above.

3. THE MEDICAID MANAGED CARE PROCUREMENT PROCESS

BLOCK GRANT TIP:

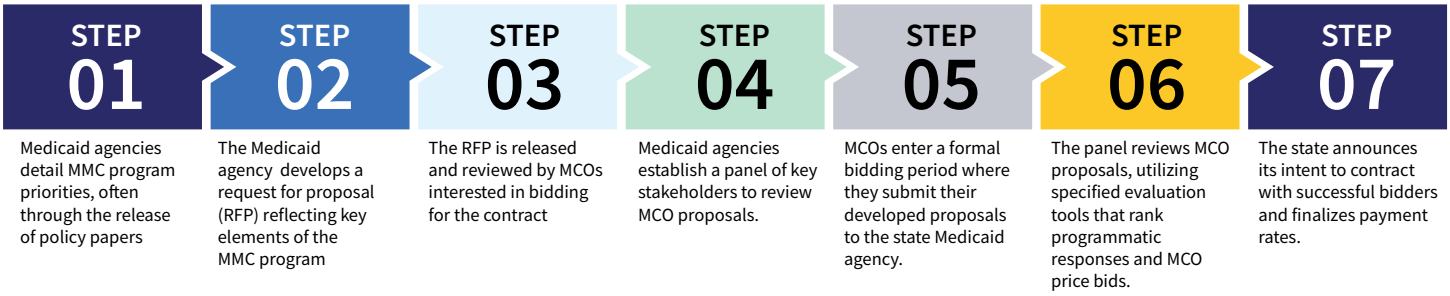
Incorporate information from this section into the Overview of the State in your Block Grant Application/Annual Report.

The MMC procurement process is the process by which state Medicaid agencies solicit bids from one or more Medicaid Managed Care Organizations (MCO), and then contract with the ones that meet their requirements to provide services to Medicaid beneficiaries in the state.

The following are the essential steps to the MMC program procurement process. It is important to note that at certain stages of the process, a state Medicaid agency will be required to enter into a "quiet period" during which external discussion of the MMC program procurement can be prohibited. As mentioned above, state contracts with MCOs vary in length. States also have specific laws and regulations for procurement timelines. Minnesota, for example, requires MCO re-procurement to occur every five years.[45]

Engagement in the MMC procurement process can be an important way for Title V to contribute their subject matter expertise to the design of a MMC program, support the alignment of Title V and Medicaid mutual goals and priorities, and improve the system of services for CYSHCN.[46]

Title V has opportunities at various stages of the MMC procurement process to collaborate with Medicaid colleagues. The examples below illustrate these opportunities.



Step 1: Medicaid agencies detail MMC program priorities, often through the release of policy papers.

- North Carolina issued a series of policy papers highlighting the state's goals and strategies for advancing primary care as it transitions to a MMC model.[47] The state's paper on their behavioral health and intellectual/developmental disability-tailored MMC program focuses on care coordination, family-centered care, and approaches to delivering whole-person care to children with complex health conditions.[48] Louisiana published a white paper on the vision for its MMC program with a focus on care coordination, health equity, and delivery system reform.[49] Policy papers can be valuable resources to learn more about and establish MMC program priorities.

[45] Marquardt, J., & Weiner, P. (2019). *Managed Care Procurement and Contracting*. Minnesota Department of Human Services. https://www.senate.mn/committees/2019-2020/3095_Committee_on_Health_and_Human_Services_Finance_and_Policy/DHS%20Managed%20Care%20Procurement.pdf

[46] Steps in the procurement process adapted from: Girmash, E., & Creveling, E. (2021). *Strengthening Title V - Medicaid Managed Care Collaborations to Improve Care for CYSHCN*. https://ciswh.org/wp-content/uploads/2021/09/MMC-mini-brief-final.pdf

[47] North Carolina Department of Health and Human Services. (n.d.). *Policy Papers*. https://www.ncdhhs.gov/divisions/aging-and-adult-services/nc-emergency-solutions-grant/policy-papers.

[48] North Carolina Department of Health and Human Services. (2019). *North Carolina's Care Management Strategy for Behavioral Health and Intellectual/Developmental Disability Tailored Plans*. https://files.nc.gov/ncdhhs/TailoredPlan-CareManagement-PolicyPaper-FINAL-20180529.pdf.

[49] Louisiana Medicaid Bureau of Health Services Financing. (2018). *Paving the Way to a Healthier Louisiana: Advancing Medicaid Managed Care*. https://ldh.la.gov/assets/HealthyLa/LDH_MCO_RFP_WP.pdf.

Step 2: The state develops a request for proposals reflecting key elements of the MMC program.

- Ohio recently released an RFP for their MMC program that focused on access to telehealth services for members as a part of a population health approach to center the needs of families and remove barriers to care.50 A recent Minnesota RFP asked potential MCOs to detail strategies for connecting families to social supports as well as efforts to address structural racism within systems and processes.[51]
- Texas uses workgroups comprised of subject matter experts to develop the priorities and details of RFPs, including service coordination, continuity of care, behavioral health services, and quality measurement.[52] In 2019, Michigan's Title V CYSHCN program joined the state Managed Care Plan Division.[53] The state's Title V program was involved in the contracting process and included language encouraging MCOs to discuss medical transition with clients transferring from pediatric to adult care in the new managed care program

FOCUS ON EQUITY:

Participating in the Medicaid Managed Care procurement process is an opportunity to advance equity in your state by:

- Engaging interested parties to ensure that managed care organizations will meet their needs
- Elevating the population-specific needs of CYSHCN in the design of managed care programs, including the needs of children in foster care
- Naming the role of ableism in impacting health outcomes
- Emphasizing network adequacy for rural populations

Step 3: The RFP is released and reviewed by MCOs interested in bidding for the contract.

Step 4: Medicaid agencies establish a panel of key stakeholders to review MCO proposals.

- During the procurement process for Virginia's largest MMC program called Medallion 4.0, the Medicaid agency invited Title V representatives to participate in the procurement review panel that selected the participating MCOs.[54]

Step 5: MCOs enter a formal bidding period where they submit their developed proposals to the state Medicaid agency for review.

Step 6: The panel reviews the submitted MCO proposals using specified evaluation tools that rank the proposals and the MCO price bids.

Step 7: The state announces its intent to contract with successful bidders and finalizes payment rates.

[50] Ohio Medicaid Managed Care. (2021, June). *Managed Care Procurement*. https://managedcare.medicaid.ohio.gov/wps/portal/gov/manc/managed-care/managed-care-procurement/managed-care-procurement

[51] Bailit Health. (2021). *Medicaid Managed Care Contract Language: Health Disparities and Health Equity*. https://www.shvs.org/wp-content/uploads/2021/02/SHVS-MCO-Contract-Language-Healthy-Equity-and-Disparities_February-2021.pdf.

[52] Mercer Health & Benefits LLC. (2019). *Medicaid Managed Care Procurements Assessment*. https://cdn.ymaws.com/www.tahp.org/resource/collection/58370A51-FC37-4215-8FDA-6CFD83BBC17D/12-17-19_HHSC_Medicaid_Managed_Care_Procuremen.pdf.

[53] Michigan Department of Health and Human Services. (2020). *Michigan Maternal and Child Health Services Title V Block Grant 2021 Application / 2019 Annual Report*. https://www.michigan.gov/documents/mdhhs/MI_Title_V_Print_Version_FY21_PUBLIC_COMMENT_v.5_693092_7.pdf

[54] Virginia Department of Health. (2019). *Virginia Maternal and Child Health Services Title V Block Grant 2020 Application / 2018 Annual Report*. https://www.vdh.virginia.gov/content/uploads/sites/16/2019/07/FINAL-FY20-FY18-VA_TitleV_PrintVersion_FY20_fbdf0bf5-17d9-44f5-a1e8-d26df865a47c.pdf.

Essential Public Health Service #4 & #7	**Reflection Questions:**	
	What stages of Medicaid Managed Care procurement have staff from your state's Title V program been engaged with to date? • What was the impact of the engagement? • What did you want the impact of the engagement to be? • What lessons did you learn from the experience?	
	What could your state's Title V role be in each of the stages? • Define and articulate Title V role • Describe assets and strengths related to that role • Identify places Title V can influence • Identify strategies or actions you might take to participate in the MMC procurement process	

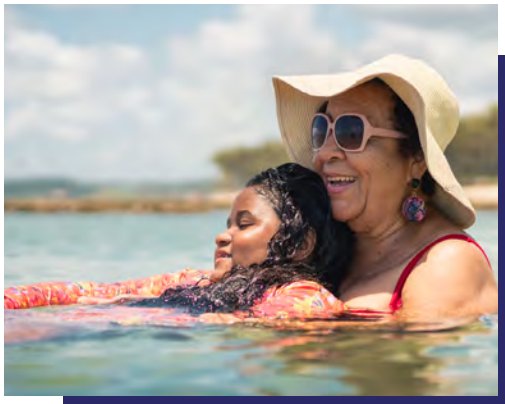
4. MEDICAID MANAGED CARE QUALITY

Quality of care and services is always important, but especially so for Medicaid beneficiaries as state Medicaid programs serve the most vulnerable individuals in the state, especially among children. The Centers for Medicare and Medicaid Services (CMS) currently uses a definition of quality from the National Academy of Medicine, "the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge."[55] States are required by federal regulation 42 CFR § 438.340 to develop and maintain a quality strategy that assesses and improves the quality of Medicaid managed care services.[56] Requirements include the development of a state quality strategy and external quality review (EQR).

55 Centers for Medicare & Medicaid Services. (2021, December 1). *Quality Measurement and Quality Improvement*. https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/MMS/Quality-Measure-and-Quality-Improvement-

56 Managed Care State Quality Strategy, 42 CFR § 438.340 (2016). https://www.law.cornell.edu/cfr/text/42/438.340.

State Quality Strategy



According to 42 CFR 438.340(c) (1) each state is responsible for submitting a copy of its quality strategy to CMS. States must also submit regular reports on the implementation and effectiveness of the quality strategy.

According to the National Health Law Program, the Healthcare Effectiveness Data and Information Set (HEDIS) is the most common set of performance measures in MMC.[57] Many states also incorporate the CMS Medicaid/CHIP Child Core Set measures into their quality strategy. The state quality strategy must include the following at a minimum:

- The state's standards for access to care, structure and operations, and quality measurement and improvement;
- Procedures for regularly monitoring and evaluating plan compliance with state standards;
- National performance measures identified and developed by the Centers for Medicare & Medicaid Services (CMS);
- Arrangements for external independent reviews of quality outcomes and access to services;
- Intermediate sanctions for plans;
- A state information system that supports operation and review of the state's quality strategy
- State-defined network adequacy and availability of services standards for managed care;
- Measurable goals and objectives for continuous quality improvement, taking into account population health status;
- Performance targets, performance measures, quality measures, and performance outcomes that will be measured and reported;
- Performance improvement projects and other interventions proposed to improve access, quality, or timeliness of care;
- Description of the state's care transition policy;
- Description of the state's plan to address health care disparities; and,
- Mechanisms to identify persons who need long-term services and supports or persons with special health care needs (42 CFR 438.340).

States must make the quality strategy available for public comment and obtain input from its medical care advisory committee, beneficiaries, and other stakeholders before submitting the draft strategy to CMS for review. States must also conduct an evaluation of the effectiveness of the quality strategy and update the strategy as needed, but no less than once every three years. The quality strategy must also be made available online to the public.

[57] Machledt, D. (2021). *Finding and Analyzing Medicaid Quality Measures*. https://healthlaw.org/wp-content/uploads/2021/01/NHeLP_AnalyzingCoreMeasures01202021_embeddedlinks.pdf.

You should be able to find your state's Medicaid Quality Strategy through an internet search. Take a moment to search for it now and bookmark the website. If the state quality strategy is open for public comment, consider lending Title V's expertise to comment on the strategy.

External Quality Review

States that utilize MMC must also contract with at least one External Quality Review Organization (EQRO). Under its contract, the EQRO conducts the annual External Quality Review (EQR) and produces an annual EQR report. According to CMS, an External Quality Review is the analysis and evaluation by an external review organization of information on quality, timeliness, and access to health care services that a managed care plan provides to Medicaid beneficiaries.[58]

Required EQR activities are described in 42 CFR 438.358. CMS requires that all states have final EQR reports available to CMS and the public by April 30 of each year.

Explore the EQR report for your state and enter some of your state's data in the table below.

Essential Public Health Service #1 & #7	Data available here: https://www.medicaid.gov/medicaid/quality-of-care/medicaid-managed-care/quality-of-care-external-quality-review/index.html Scroll down to "EQR Annual Reporting" and download the findings from the 2020-2021 reporting cycle. Open the document "EQR_Table_1_EQROs" and find your state.	
	What is the name of the EQRO for your state?	
	Open the document "EQR_Table_3_Measures" Did your state include the following performance measures in the 2020-2021 EQR report? If so, record the data in the corresponding cell below.	
	Childhood Immunization Status	
	Developmental Screening in the first three years of life	
	Leading screening in children	
	Well-child visits in the first 15 months of life	
	Follow-up care for children prescribed ADHD medication	
	Further, explore Table 3 or other table and record two additional items of interest below.	
	Indicator 1:	
	Indicator 2:	

[58] United States Department of Health and Human Services. (n.d.-a). *Quality of Care External Quality Review*. https://www.medicaid.gov/medicaid/quality-of-care/medicaid-managed-care/quality-of-care-external-quality-review/index.html

Essential Public Health Service #4	**Reflection Questions:**	
	What is Title V's current role related to MMC quality and CYSHCN?	
	What would you like Title V's role related to MMC quality and CYSHCN to be?	

5. MEDICAID MANAGED CARE DATA

Medicaid Managed Care organizations collect their own data, and as described above, data is collected and reported as part of the process for ensuring quality under a managed care model.

Essential Public Health Service #4	Reviewing the state Medicaid and/or state MCO websites and any reports you found related to the MCOs that serve CYSHCN in the state, complete the table below.			
	MCO Name	**What quality-related data is reported that has relevance to CYSHCN?**	**Is the data related to CYSHCN available by demographic categories? (e.g., race/ethnicity, age, geography, primary language, etc.)**	**Does Title V and the MCO have a data sharing agreement? If so, what data relevant to CYSCHN does it include?**

Essential Public Health Service #1 & #4	**Reflection Questions:**	
	What data that Title V collects could be shared with MCOs?	
	What data from MCOs would Title V find valuable?	

6. TITLE V ROLE AND MEDICAID MANAGED CARE

As described in the introduction, the 10 Essential Public Health Services are a key framework underpinning this workbook. Complete the table below to assess your state Title V program's level of activity related to Medicaid Managed Care and level of capacity to participate in work related to MMC.

In addition to the examples of Title V collaboration in the MMC Procurement process described in Section 3, state Title V agencies can also:

- Share their expertise in delivering services, including care coordination, to CYSHCN[59]
- Elevate the importance of transition planning as an important service within managed care arrangements and contribute to establishing financing for transition services within managed care[60, 61]
- Partner with MMC to establish quality measures that reflect the needs of CYSHCN[62]
- Elevate examples of MCO contract language that is specifically tailored to support CYSHCN. The Following resources may be especially helpful:
    - Serving Children and Youth with Special Health Care Needs in Medicaid Managed Care: Contract Language and the Contracting Process
- Elevate the *National Standards for CYSHCN* as a resource to inform MMC contracting processes
    - For examples, see How States Use the National Standards for CYSHCN to Strengthen Medicaid Managed Care for Children with Special Health Care Needs

[59] Eichner, H., & Honsberger, K. (2018, July 18). *How State Medicaid and Title V Partnerships Improve Care for Children with Special Health Care Needs in Medicaid Managed Care*. https://www.nashp.org/how-state-medicaid-and-title-v-partnerships-improve-care-for-children-with-special-health-care-needs-in-medicaid-managed-care/

[60] McManus, M., White, P., & Schmidt, A. (n.d.). *A Guide for Designing a Value-Based Payment Initiative for Pediatric-to- Adult Transitional Care*. https://static1.squarespace.com/static/5871c0e9db29d687bc4726f2/t/62a1430da00186530349c9fc/1654735630307/Guide+for+Designing+VBP+Initiative+for+HCT+-+Updated.pdf

[61] Eichner, H., & Honsberger, K. (2018, July 18). *How State Medicaid and Title V Partnerships Improve Care for Children with Special Health Care Needs in Medicaid Managed Care*. https://www.nashp.org/how-state-medicaid-and-title-v-partnerships-improve-care-for-children-with-special-health-care-needs-in-medicaid-managed-care/

[62] Girmash, E., & Creveling, E. (2021). *Strengthening Title V - Medicaid Managed Care Collaborations to Improve Care for CYSHCN*. https://ciswh.org/wp-content/uploads/2021/09/MMC-mini-brief-final.pdf

The table below is adapted from State Title V Roles in Health Reforms Including the Affordable Care Act: A Title V State Access to Care Assessment Tool*, A product of the National MCH Workforce Development Center.*

1 – Not applicable 2 – No activity/capacity 3 – Low activity/capacity 4 – Moderate activity/capacity 5 – Strong activity/capacity

Essential Public Health Service	Current Activity and Capacity	Comments
Assess and monitor population health status, factors that influence health, and community needs and assets	Activity ☐1 ☐2 ☐3 ☐4 ☐5 Capacity ☐1 ☐2 ☐3 ☐4 ☐5	
Investigate, diagnose, and address health problems and hazards affecting the population	Activity ☐1 ☐2 ☐3 ☐4 ☐5 Capacity ☐1 ☐2 ☐3 ☐4 ☐5	
Communicate effectively to inform and educate people about health, factors that influence it, and how to improve it	Activity ☐1 ☐2 ☐3 ☐4 ☐5 Capacity ☐1 ☐2 ☐3 ☐4 ☐5	
Strengthen, support, and mobilize communities and partnerships to improve health	Activity ☐1 ☐2 ☐3 ☐4 ☐5 Capacity ☐1 ☐2 ☐3 ☐4 ☐5	
Create, champion, and implement policies, plans, and laws that impact health	Activity ☐1 ☐2 ☐3 ☐4 ☐5 Capacity ☐1 ☐2 ☐3 ☐4 ☐5	
Utilize legal and regulatory actions designed to improve and protect the public's health	Activity ☐1 ☐2 ☐3 ☐4 ☐5 Capacity ☐1 ☐2 ☐3 ☐4 ☐5	
Assure and effective system that enables equitable access to the individual services and care needed to be healthy	Activity ☐1 ☐2 ☐3 ☐4 ☐5 Capacity ☐1 ☐2 ☐3 ☐4 ☐5	
Build and support a diverse and skilled public health workforce	Activity ☐1 ☐2 ☐3 ☐4 ☐5 Capacity ☐1 ☐2 ☐3 ☐4 ☐5	
Improve and innovate public health functions through ongoing evaluation, research, and continuous quality improvement	Activity ☐1 ☐2 ☐3 ☐4 ☐5 Capacity ☐1 ☐2 ☐3 ☐4 ☐5	
Build and maintain a strong organizational structure for public health	Activity ☐1 ☐2 ☐3 ☐4 ☐5 Capacity ☐1 ☐2 ☐3 ☐4 ☐5	

7. RESOURCES

- The Association of Maternal and Child Health Programs & the National Academy for State Health Policy. 2018. Serving Children and Youth with Special Health Care Needs in Medicaid Managed Care: Contract Language and the Contracting Process. https://amchp.org/resources/serving-children-and-youth-with-special-health-care-needs-in-medicaid-managed-care-contract-language-and-the-contracting-process/
- The Commonwealth Fund. Medicaid Managed Care Database. https://www.commonwealthfund.org/medicaid-managed-care-database#/
- Georgetown Center for Children and Families. 2021. Medicaid Learning Lab, Session 6: Medicaid Managed Care. https://ccf.georgetown.edu/2021/02/05/medicaid-learning-lab/
- Georgetown Center for Children and Families. Managed Care Resource Page. https://ccf.georgetown.edu/subtopic/managed-care/
  Kaiser Family Foundation. 2022. 10 Things to Know about Medicaid Managed Care. https://ccf.georgetown.edu/2021/02/05/medicaid-learning-lab/
- Kaiser Family Foundation. Medicaid Managed Care Market Tracker. https://www.kff.org/data-collection/medicaid-managed-care-market-tracker/
- Manatt. 2018. Webinar: Children with Special Healthcare Needs in Medicaid Managed Care. https://www.manatt.com/insights/webinars/nine-part-medicaid-managed-care-webinar-series
- Medicaid and CHIP Access and Payment Commission (MACPAC). Managed Care Topic Page. https://www.macpac.gov/topics/managed-care/
- Medicaid.gov. Managed Care Topic Page. https://www.medicaid.gov/medicaid/managed-care/index.html
- National Academy for State Health Policy. Medicaid Managed Care Resource Center. https://www.nashp.org/noslo-medicaid-managed-care/
- National Academy for State Health Policy. 2020. State Medicaid Managed Care Program Design for Children and Youth with Special Health Care Needs. https://www.nashp.org/state-medicaid-managed-care-program-design-for-children-and-youth-with-special-health-care-needs/
- National Health Law Program. 2021. Addressing Health Equity in Medicaid Managed Care. https://healthlaw.org/resource/addressing-health-equity-in-medicaid-managed-care/
- National Health Law Program. 2020. Medicaid External Quality Review: An Updated Overview. https://healthlaw.org/resource/medicaid-external-quality-review-an-updated-overview/
- Robert Wood Johnson Foundation. 2020. Analyzing Medicaid Managed Care Organizations: State Practices for Contracting with Managed Care Organizations and Oversight of Contractors. Value-Based Payment Reform. https://www.rwjf.org/en/library/research/2020/08/analyzing-medicaid-managed-care-organizations--state-practices-for-contracting-with-managed-care-organizations-and-oversight-of-contractors.html.

04

Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) Benefit

04

Person completing this chapter: _____

Role: _____

Date: _____

Additional Collaborative Partners for this chapter: _____

_____

_____

CHAPTER CONTENTS

WHO THIS CHAPTER IS FOR:

- The primary audience for this chapter is state Title V Children and Youth with Special Health Care Needs (CYSHCN) program leaders and staff.
- If applicable, we encourage you to collaborate with colleagues in other departments within Title V or other state agencies who may play a larger role in EPSDT in your state.
- If you do direct service work with families, you may find Sections 3 & 4 particularly helpful.

WHY THIS CHAPTER MATTERS:

- Medicaid is a significant source of health care coverage for CYSHCN. As described further in Section 2 of this chapter, the EPSDT benefit is a source of robust coverage for all children enrolled in the Medicaid program, ensuring payment for all medically necessary services, even if the services are not covered under the state Medicaid plan. It is especially important to CYSHCN, who by definition use more health care services than children in general.
- State Title V programs are statutorily required to collaborate with Medicaid on EPSDT (see Section 5 for more details on this collaboration).[63] Title V expertise can help ensure equitable implementation of the EPSDT program and ensure CYSHCN are able to utilize this benefit to access needed services.

According to the National Survey of Children's Health 2019–2020 Combined Data Set, among CYSHCN:

- 36.4% have public insurance only (public insurance includes Medicaid and CHIP)
- 51% have private insurance only
- 8.6% have public and private insurance
- 3.9% were uninsured at the time of the survey

WHAT YOU WILL LEARN:

- An overview of the EPSDT benefit, medical necessity, and administrative responsibilities of the EPSDT program
- The process of medical necessity determinations within fee-for-service Medicaid and Medicaid Managed Care
- Opportunities to examine data related to EPSDT
- Opportunities to collaborate with Medicaid on efforts related to the EPSDT benefit

Throughout this tool, we invite you to reflect on and assess Title V's role in supporting implementation of EPSDT, and offer tools to identify potential roles. As with each chapter in this tool, it is not necessary to complete every single question for the tool be useful to you.

If you would like support, the Catalyst Center is here to help. Reach out to us at cyshcn@bu.edu.

63 United States Health Resources and Services Administration. (n.d.-a). *Early Periodic Screening, Diagnosis, and Treatment*. Retrieved August 2, 2022, from https://mchb.hrsa.gov/programs-impact/programs/early-periodic-screening-diagnosis-treatment.

1. INTRODUCTION

The Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit is required for all children and youth enrolled in Medicaid under age 21. This benefit requires Medicaid to cover any service that is deemed "medically necessary" for an enrollee regardless of whether or not it is a service covered by the state plan. 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 children typically do.

FOR YOUR INFORMATION:

Medicaid.gov is a great general resource where you can view your state's State Plan Amendments (SPAs) and waivers.

2. THE DETAILS OF THE EPSDT BENEFIT

This federally mandated benefit ensures that all children younger than 21 years old who are enrolled in Medicaid receive preventive screenings and comprehensive health services in the amount, scope, and duration they need to develop and thrive. The EPSDT benefit requires that Medicaid 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 cover treatment to control, correct, or reduce the identified health problems. The elements of EPSDT are:

E	Early: Assess and identify problems as early as possible
P	Periodic: Check children's health status at regular, periodic, age-appropriate intervals • Each state must develop periodicity schedules, or timeframes in which screenings take place, especially during children's early years, to facilitate timely diagnosis[64] ○ Bright Futures, an initiative led by the American Academy of Pediatrics, have developed recommendations for preventive screenings. The Bright Futures periodicity schedule is available here. • Children are also entitled to medically necessary screenings that fall outside of the state's periodicity schedule (also known as interperiodic screening; e.g. vision testing based on school nurse referral that falls outside the periodicity schedule)[65,66]
S	Screening: Provide physical, mental, developmental, dental, hearing, vision, and other screening tests to detect potential problems. Screening services include:[67] • Unclothed physical examination • Comprehensive health and developmental history (including assessment of both physical and mental health development) • Immunizations recommended by the CDC Advisory Committee on Immunization Practices (ACIP) • Health education and anticipatory guidance
D	Diagnostic: Perform diagnostic tests to follow up (rule out or confirm) when screening identifies a risk or potential problem
T	Treatment: Control, correct, or reduce health problems found

[64] Centers for Medicare & Medicaid Services. (n.d.-c). *Early and Periodic Screening, Diagnostic, and Treatment*. Retrieved August 2, 2022, from https://www.medicaid.gov/medicaid/benefits/early-and-periodic-screening-diagnostic-and-treatment/index.html.

[65] Centers for Medicare & Medicaid Services. (n.d.-h). *What You Need to Know About EPSDT*. Retrieved August 2, 2022, from https://www.medicaid.gov/sites/default/files/2019-12/what-you-need-to-know-about-epsdt.pdf.

[66] Example adapted from Medicaid and CHIP Payment and Access Commission. (n.d.-a). *EPSDT in Medicaid*. Retrieved August 2, 2022, from https://www.macpac.gov/subtopic/epsdt-in-medicaid/

[67] Screening content adapted from: Comeau, M., Chaudry, A., & McCoy, C. (n.d.) *EPSDT 101 – An overview for Louisiana Title* V [Slide Deck]. The Catalyst Center, Boston University.

Medicaid-enrolled children are eligible for the EPSDT benefit regardless of how they qualify for Medicaid (i.e., whether they are eligible through income criteria, disability, or through a waiver program). There is no EPSDT entitlement for children enrolled in separate CHIP programs (unless specified within the CHIP plan language) or State Health Insurance Marketplace plans.[68]

According to the National Survey of Children's Health 2019–2020 Combined Data Set, 8.6% of families report that their child or youth with special health care needs has a combination of private and public health insurance. When a child is enrolled in both private coverage and Medicaid, the private insurance is their primary coverage. Federal regulations require that third parties (payors other than the individual receiving services or Medicaid) are responsible for payment for services provided to a Medicaid beneficiary before the state Medicaid agency pays.[69] Under this "Third Party Liability" policy, states must seek payment from another payor, often a private insurance plan.[70] For preventive pediatric services, however, states must "pay and chase", meaning that they pay for services and then seek reimbursement from a third party.[71] Services can be covered under EPSDT after third party options have been exhausted.

Medical Necessity

The Medicaid state plan describes what services are covered for all Medicaid enrollees. Within the state plan, mandated benefits are those required by federal law in a state Medicaid plan—EPSDT is an example of such a benefit. Optional benefits are services that state Medicaid programs can choose to cover, but are not required by federal law. The EPSDT benefit for children is especially robust because it stipulates that any "medically necessary" service must be covered whether it is included in the state plan or not.[72]

Federal law establishes a broad standard for medical necessity. The operational definition varies by state, but in general, medically necessary services are those that:[73]

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

STATE SPOTLIGHT:

In Vermont, the Title V CYSHCN program developed a system for tracking coverage denials based on family report. They noticed that particular services were repeatedly denied. They reached out to their state's Medicaid staff focused on EPSDT and informed them of this trend. The Medicaid agency affirmed that the services should have been covered under EPSDT and implemented agency change to prevent future denials.

(Source: Interview with Vermont Title V CYSHCN Staff, May 2020)

[68] Medicaid and CHIP Payment and Access Commission. (n.d.-a). *EPSDT in Medicaid*. Retrieved August 2, 2022, from https://www.macpac.gov/subtopic/epsdt-in-medicaid/.

69 Centers for Medicare & Medicaid Services. (n.d.-a). *Coordination of Benefits & Third Party Liability*. Retrieved August 2, 2022, from https://www.medicaid.gov/medicaid/eligibility/coordination-of-benefits-third-party-liability/index.html.

[70] Medicaid and CHIP Payment and Access Commission. (n.d.-b). *Third Party Liability*. Retrieved August 2, 2022, from https://www.macpac.gov/subtopic/third-party-liability/.

[71] Centers for Medicare & Medicaid Services. (2020). *Coordination of Benefits and Third Party Liability (COB/TPL) In Medicaid*. https://www.medicaid.gov/medicaid/eligibility/downloads/cob-tpl-handbook.pdf.

[72] Adapted from: Rosenthal, J., Henderson, M., Dolatshahi, J., Hess, C., Tobias, C., Bachman, S., Comeau, M., Dworetzky, B., & Wilson, K. (2017). *Public Insurance Programs and Children with Special Health Care Needs: A Tutorial on the Basics of Medicaid and the Children's Health Insurance Program (CHIP)*. http://ciswh.org/resources/Medicaid-CHIP-tutorial

[73] National Academy for State Health Policy. (2021, April 23). *State Definitions of Medical Necessity under the Medicaid EPSDT Benefit* . http://www.nashp.org/medical-necessity/.

States have the ability to establish their own criteria for deciding if a service is medically necessary, as long as the definition is not more restrictive than what is written in federal law. States may define medical necessity in their Medicaid manuals, administrative code, or using other mechanisms. In situations where medical necessity determinations are required, they must be assessed on a case-by-case basis.

Use the resource (updated April 2021) below to complete the following table. *https://www.nashp.org/medical-necessity/#:~:text=Medicaid%20provider%20manuals%20in%20the,or%20treat%20a%20medical%20condition.%E2%80%9D*	
Your state definition of medical necessity:	
Where medical necessity is defined in your state (e.g., Medicaid manual, administrative code, code of regulations, etc.):	
Date the definition of medical necessity was last updated in your state:	
Is there a separate definition of medical necessity for children and youth under age 21 in your state?	*If yes, list the definition here.*

Reflection Question:	
How does your state's definition of medical necessity align with how you think of medical necessity? What surprised you about the definition?	

Administrative, Education, and Reporting Requirements

In addition to covering medically necessary health services under the EPSDT benefit, state Medicaid agencies must provide education and enabling services to families of children enrolled in Medicaid. According to federal statute, state Medicaid agencies must:

- Provide information about the EPSDT benefit to families of eligible children within 60 days of an eligibility determination.[74]
- Help families access care by providing services such as transportation, assistance with scheduling appointments, and connections to other supports, particularly services offered by state Women, Infants, and Children (WIC) programs, and Title V.[75]

[74] Medicaid and CHIP Payment and Access Commission. (n.d.-a). *EPSDT in Medicaid*. Retrieved August 2, 2022, from https://www.macpac.gov/subtopic/epsdt-in-medicaid/.

[75] Ibid.

In addition to the above administrative requirements, states must meet specific Medicaid reporting requirements. States report annually on EPSDT data using CMS Form 416. This form captures the "number of children provided child health screening services, [the] number of children referred for corrective treatment, [the] number of children receiving dental services, [and the] state's results in attaining goals set under section 1905(r) of the Social Security Act."[76] In Form 416, states are required to demonstrate that at least 80% of children and youth enrolled in Medicaid participate in well-care services.[77]

Using the downloadable Form 416 data available on Medicaid.gov (direct link below); enter your state's data in the table below.

Public Health Essential Services-Assessment #1	Data available here: https://www.medicaid.gov/medicaid/benefits/early-and-periodic-screening-diagnostic-and-treatment/index.html Scroll down to "Annual EPSDT Reporting Using the Form CMS-416" and select the most recent data download under "Annual Reporting Data Files." Open the document with "StateRpt" in the name, and scroll to the data set for your state.	
	Total Screening Ratio: *The Total Screening Ratio "indicates the extent to which EPSDT eligibles received the number of initial and periodic screening services required by the state's periodicity schedule, prorated by the proportion of the year for which they were EPSDT eligible."*[78]	
	Total Participant Ratio: *The Total Participant Ratio "indicates the extent to which eligibles are receiving any initial and periodic screening services during the year."*[79]	
	Total eligible receiving any preventive dental or oral health service:	
	Total eligible enrolled in managed care:	

[76] Centers for Medicare & Medicaid Services. (n.d.-c). *Early and Periodic Screening, Diagnostic, and Treatment*. Retrieved August 2, 2022, from https://www.medicaid.gov/medicaid/benefits/early-and-periodic-screening-diagnostic-and-treatment/index.html

[77] United States Government Accountability Office. (2019). *Additional CMS Data and Oversight Needed to Help Ensure Children Receive Recommended Screenings*. https://www.gao.gov/assets/gao-19-481.pdf

[78] Centers for Medicare & Medicaid Services. (2019). *Instructions for Completing Form CMS-416: Annual Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) Participation Report*. https://www.medicaid.gov/medicaid/benefits/downloads/cms-416-instructions.pdf

[79] Ibid.

Reflection questions:	
What do you notice about the information in the table above?	
What role does your state Title V agency have related to activities described in the data above (e.g., developmental screening, relationships with managed care entities)?	
What else would you need to know to be able to understand what this data is suggesting? How would you go about getting more information?	
What opportunities can you think of to intervene/address gaps you may see through the data?	
What specific opportunities do you see to support families based on what you have learned?	

Federal statute requires that Title V and Medicaid share data collection responsibilities.[80] Data related to EPSDT can form the basis for collaboration between the two entities to ensure access to quality care for CYSHCN.

FOCUS ON EQUITY:

What does EPSDT data look like in your state? Is it broken down by race/ethnicity? When examining EPSDT data, note any disparities in race and ethnicity, primary language, geography, or other indicators.

[80] United States Health Resources and Services Administration. (n.d.-a). *Early Periodic Screening, Diagnosis, and Treatment*. Retrieved August 2, 2022, from https://mchb.hrsa.gov/programs-impact/programs/early-periodic-screening-diagnosis-treatment.

Public Health Essential Services—Assessment #1, Policy Development #4 and 7	Does your state Title V program have access to data about prior authorization decisions (this may include publicly available data or data accessible through a data sharing agreement)? • Types of data may include: ○ Number of approvals ○ Number of denials ○ Type of services approved or denied ○ Patient demographics attached to decision data (relevant for equity) ○ Other	*If yes, indicate the data sets you have access to.*
	Does your state Title V agency have access to data about prior authorization denials and appeals (this may include publicly available data or data accessible through a data sharing agreement)? • Categories may include: ○ Number of approvals ○ Number of denials ○ Type of services approved or denied ○ Patient demographics attached to decision data (relevant for equity) ○ Other	*If yes, indicate the data you have access to.*
	Are there any state-specific reports that speak to the health, performance, or functioning of the EPSDT system available in your state?	*If yes, link to the report and describe key indicators.*
	Does your state Title V agency have a mechanism for learning from families about services received under EPSDT?	*If yes, briefly describe the mechanism.*

Allowable Limitations

While flat limits or monetary caps on services are not permitted under EPSDT, states may impose "soft caps" to control utilization or maximize cost-effectiveness. These allowable limitations include the following:[81,82]

- In determining medical necessity definitions, states may adopt a definition of medical necessity that imposes tentative limits on services, dependent on case-specific determinations. For example, a state could impose a "soft limit" on the number of allowed annual visits for a specific treatment, but if those services were determined to be medically necessary in an individual child's case, the services would have to be covered.

[81] Medicaid and CHIP Payment and Access Commission. (n.d.-a). EPSDT in Medicaid. Retrieved August 2, 2022, from https://www.macpac.gov/subtopic/epsdt-in-medicaid/

[82] Centers for Medicare & Medicaid Services. (2014). *EPSDT - A Guide for States: Coverage in the Medicaid Benefit for Children and Adolescents*. https://www.hhs.gov/guidance/sites/default/files/hhs-guidance-documents/epsdt_coverage_guide_68.pdf

- States are not required to cover experimental treatments. However, according to guidance from the Department of Health and Human Services, "[such] services and items may, however, be covered at the state's discretion if it is determined that the treatment or item would be effective to address the child's condition."[83]
- A state cannot deny a medically necessary service based only on cost, but it can consider cost as part of the prior authorization process. States can cover services in the most cost-effective manner, as long as the services are equally effective and available.
- Services provided under EPSDT must fall into one of the categories of services listed in Section 1905(a) of the Social Security Act.[84,85] This means that home modifications and respite are excluded under EPSDT, but may be covered under certain home- and community-based waiver programs.
- A state may require prior authorization for certain treatment services, but not for EPSDT screening services. States may not use the prior authorization process to delay care. The following sections examine prior authorization in more detail.

TIPS FOR FINDING THE INFORMATION IN THIS SECTION:

- Suggested internet searches: [State name] Medicaid provider manual; [State name] Medicaid member handbook
- Visit your state's Medicaid agency website and use the site map to navigate to pages that may focus specifically on information for providers, EPSDT, prior authorization, benefits, or medical necessity
- If you get stuck, reach out to the Catalyst Center at cyshcn@bu.edu

3. MEDICAID FEE-FOR-SERVICE: THE MEDICAL NECESSITY DETERMINATION PROCESS AND EPSDT

Prior Authorization is the primary mechanism of applying medical necessity criteria in the EPSDT benefit. Many services do not require prior authorization. For those that do, typically, providers submit letters of medical necessity, and the state Medicaid agency or its designee reviews the request and makes a determination.

Understanding who is involved and how the prior authorization process works contributes to a better understanding of opportunities to conduct data surveillance, potential areas of collaboration with state Medicaid agencies and other partners, and how to support families in navigating this process.

[83] Centers for Medicare & Medicaid Services. (2014). *EPSDT - A Guide for States: Coverage in the Medicaid Benefit for Children and Adolescents*. https://www.hhs.gov/guidance/sites/default/files/hhs-guidance-documents/epsdt_coverage_guide_68.pdf

[84] Social Security Act, 42 U.S.C. § 1905 (1935. Retrieved from https://www.ssa.gov/OP_Home/ssact/title19/1905.htm

[85] Centers for Medicare & Medicaid Services. (2014). *EPSDT - A Guide for States: Coverage in the Medicaid Benefit for Children and Adolescents*. https://www.hhs.gov/guidance/sites/default/files/hhs-guidance-documents/epsdt_coverage_guide_68.pdf

Medicaid fee-for-service describes a payment model where Medicaid reimburses providers for specific services in the amount and duration delivered to Medicaid enrollees. As described below, many states use a managed care model to pay for at least some of the services provided to enrollees. In such models, providers may receive a flat monthly rate to deliver services to patients.

Points of contact

Public Health Essential Services—Policy Development #4, Assurance #10

Who is/are the staff in the state Medicaid program that focus on EPSDT (e.g., EPSDT Coordinator)? What is their contact information?

Staff Name	**Job Title**	**Contact Information**	**Brief Role Description**

For each of the individuals above, assess the relationship with Title V using the scale below:

Staff Name:

Relationship:

I just looked up their name today | I can contact this person any time and they will help me | I have a defined collaborative working relationship with this contact

Staff Name:

Relationship:

I just looked up their name today | I can contact this person any time and they will help me | I have a defined collaborative working relationship with this contact

Staff Name:

Relationship:

I just looked up their name today | I can contact this person any time and they will help me | I have a defined collaborative working relationship with this contact

Reflection question:	
What steps would you need to take to move your relationship with each person further along this continuum?	

BLOCK GRANT TIP:

Consider including information from the section above in the "Overview of the State" and/or "State Action Plan Narrative Overview" section of the Block Grant Application.

Prior authorization process for Medicaid Fee-For-Service under EPSDT

To help understand the process of prior authorization in your state, please answer the questions in the table below using the provider manual you found at the beginning of this section, the member handbook for your state's Medicaid program, or the "2021 Prior Authorization State Law Chart" from the American Medical Association.

Public Health Essential Services—Assurance #7	Locate the provider manual for the state Medicaid program.	*Link to document:*
	Locate the member handbook for the state Medicaid program.	*Link to document:*
	Initiating a Prior Authorization Request	
	What is the role of the health care provider in the prior authorization process?	
	Does the provider or member handbook describe specific services that require prior authorization?	
	What are the criteria for authorization?	
	Does the Medicaid Fee-For-Service program use a third-party vendor for prior authorization? a. If yes, document the name and contact information for the vendor (if available):	
	Decisions about Prior Authorization in the Medicaid Fee-For-Service program	
	What is the timeframe for decisions about prior authorization?	
	Who can the provider or family contact to ask about the status of a decision? *Tip: In some states, the state Medicaid agency operates a provider portal where they can check on the status of prior authorization requests. Check your state Medicaid agency's website for information about their provider portal, if applicable.*	
	How does Medicaid communicate decisions about prior authorization?	
	Appealing Decisions in the Medicaid Fee-For-Service program If a state Medicaid agency or Medicaid Managed Care (MMC) entity denies a prior authorization request, they must provide notice to a child (or child's family) informing them of this decision, explaining the rationale for the decision, and describing options for appealing the decision.[86]	
	What is the timeline for submitting an appeal?	
	What is the timeframe for decisions about appeals?	
	Who can the provider or family contact to ask about the status of an appeal?	
	How does Medicaid communicate decisions about appeals in your state?	

[86] Centers for Medicare & Medicaid Services. (2014). *EPSDT - A Guide for States: Coverage in the Medicaid Benefit for Children and Adolescents*. https://www.hhs.gov/guidance/sites/default/files/hhs-guidance-documents/epsdt_coverage_guide_68.pdf

4. MEDICAID MANAGED CARE (MMC): THE MEDICAL NECESSITY DETERMINATION PROCESS AND EPSDT

BLOCK GRANT TIP:

Use information from this section to inform the "Overview of the State" and "State MCH Capacity to Advance Effective Public Health Systems" sections of the Title V Block Grant/Annual Report.

Health care services for Medicaid enrollees are increasingly overseen by contracts between the state Medicaid program and organizations known as Medicaid managed care organizations (Medicaid MCOs). These organizations are paid under a contract to coordinate, manage, and deliver services to Medicaid enrollees. Children enrolled in Medicaid Managed Care are entitled to the EPSDT benefit. Medicaid Managed Care (MMC) contracts describe what services MCOs are responsible for covering. Medicaid MCOs may provide EPSDT services directly. In other states, the state Medicaid agency may be responsible for services covered under EPSDT that are not included in the MCO contract.

For more details about MMC, please visit Chapter 3 of this tool.

Managed Care Organizations in Your State

What are the Medicaid Managed Care organizations in your state that serve CYSHCN? This may include MCOs that are explicitly designed to serve CYSHCN or MCOs that serve all children or children and adults. Revisit the MCOs you identified in the MMC Chapter of this tool to complete the table below.

Medicaid Managed Care Organization Name	Notes (e.g. coverage group, etc.)

Medical Necessity definitions in Medicaid Managed Care

According to Medicaid regulations, definitions of medical necessity for children may not be more restrictive than the state's definition. State Medicaid agencies can include specific medical necessity language in managed care contracts to ensure that this criterion is met.[87] Locate the provider manual and member handbook for each of the MMC organizations listed above and copy and paste the URL into the corresponding box.

[87] Centers for Medicare & Medicaid Services. (2014). *EPSDT - A Guide for States: Coverage in the Medicaid Benefit for Children and Adolescents*. https://www.hhs.gov/guidance/sites/default/files/hhs-guidance-documents/epsdt_coverage_guide_68.pdf

Medicaid Managed Care Organization Name	Provider manual	Member Handbook

For the MMC organizations you listed above, how do they define medical necessity?

Medicaid Managed Care Program	Definition of Medical Necessity

Reflection Question:	
Are there differences between the definitions identified in Section 4, above, and those outlined for Medicaid Managed Care organizations? If so, describe them here:	

Medicaid Managed Care: The Medical Necessity Determination Process and EPSDT

Similar to Medicaid Fee-For-Service, prior authorization is the primary mechanism of applying medical necessity criteria in the EPSDT benefit for Medicaid Managed Care organizations.

Points of contact

Public Health Essential Services—Policy Development #4, Assurance #10

Who is/are the staff in the MMC organization(s) that focus on EPSDT (e.g., EPSDT Coordinator)? What is their contact information?

MCO Name	Staff Name	Job Title	Contact Information	Brief Role Description

For each of the individuals above, assess the relationship with Title V using the scale below:

Staff Name:

Relationship:

I just looked up their name today | I can contact this person any time and they will help me | I have a defined collaborative working relationship with this contact

Staff Name:

Relationship:

I just looked up their name today | I can contact this person any time and they will help me | I have a defined collaborative working relationship with this contact

Staff Name:

Relationship:

I just looked up their name today | I can contact this person any time and they will help me | I have a defined collaborative working relationship with this contact

Reflection question:	
What steps would you need to take to move your relationship with each person further along this continuum?	

Public Health Essential Services—Assurance #7	Using information that you have collected from the MMC provider manuals, MMC member handbooks, and your contacts at MMC organizations, answer the following questions.		
	What is the role of the health care provider in the prior authorization process?		
	Does the provider or member handbook describe specific services that require prior authorization?		
	What are the criteria for authorization?		
	Does the MMC program use a third party vendor for prior authorization? If so, document it below:		
	MCO Name	**Yes (include name and contact information)**	**No**
	Decisions about Prior Authorization in the MMC program		
	What is the timeframe for decisions about prior authorization?		
	Who can the provider or family contact to ask about the status of a decision?		
	How does Medicaid communicate decisions about prior authorization?		
	Appealing Decisions in the MMC program		
	What is the timeline for submitting an appeal?		
	Who reviews the appeal?		
	What is the timeframe for decisions about appeals?		
	Who can the provider or family contact to ask about the status of an appeal?		
	How does Medicaid communicate decisions about appeals in your state?		

5. TITLE V/MEDICAID PARTNERSHIP AND EPSDT

Statutory Requirements

Interagency coordination is a statutory requirement for both Title V and Medicaid programs. This collaboration can take different forms in different states, and is described in each state's interagency agreement. Title V expertise working with CYSHCN and their families and focus on direct, enabling, and public health services are assets for informing the content of effective interagency agreements. Statutory requirements for collaboration as described by the Maternal and Child Health Bureau include:[88]

- Assist with coordination of EPSDT to ensure programs are carried out without duplication of effort. (Section 505 [42 U.S.C. 705] (a)(5)(F)(i) and Section 509 [42 U.S.C. 709] (a)(2))
- Assist in coordination with other federal programs, including supplement food programs, related education programs, and other health and developmental disability programs. (Section 505 [42 U.S.C. 705] (a)(5)(F)(iii)
- Provide, directly or through contracts, outreach, and assistance with applications and enrollment of Medicaid-eligible children and pregnant women. (Section 505 [42 U.S.C. 705] (a)(5)(F)(iv)
- Share data collection responsibilities, particularly related to services provided for pregnant women and infants eligible for Medicaid or CHIP. (Section 505 [42 U.S.C. 705] (a)(3)(D))"

STATE SPOTLIGHT:

The Virginia Medicaid program has a Memorandum of Agreement (MOA) with their state health department, which manages the Title V program. These two state agencies have a long history of working together to address different aspects of care for CYSHCN. As an example, in an effort to increase the rate of developmental screenings, Medicaid has collaborated with the Title V program to promote Bright Futures (child health guidelines developed by the American Academy of Pediatrics) along with the EPSDT benefit. They are working to update their business-associated agreement with the state health department, which includes a variety of services in addition to the CYSHCN program.

(Excerpted from EPSDT section of the Catalyst Center website)

Opportunities for Partnership

As stated above, state Medicaid agencies are required to ensure that children receive the services that they are entitled to under EPSDT. Evidence suggests that children do not always receive these services.[89, 90] In particular, families face barriers to accessing treatment services including: low provider participation in Medicaid, lack of coordinated support to follow up on specialty referrals, gaps in Medicaid coverage, difficulty scheduling follow up appointments due to limited availability, and challenges posed by the location of specialty providers.[91]

[88] Content in this list adapted from: Rosenthal, J., Henderson, M., Dolatshahi, J., Hess, C., Tobias, C., Bachman, S., Comeau, M., Dworetzky, B., & Wilson, K. (2017). *Public Insurance Programs and Children with Special Health Care Needs: A Tutorial on the Basics of Medicaid and the Children's Health Insurance Program (CHIP)*. http://ciswh.org/resources/Medicaid-CHIP-tutorial; and United States Health Resources and Services Administration. (n.d.-a). *Early Periodic Screening, Diagnosis, and Treatment*. Retrieved August 2, 2022, from https://mchb.hrsa.gov/programs-impact/programs/early-periodic-screening-diagnosis-treatment

[89] United States Government Accountability Office. (2019). *Additional CMS Data and Oversight Needed to Help Ensure Children Receive Recommended Screenings*. https://www.gao.gov/assets/gao-19-481.pdf

[90] Johnson, K. (2010). *Managing the "T" in EPSDT services*. https://www.nashp.org/wp-content/uploads/sites/default/files/ManagingTheTinEPSDT.pdf

[91] Ibid.

Collaborations between Title V and Medicaid around EPSDT can lead to improvements in the system of care for CYSHCN by facilitating access to crucial screening and treatment services. Such opportunities for Title V and Medicaid partnership include:

- Aligning and streamlining data systems to monitor children's insurance status, other needed resources and referrals, and health outcomes.[92]
- Conducting quality assurance/improvement.[93]
- Providing outreach and enrollment activities to make families aware of Medicaid eligibility, screening children for eligibility, or referring them to Medicaid[94]
- Collaborating to identify CYSHCN.[95] Tailoring programs to CYSHCN can help ensure they receive appropriate care. However, doing so first requires identifying them.[96] Title V CYSHCN programs are familiar with the CAHMI screener and have experience implementing eligibility criteria for their own programs that they can bring to a collaborative effort to identify CYSHCN in Medicaid.[97]
    - *Tip: Title V and Medicaid typically use different terms to describe CYSHCN as a population. For more information about defining CYSHCN, please see the issue brief* 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, *available here: https://ciswh.org/resources/the-role-of-state-medicaid-and-title-v-program-definitions-of-cyshcn-in-the-provision-of-services-and-supports/*
- Partnering to create new billing codes to streamline the prior approval process to facilitate access to services and prescriptions[98]
- Conducting parent education regarding the EPSDT benefit through Title V programs such as home visiting programs, newborn screening, and early intervention[99]
    - *Tip: Check out the Catalyst Center's website for additional resources to help inform education and outreach activities. https://ciswh.org/project/the-catalyst-center/*
- Educating and providing information to family leadership organizations such as Family Voices, providers, and other stakeholders to support understanding of medical necessity and the EPSDT benefit. Providers in particular may be unfamiliar with the process of effectively documenting medical necessity for Medicaid prior authorizations.[100] Increasing provider capacity can help ensure that prior authorizations are approved.
    - *Tip: The Catalyst Center and the National Coordinating Center for the Regional Genetics Network hosted a series of webinars about medical necessity in the summer of 2022. These webinars incorporate both the provider and family perspective. Access the webinars here: https://ciswh.org/resources/medical-necessity-webinar-series/*

[92] Rosenthal, J., Henderson, M., Dolatshahi, J., Hess, C., Tobias, C., Bachman, S., Comeau, M., Dworetzky, B., & Wilson, K. (2017). *Public Insurance Programs and Children with Special Health Care Needs: A Tutorial on the Basics of Medicaid and the Children's Health Insurance Program (CHIP)*. http://ciswh.org/resources/Medicaid-CHIP-tutorial

[93] Ibid.

[94] Ibid.

[95] Johnson, K. (2010). *Managing the "T" in EPSDT services*. https://www.nashp.org/wp-content/uploads/sites/default/files/ManagingTheTinEPSDT.pdf

[96] Ibid.

[97] Ibid.

[98] Rosenthal, J., Henderson, M., Dolatshahi, J., Hess, C., Tobias, C., Bachman, S., Comeau, M., Dworetzky, B., & Wilson, K. (2017). *Public Insurance Programs and Children with Special Health Care Needs: A Tutorial on the Basics of Medicaid and the Children's Health Insurance Program (CHIP)*. http://ciswh.org/resources/Medicaid-CHIP-tutorial

[99] Ibid

[100] Johnson, K. (2010). *Managing the "T" in EPSDT services*. https://www.nashp.org/wp-content/uploads/sites/default/files/ManagingTheTinEPSDT.pdf

- Writing medical necessity policy review into Interagency Agreements/Memoranda of Understanding
- Drawing on Title V's expertise developed through relationships with CYSHCN and families to elevate the experiences of Medicaid enrollees. For example, many state Title V programs have done work to promote and implement the medical home model, or have delivered care coordination services.[101] The medical home model positions a provider or practice in the role of monitoring care plans and following up to ensure that families access referral services.[102] Title V CYSCHN programs can share the skills and knowledge developed through this work to inform efforts to ensure Medicaid-enrolled children's access to treatment services.

Public Health Essential Services—Policy Development #6	Review your state Title V/Medicaid interagency agreement. What does it include explicitly about EPSDT? (Interagency agreements available here: https://mchb.tvisdata.hrsa.gov/Home/IAAMOU)	
	List any additional roles and responsibilities of Title V related to EPSDT in your state:	
Public Health Essential Services—Policy Development #3	What is the mechanism in your Title V program for educating families about EPSDT?	

[101] Ibid.

[102] Ibid.

Reflection questions:	
Drawing on what you have learned throughout this chapter, consider the following.	
What are some ideas for opportunities to deepen existing partnerships with Medicaid around EPSDT?	
What are some ideas for opportunities to expand to new areas of focus within your partnership with Medicaid?	
Based on what you have learned from completing this section, describe the Title V role in the system of services for CYSHCN related to EPSDT. Indicate where you fall on this scale: • I have a clearly defined role in relation to EPSDT. • I have a clearly defined role in relation to an aspect of EPSDT. • Some of my work involves collaboration with colleagues whose work focuses on EPSDT. • I do not do work that relates directly to EPSDT. • Not sure	
Describe the Title V role	
What is your team's role in relation to EPSDT?	
What would you like your team's role to be?	
What capacity does your team have to move toward that role?	

As described in the introduction, the 10 Essential Public Health Services are a key framework underpinning this workbook. Complete the table below to assess your state Title V program's level of activity related to the Medicaid EPSDT benefit and level of capacity to participate in work related to ESPDT.

The table below is adapted from State Title V Roles in Health Reforms Including the Affordable Care Act: A Title V State Access to Care Assessment Tool*, a product of the National MCH Workforce Development Center.*

1 – Not applicable 2 – No activity/capacity 3 – Low activity/capacity 4 – Moderate activity/capacity 5 – Strong activity/capacity

Essential Public Health Service	Current Activity and Capacity	Comments
Assess and monitor population health status, factors that influence health, and community needs and assets	Activity ☐1 ☐2 ☐3 ☐4 ☐5 Capacity ☐1 ☐2 ☐3 ☐4 ☐5	
Investigate, diagnose, and address health problems and hazards affecting the population	Activity ☐1 ☐2 ☐3 ☐4 ☐5 Capacity ☐1 ☐2 ☐3 ☐4 ☐5	
Communicate effectively to inform and educate people about health, factors that influence it, and how to improve it	Activity ☐1 ☐2 ☐3 ☐4 ☐5 Capacity ☐1 ☐2 ☐3 ☐4 ☐5	
Strengthen, support, and mobilize communities and partnerships to improve health	Activity ☐1 ☐2 ☐3 ☐4 ☐5 Capacity ☐1 ☐2 ☐3 ☐4 ☐5	
Create, champion, and implement policies, plans, and laws that impact health	Activity ☐1 ☐2 ☐3 ☐4 ☐5 Capacity ☐1 ☐2 ☐3 ☐4 ☐5	
Utilize legal and regulatory actions designed to improve and protect the public's health	Activity ☐1 ☐2 ☐3 ☐4 ☐5 Capacity ☐1 ☐2 ☐3 ☐4 ☐5	
Assure and effective system that enables equitable access to the individual services and care needed to be healthy	Activity ☐1 ☐2 ☐3 ☐4 ☐5 Capacity ☐1 ☐2 ☐3 ☐4 ☐5	
Build and support a diverse and skilled public health workforce	Activity ☐1 ☐2 ☐3 ☐4 ☐5 Capacity ☐1 ☐2 ☐3 ☐4 ☐5	
Improve and innovate public health functions through ongoing evaluation, research, and continuous quality improvement	Activity ☐1 ☐2 ☐3 ☐4 ☐5 Capacity ☐1 ☐2 ☐3 ☐4 ☐5	
Build and maintain a strong organizational structure for public health	Activity ☐1 ☐2 ☐3 ☐4 ☐5 Capacity ☐1 ☐2 ☐3 ☐4 ☐5	

6. RESOURCES

- EPSDT—A Guide for States: Coverage in the Medicaid Benefit for Children and Adolescents—https://www.medicaid.gov/sites/default/files/2019-12/epsdt_coverage_guide.pdf
- A Review of Title V and Title XIX Interagency Agreements—https://www.ncemch.org/IAA/resources/C_State_MCH_Medicaid_Chapter2.pdf
- Managing the "T" in EPSDT Services—https://www.nashp.org/wp-content/uploads/sites/default/files/ManagingTheTinEPSDT.pdf
- Keeping Medicaid's Promise: Strengthening Access to Services for Children and Youth with Special Health Care Needs (2017, Manatt) https://www.manatt.com/insights/white-papers/2019/keeping-medicaids-promise-strengthening-access-to
- Strengthening the Title V-Medicaid Partnership: Strategies to Support the Development of Robust Interagency Agreements between Title V and Medicaid: https://nashp.org/wp-content/uploads/2017/04/Strengthening-the-Title-V-Updated.pdf

05

Pathways to Medicaid Coverage for Children who Require an Institutional Level of Care: TEFRA/Katie Beckett and Home- and Community-Based Services Waivers

05

Person completing this chapter: _____

Role: _____

Date: _____

Additional Collaborative Partners for this chapter: _____

_____

_____

CHAPTER CONTENTS

WHO THIS CHAPTER IS FOR:

- The primary audience for this chapter is state Title V program leaders and staff.
- If applicable, we encourage you to collaborate with colleagues in other departments within Title V or other state agencies who may play a larger role in work related to pathways to Medicaid for CYSHCN who require an institutional level of care.

WHY THIS CHAPTER MATTERS:

- Home- and Community-Based Services Waivers and TEFRA are key ways to access Medicaid coverage for CYSHCN with complex medical needs.
- Receiving services in the home-and community is critical for equity for all children; home- and community-based services allow CYSHCN and their families to participate fully in life.

WHAT YOU WILL LEARN:

- The history of the TEFRA/Katie Beckett state plan option
- Eligibility criteria for state TEFRA programs and the benefits of TEFRA for CYSHCN
- A broad overview of home- and community-based services (HCBS) waivers, their importance for CYSHCN, and opportunities for HCBS under the American Rescue Plan Act.

Throughout this tool, we invite you to reflect on and assess Title V's role in relation to TEFRA and HCBS waivers, and offer tools to identify potential roles. As with each chapter in this tool, it is not necessary to complete every single question for the tool to be useful to you.

If you would like support, the Catalyst Center is here to help. Reach out to us at cyshcn@bu.edu.

1. INTRODUCTION

As described in Chapter 1, CYSHCN may enroll in Medicaid via several pathways. In addition to qualifying based on income, income and disability, and as a child in foster care, CYSHCN may be able to access Medicaid coverage through programs that create additional pathways for children who require an institutional level of care. States may implement such programs using either of the following authorities:

- 1915 Home- and Community-Based Services Waivers
- The TEFRA state plan option (named for The Tax Equity and Fiscal Responsibility Act of 1982 that created this option)

These two options are similar in some ways, but also have substantial differences. See a comparison of the TEFRA state plan option and 1915 Home- and Community-Based Services Waivers in the chart below. This chapter will describe both of these options in greater depth and help you understand the role they play in your state's system of care for CYSHCN.

	HCBS Waivers	TEFRA State Plan Option
Who Qualifies?	Children (and others as defined by age, diagnosis, or other criteria established by the state) who: • Meet their state's definition of requiring 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[1,2]	Children, birth to age 18 who: • Meet their state's definition of requiring 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[103,104]
What authority do states use to offer these programs?	Home- and community-based service waivers: • Allow states to request that certain Medicaid requirements be waived. States can use this to provide additional services not usually covered by Medicaid to help individuals remain in the community • With federal approval, states do not have to comply with certain federal Medicaid rules (i.e., specific Medicaid regulations are "waived" to make an exception) • Services can be provided to specific groups (e.g., based on diagnosis and/or age and/or other criteria) • Waiting lists are allowed[3,4]	State plan option (a.k.a. state plan amendment or SPA. Please see Chapter 2 for more information about SPAs.): • Allows states to change their individualized state plan, which outlines the way their Medicaid program operates. States may use this to add optional services or change eligibility requirements • States must still follow federal Medicaid rules (e.g., a state cannot use a state plan option to cut mandated services)All services in the state plan option must be available to all children who qualify for Medicaid in the state • No waiting lists are allowed[105,106]

2. HISTORY OF THE KATIE BECKETT WAIVER AND TEFRA PROGRAM

"Katie Beckett" is an umbrella term that states sometimes use to refer to both waivers and state plan options that create a pathway to Medicaid for disabled children who require an institutional level of care. Katie Beckett contracted encephalitis, a viral brain infection, when she was just five months old.[107] In the beginning, the Beckett's private insurance covered Katie's medical expenses, but during her extended hospitalization, she became eligible for Supplemental Security Income (SSI), which meant she also became eligible for Medicaid coverage.[108] After nearly three years in the hospital, her condition improved to the point where she was medically able to go home with her parents

[103] Semansky, R. M., & Koyanagi, C. (2004). The TEFRA Medicaid Eligibility Option for Children With Severe Disabilities: A National Study. *The Journal of Behavioral Health Services & Research*, *31*(3), 334–342.

[104] Smith, G., O'Keefe, J., Carpenter, L., Doty, P., Gavin, K., Burwell, B., & Williams, L. (2000). *Understanding Medicaid home and community services: A primer*. https://aspe.hhs.gov/reports/understanding-medicaid-home-community-services-primer-0#noteC1-25

[105] Mahan, D. (2012). *State plan amendments and waivers: How states can change their Medicaid programs*. https://www.sfdph.org/dph/files/CBHSdocs/QM2017/4Families-USA-IssueBrief2012StatePlanAmendmentsWaivers.pdf

[106] Ghandour, R. M., Comeau, M., Tobias, C., Dworetzky, B., Hamershock, R., Honberg, L., Mann, M. Y., & Bachman, S. S. (In press). Assuring adequate health insurance for children with special health care needs: Progress from 2001 to 2009- 2010. Academic Pediatrics, 1-10. https://pubmed.ncbi.nlm.nih.gov/25864809/

[107] Shapiro, J. (2010). *Katie Beckett: Patient turned home-care advocate*. National Public Radio. http://www.npr.org/templates/story/story.php?storyId=131145687.

[108] In 209(b) states, SSI does not confer automatic Medicaid eligibility; people with disabilities must submit a separate application for Medicaid benefits and are generally required to meet stricter income, asset, or disability criteria. The 209(b) states are: CT, HI, IL, MN, MO, NH, ND, OK and VA. Source: United States Social Security Administration. (2017). *Program Operations Manual System*. https://secure.ssa.gov/poms.nsf/lnx/0501715010

but the out-of-pocket cost of her care was too expensive for the Becketts to be able to afford without Medicaid.

In the early 1980s, if a child with disabilities who lived at home needed Medicaid coverage, the family income and assets were considered as part of the eligibility determination process, and the child had to be living in a household with very low income to receive Medicaid benefits. If the same child were institutionalized in a hospital, nursing home, or an intermediate care facility for people with intellectual disabilities for 30 days or more, the parent's income was not counted under Medicaid eligibility requirements.[109] This meant that parents who did not financially qualify for Medicaid but could not afford their child's medical care had to place their child with a disability in an institutional setting in order to pay for their care.[110] The only other ways to qualify for Medicaid were to become impoverished or relinquish custody.[111]

All this changed in 1981 when the federal government created the Katie Beckett waiver which changed the Medicaid rules to make an exception (the rules were "waived", hence the term) that allowed Katie, and children like her, to receive their care at home, while retaining their Medicaid coverage.[112, 113] Iowa, where the Becketts lived, was the first state to offer the Katie Beckett waiver. It provided long-term care services to children with significant disabilities in a less restrictive and more cost-effective way.

As described below, this first waiver paved the way for similar home-and community-based services waivers in other states and the TEFRA state plan option.

A note on terminology:

States may refer to their TEFRA programs as Katie Beckett programs or state plan options.

In this resource, the Catalyst Center uses the term TEFRA to specifically refer to the TEFRA state plan option.

Some states have TEFRA look-alike programs that they have implemented through state statute or other state plan amendment authorities. For more information about look-alike programs, click **here**.

All states currently offer a version of a TEFRA/Katie Beckett program, either through a state plan amendment (SPA) or a similar waiver. See Appendix Table 1 of **this resource** to find out about your state.

[109] Smith, G., O'Keefe, J., Carpenter, L., Doty, P., Gavin, K., Burwell, B., & Williams, L. (2000). *Understanding Medicaid home and community services: A primer*. https://aspe.hhs.gov/reports/understanding-medicaid-home-community-services-primer-0#noteC1-25

[110] Musumeci, M. (2011). Modernizing Medicaid eligibility criteria for children with significant disabilities: Moving from a disabling to an enabling paradigm. American Journal of Law and Medicine, 37(2011):81-127. https://journals.sagepub.com/doi/abs/10.1177/009885881103700103

[111] Semansky, R.M. & Koyanagi, C. (2004). The TEFRA Medicaid eligibility option for children with severe disabilities: A national study. The Journal of Behavioral Health Services and Research, 31(3); 334-342. https://pubmed.ncbi.nlm.nih.gov/15263871/

[112] Musumeci, M. (2011). Modernizing Medicaid eligibility criteria for children with significant disabilities: Moving from a disabling to an enabling paradigm. American Journal of Law and Medicine, 37(2011):81-127. https://journals.sagepub.com/doi/abs/10.1177/009885881103700103

[113] Shapiro, J. (2010). *Katie Beckett: Patient turned home-care advocate*. National Public Radio. http://www.npr.org/templates/ story/story.php?storyId=131145687

3. 1915C HOME- AND COMMUNITY-BASED SERVICES WAIVERS

States may cover specific groups of individuals by requesting a waiver from the Centers for Medicare and Medicaid Services (CMS). The request to CMS asks for permission to "waive" certain requirements of the Social Security Act, such as statewide availability of services, freedom of choice of providers, and universal access to all benefits. For more information about waivers in general, please see Chapter 1.

Since 1983, 1915 (c) waivers have allowed states to provide home- and community-based services (HCBS) to children who otherwise would be eligible for Medicaid only if they resided in an institution.

COST NEUTRALITY AND HCBS WAIVERS

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

Similar to the TEFRA state plan option, Home- and Community-Based Services (HCBS) waivers allow states to disregard family income for children with severe disabilities who are cared for at home but who might otherwise live in institutional settings. Many states operate HCBS waivers for adults and children with developmental disabilities. These waivers sometimes raise the income eligibility level for Medicaid coverage, and, unlike TEFRA, may provide coverage for additional benefits such as family support services, care coordination, specialized equipment, medical supplies, respite care, medical day care, or home or vehicle modifications. Other HCBS waivers that include certain groups of CYSHCN include autism waivers, waivers for children who are medically fragile or technology dependent, and waivers for individuals with traumatic brain injuries. States are allowed to restrict eligibility for HCBS waivers by age, geographic region, and/or diagnosis. In contrast with the TEFRA state plan option, states can limit the number of waiver slots available, which often results in waiting lists.

What HCBS waivers in your state serve children? In the cells below, list the specific waivers, link to your state's website or waiver summary on Medicaid.gov, and describe the eligible population and services included in the waiver program. Finally, describe what families must do to apply for each waiver program.

On this website, filter for 1915(c) waivers and your state name: https://www.medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/index.html

This website includes a summary of waivers that serve children. It is maintained by the Complex Child Magazine, so all information provided should be verified. However, it may be a place to start if you are feeling stuck: https://www.kidswaivers.org/

Reach out to the Catalyst Center at cyshcn@bu.edu for support identifying waivers that serve children in your state.

• Waiver/Program Name ◦ *Link* ◦ *Eligibility criteria (e.g. age, diagnosis, geography)* ◦ *Services provided* ◦ *How to apply*	
• Waiver/Program Name ◦ *Link* ◦ *Eligibility criteria (e.g. age, diagnosis, geography)* ◦ *Services provided* ◦ *How to apply*	
• Waiver/Program Name ◦ *Link* ◦ *Eligibility criteria (e.g. age, diagnosis, geography)* ◦ *Services provided* ◦ *How to apply*	
• Waiver/Program Name ◦ *Link* ◦ *Eligibility criteria (e.g. age, diagnosis, geography)* ◦ *Services provided* ◦ *How to apply*	

Essential Public Health Services #4 & #7	**Reflection Questions:**	
	What challenges around HCBS waivers are you aware of in your state?	
	What opportunities exist to help families with these challenges?	
	What is your state Title V CYSHCN program capacity to partner with Medicaid to share input related to HCBS waivers?	

HCBS and the American Rescue Plan Act

The American Rescue Plan Act (passed in March 2021) gave states the option of receiving extra financial support for providing Home- and Community-Based Services (HCBS) to Medicaid beneficiaries. Specifically, the law provides for a 10-percentage point increase in the state's Federal Medical Assistance Percentage, or FMAP (see Chapter 1 for more on the FMAP). States must use the additional funds they receive under the ARP FMAP increase to expand and enhance HCBS for Medicaid beneficiaries.

RESOURCES:

You can find more information about HCBS and the American Rescue Plan Act in this Catalyst Center Explainer and this scan of state spending plans from the National Academy for State Health Policy (NASHP).

The provision in the ARPA for additional HCBS funding covers approved expenditures from April 1, 2021, to March 31, 2022. States must spend these funds by March 31, 2025. If a state takes advantage of the option for the increased FMAP for HCBS, the state must also meet the following requirements:

1. They must maintain their current spending on HCBS. States cannot use the increased FMAP to supplant or replace state funds for HCBS.
2. The state must use the extra money to support additional HCBS spending. The ARPA specifies that the state must use the money to "enhance, expand, or strengthen" Home- and Community-Based Services for Medicaid beneficiaries.

On May 13, 2021, CMS issued a letter to state Medicaid directors providing guidance on the implementation of this provision, including how to request and use the funds.[114] The May 13 CMS letter describes services that are eligible for the increased FMAP, including home health care, personal care services, self-directed personal care services, case management, school-based services, rehabilitative services, and private duty nursing. The CMS letter also describes activities that states can implement with the additional funds to enhance, expand, and/ or strengthen HCBS. These activities are organized into nine categories: increased access to HCBS, HCBS provider payment rate and benefit enhancements, supplies and equipment, workforce support, support for improving the functional capabilities of persons with disabilities, support for transitions during COVID-19, support for mental health and substance use disorder services, outreach, and access to COVID-19 vaccines.

States must submit state spending plans quarterly to CMS. Those spending plans are available here: https://www.medicaid.gov/medicaid/home-community-based-services/guidance/strengthening-and-investing-home-and-community-based-services-for-medicaid-beneficiaries-american-rescue-plan-act-of-2021-section-9817-spending-plans-and-narratives/index.html	
What activities related to wait lists are included in your state's spending plan?	
What activities related to the HCBS workforce are included in your state's spending plan?	
What activities related to behavioral health services are included in your state's spending plan?	
When was the latest spending plan submitted? What activities has your state implemented funded by the ARPA HCBS FMAP bump?	

[114] Costello, A. (May 13, 2021). Implementation of American Rescue Plan Act of 2021 Section 9817: Additional Support for Medicaid Home and Community-Based Services during the COVID-19 Emergency. United States Department of Health and Human Services, Centers for Medicare and Medicaid Services. https://www.medicaid.gov/federal-policy-guidance/downloads/smd21003.pdf

Reflection Questions:	
What stood out to you about your state's spending plan?	
What priority need do you think exists related to HCBS in your state? Is it addressed in the state's spending plan?	

4. TEFRA PROGRAM

Under the Tax Equity and Fiscal Responsibility Act (TEFRA) of 1982 (PL No. 97-248, Section 134), states may provide Medicaid coverage to children with severe disabilities younger than 19 who require a level of care that could be reasonably provided in a hospital, skilled nursing facility, or an intermediate care facility for individuals with intellectual disabilities (ICF/IID), without using household income as an eligibility criterion.

When a child receives extended care in an institutional setting, Medicaid disregards family income as an eligibility requirement and makes the determination based solely on the child's income. The TEFRA State Plan Option makes it possible to do the same for a family whose child requires care at the level provided in an institution, but who can safely be cared for at home, as long as it is cost neutral to the state to do so.

Because states vary widely in the availability of institutional care for children and in the clinical criteria they use for determining a child's level of care needs, the number of children and youth with disabilities who receive Medicaid benefits under this state option varies widely from state to state. Depending on where a child lives, they may or may not meet that state's institutional level of care criteria.

Adopting a TEFRA state plan option offers four main benefits for CYSHCN:

- TEFRA enables Medicaid to pay for services, which allows children to remain at home and receive care in the community, rather than in an institution.
- TEFRA provides more children with disabilities access to Medicaid's comprehensive Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit (see Chapter 4 for more about EPSDT).
    - Access to Medicaid is important for children with disabilities because of the Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit that federal Medicaid regulations require states to provide. EPSDT requires that Medicaid cover all services that are medically necessary for enrollees under age 21, even if the service is not part of the state's list of mandatory and optional services under the state

plan.[115] Additionally, because there are extremely limited copays, deductibles, or coinsurance associated with Medicaid, TEFRA provides children with disabilities access to more robust benefits at a much lower cost to families than private insurance.

- TEFRA allows families greater employment flexibility.
    - Since family income is disregarded when considering eligibility for state TEFRA programs, families are able to continue working without risk of losing a child's Medicaid benefits because they earn more than the income eligibility limit allows. According to the 2019–2020 National Survey of Children's Health, nearly one-fifth of families raising CYSHCN reported that a family member left a job, took a leave of absence, or cut down on hours worked because of their child's health or health conditions.[116] For some families, these decisions may have been made in order to access Medicaid
- TEFRA may provide wrap-around coverage to supplement private health insurance.
    - About half of CYSHCN have private insurance only;[117] however, even among CYSHCN who are insured, inadequate benefits and high out-of-pocket cost sharing often create financial hardship for families. Many services that children with disabilities need may not be covered by private insurance or may require significant cost sharing (copays, coinsurance, deductibles, etc.).[118] In these cases, the TEFRA option can allow families to use Medicaid as a secondary form of coverage for their child with a disability to help with the costs associated with covered services or to access services that their private insurance does not cover. As noted above, family members can continue to work and use their employer-sponsored insurance coverage for themselves, their children with disabilities, and other family members.

BLOCK GRANT TIP:

Use information from this section to inform the Health Services Infrastructure portion of the "Overview of the State" section of the Block Grant/Annual Report.

[115] Centers for Medicare & Medicaid Services. (n.d.-c). *Early and Periodic Screening, Diagnostic, and Treatment*. Retrieved August 2, 2022, from https://www.medicaid.gov/medicaid/benefits/early-and-periodic-screening-diagnostic-and-treatment/index.html

[116] Child and Adolescent Health Measurement Initiative. 2019-2020 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 from https://www.childhealthdata.org/browse/survey/results?q=8779&r=1&g=921

[117] Ibid.

[118] 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. https://journals.sagepub.com/doi/abs/10.1177/009885881103700103.

Does your state have a TEFRA program (a state plan amendment)?	*Tip: Use the "Medicaid Financial Eligibility for Seniors and People with Disabilities" resource from KFF as a starting point. Appendix Table 1 includes data about whether states have a Katie Beckett program, and whether it is implemented through a waiver or state plan amendment (SPA). If your state includes a check mark and "waiver", we will come back to that later on in this chapter: https://www.kff.org/report-section/medicaid-financial-eligibility-for-seniors-and-people-with-disabilities-findings-from-a-50-state-survey-appendix-tables/*
If yes, include the program name and link to any relevant web pages that provide information about enrollment and eligibility.	*Next, visit your state's Medicaid agency website to learn more. Include the program link here.*
What do families need to do to apply for your state TEFRA program?	*Include instructions that families must follow to enroll a child in the state TEFRA program.*
What are your state's criteria for determining an institutional level of care?	

Public Health Essential Service #1, # 3 & #7	**Reflection Questions:**	
	What role does your state Title V CYSHCN program play in promoting your state's TEFRA program?	
	What is your capacity to promote or provide education to families and others about your state's TEFRA program?	
	What opportunities does your Title V program have to hear about families' experiences with TEFRA?	

5. TITLE V ROLE IN TEFRA AND HCBS

State Title V CYSHCN programs are knowledgeable about the needs of CYSHCN and their families and have relationships with family leader organizations, community-based organizations, and Medicaid, making them well positioned to support access to HCBS and TEFRA programs and provide input on their implementation and evaluation.

Title V roles can include:

- Providing input on new eligibility and enrollment systems to ensure that CYSHCN who are Medicaid eligible under TEFRA are enrolled in Medicaid and therefore have services covered under the EPSDT benefit
- Writing outreach and enrollment activities into the cooperative agreement with the Medicaid program; outreach efforts should address health literacy, culture, and language needs of racially and ethnically diverse families
- Collaborating with state Medicaid agencies to monitor data related to HCBS enrollment and wait lists

FOCUS ON EQUITY:

Ableism and disability prejudice often impact the portion of Medicaid long-term services and supports expenditures that are directed toward HCBS. Title V programs can use their relationships with families to elevate the importance of HBCS in quality of life for CYSHCN.

Source: Friedman, C. & VanPuymBrouk, L. (July 2019). The relationship between disability prejudice and Medicaid home and community-based services spending. *Disability and Health Journal.* https://www.sciencedirect.com/science/article/pii/S1936657419300330

As described in the introduction, the 10 Essential Public Health Services are a key framework underpinning this workbook. Complete the table below to assess your state Title V program's level of activity related to Medicaid Managed Care and level of capacity to participate in work related to MMC.

The table below is adapted from State Title V Roles in Health Reforms Including the Affordable Care Act: A Title V State Access to Care Assessment Tool*, A product of the National MCH Workforce Development Center.*

1 – Not applicable 2 – No activity/capacity 3 – Low activity/capacity 4 – Moderate activity/capacity 5 – Strong activity/capacity

Essential Public Health Service	Current Activity and Capacity	Comments
Assess and monitor population health status, factors that influence health, and community needs and assets	Activity ☐1 ☐2 ☐3 ☐4 ☐5 Capacity ☐1 ☐2 ☐3 ☐4 ☐5	
Investigate, diagnose, and address health problems and hazards affecting the population	Activity ☐1 ☐2 ☐3 ☐4 ☐5 Capacity ☐1 ☐2 ☐3 ☐4 ☐5	
Communicate effectively to inform and educate people about health, factors that influence it, and how to improve it	Activity ☐1 ☐2 ☐3 ☐4 ☐5 Capacity ☐1 ☐2 ☐3 ☐4 ☐5	
Strengthen, support, and mobilize communities and partnerships to improve health	Activity ☐1 ☐2 ☐3 ☐4 ☐5 Capacity ☐1 ☐2 ☐3 ☐4 ☐5	
Create, champion, and implement policies, plans, and laws that impact health	Activity ☐1 ☐2 ☐3 ☐4 ☐5 Capacity ☐1 ☐2 ☐3 ☐4 ☐5	
Utilize legal and regulatory actions designed to improve and protect the public's health	Activity ☐1 ☐2 ☐3 ☐4 ☐5 Capacity ☐1 ☐2 ☐3 ☐4 ☐5	
Assure and effective system that enables equitable access to the individual services and care needed to be healthy	Activity ☐1 ☐2 ☐3 ☐4 ☐5 Capacity ☐1 ☐2 ☐3 ☐4 ☐5	
Build and support a diverse and skilled public health workforce	Activity ☐1 ☐2 ☐3 ☐4 ☐5 Capacity ☐1 ☐2 ☐3 ☐4 ☐5	
Improve and innovate public health functions through ongoing evaluation, research, and continuous quality improvement	Activity ☐1 ☐2 ☐3 ☐4 ☐5 Capacity ☐1 ☐2 ☐3 ☐4 ☐5	
Build and maintain a strong organizational structure for public health	Activity ☐1 ☐2 ☐3 ☐4 ☐5 Capacity ☐1 ☐2 ☐3 ☐4 ☐5	

6. RESOURCES

- Medicaid.gov, State Waivers List—https://www.medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/index.html
- MACPAC, Waivers—https://www.macpac.gov/subtopic/overview/
- Medicaid.gov, Home-and Community-Based Services Quality Measure Set, 2022—https://www.medicaid.gov/federal-policy-guidance/downloads/smd22003.pdf
- Catalyst Center, The American Rescue Plan Act: Opportunities for Improving Home- and Community-Based Services For Children and Youth with Special Health Care Needs, 2021—https://ciswh.org/wp-content/uploads/2021/10/ARP-HCBS-Resource_final.pdf

06

Bringing it all Together: Building a Strategy for Your State

06

Person completing this chapter: _____

Role: _____

Date: _____

Additional Individuals and Affiliations Completing this Chapter: _____

_____

_____

CHAPTER CONTENTS

WHO THIS CHAPTER IS FOR:

- The primary audience for this chapter is state Title V program leaders and staff.
- If applicable, we encourage you to collaborate with colleagues in other departments within Title V or other state agencies who play a role in financing the system of services for CYSHCN.

WHY THIS CHAPTER MATTERS:

- This chapter is intended to bring together what you have learned about coverage and financing from this workbook and how you may apply it to your work in your state. In this chapter, you will begin to design your own roadmap to guide your work to improve coverage and financing of care for CYSHCN.
- In this chapter, consider priority needs and goals through the lens of Medicaid and financing. Consider how you can utilize financing strategies to address the needs of CYSHCN in your state.

WHAT YOU WILL LEARN:

- You will map topics from this workbook onto the priority needs of CYSHCN in your state.
- How to conduct a SWOT analysis
- How to write SMART objectives
- You will practice applying systems thinking when considering your role in financing the system of services for CYSHCN

1. INTRODUCTION

As you have worked through the chapters of this resource, we hope that you have increased your knowledge of financing and the system of services for CYSHCN and have begun to consider ways that you can bring a focus on financing to your public health role, whatever that may be. As a reminder, the purpose of this resource is threefold:

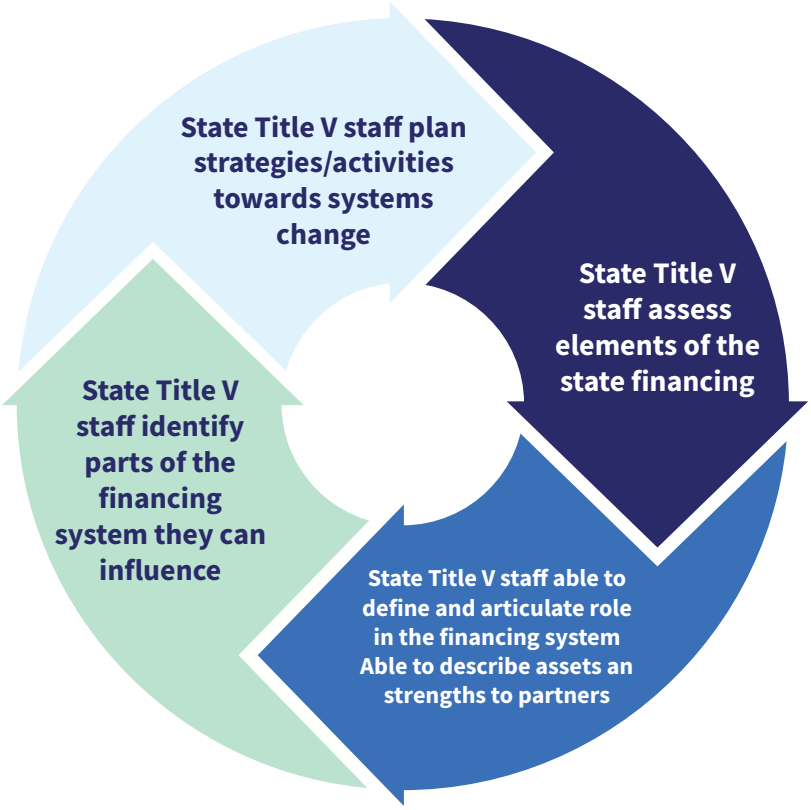
- To increase Title V program staff knowledge about topics related to financing and the system of services for CYSHCN, especially Medicaid.
- To increase Title V staff ability to describe their role in financing and the system of services for CYSHCN.
- To facilitate the identification of strategic priorities for state Title V programs and specific levers and concrete steps to address those priorities

Thinking at a systems level is an important step in creating change that results in improved health outcomes.[119] The role of financing in the system of services for CYSHCN is complex, but throughout this workbook, you have gained a deeper understanding of the roles of Title V and Medicaid in that system. You have assessed elements of your state financing system by identifying key data indicators, naming entities that play a role in the financing landscape, and describing processes and programs. By reflecting on your contributions related to financing, you have practiced articulating your role in financing the system of services for CYSHCN and started to think about what elements of the financing system you may be able to influence.

[119] National MCH Workforce Development Center. (n.d.). *Introduction to Systems Thinking* [Video]. MCH Navitaor. https://www.mchnavigator.org/transformation/systems-integration.php

This chapter offers guidance for how you can identify areas of alignment between your knowledge of the needs of CYSHCN in your state based on your Title V Needs Assessment and what you have learned from this workbook. It also presents opportunities to further practice describing your assets and strengths. After identifying intersections between key topics in your state and financing concepts, you will select a priority focus area and write objectives to assist you in addressing this need.

Figure 1. Purpose of the Workbook



As you develop goals and objectives in this chapter, the activities and questions in this chapter will draw on your responses to the reflection questions and 10 Essential Public Health Services questions in previous chapters.

2. IDENTIFY CYSHCN PRIORITY AREAS IN YOUR STATE

As part of your state Title V Block Grant needs assessment, you have already described many of the strengths and barriers in the system of services for CYSHCN in your state. This section will help you identify opportunities to apply the knowledge, skills, and insights you gained from engaging with this workbook to priority issues for CYSHCN.

For this section, please refer to your state Title V Needs Assessment, specifically the section related to CYSHCN, or other information you may have about the needs of CYSHCN in your state. You may also consider consulting with family partners within your Title V program or colleagues within your state's Family to Family Health Information Center, Family Voices chapter, or community-based organizations. Take the needs that you identify and use them to complete the table below. The needs you list in this section may be "Priority Needs" that you used as the basis for writing State Action Plans, or they may be needs you have not yet done strategic planning around. To inform your thinking, we encourage you to revisit your responses to questions in previous chapters that asked you to reflect on your roles and partnerships.

Example Priority Need

Need identified from needs assessment	**Topic from this workbook** *Check boxes for topics relevant in your state that relate to the need. Revisit your responses to questions throughout previous chapters to remind yourself of ways that your work may intersect with these elements of Medicaid, and include notes about the links between the topics and the priority need.*
Sample Response: Increase access to treatment following a positive developmental screening result	☐ State Plan Amendments *Notes:* ☐ Waivers (including HCBS Waivers) *Notes:* ☐ Medicaid Eligibility *Notes:* ☐ Medicaid Enrollment *Notes:* ☐ TEFRA *Notes:* ☐ Health Homes *Notes:* ☐ Medicaid Managed Care *Notes:* ☑ Medical Necessity/Prior Authorizations *Notes: Title V CYSHCN staff hear feedback from family leaders that prior authorizations for certain services are frequently denied, suggesting an opportunity to provide education to providers and for communication with Medicaid colleagues.* ☑ EPSDT *Notes: Title V CYSHCN staff recently collaborated with the state's EPSDT coordinator, a relationship that could be built on to address treatment access issues*

Go to the next page to fill this out for your own state.

Your Turn: Use the next four pages to examine your state's priority needs

Need identified from needs assessment	**Topic from this workbook** *Check boxes for topics relevant in your state that relate to the need. Revisit your responses to questions throughout previous chapters to remind yourself of ways that your work may intersect with these elements of Medicaid, and include notes about the links between the topics and the priority need.*
Need 1:	☐ State Plan Amendments *Notes:* ☐ Waivers (including HCBS Waivers) *Notes:* ☐ Medicaid Eligibility *Notes:* ☐ Medicaid Enrollment *Notes:* ☐ TEFRA *Notes:* ☐ Health Homes *Notes:* ☐ Medicaid Managed Care *Notes:* ☐ Medical Necessity/Prior Authorizations *Notes:* ☐ EPSDT *Notes:*

Need identified from needs assessment	**Topic from this workbook** *Check boxes for topics relevant in your state that relate to the need. Revisit your responses to questions throughout previous chapters to remind yourself of ways that your work may intersect with these elements of Medicaid, and include notes about the links between the topics and the priority need.*
Need 2:	☐ State Plan Amendments *Notes:* ☐ Waivers (including HCBS Waivers) *Notes:* ☐ Medicaid Eligibility *Notes:* ☐ Medicaid Enrollment *Notes:* ☐ TEFRA *Notes:* ☐ Health Homes *Notes:* ☐ Medicaid Managed Care *Notes:* ☐ Medical Necessity/Prior Authorizations *Notes:* ☐ EPSDT *Notes:*

Need identified from needs assessment	**Topic from this workbook** *Check boxes for topics relevant in your state that relate to the need. Revisit your responses to questions throughout previous chapters to remind yourself of ways that your work may intersect with these elements of Medicaid, and include notes about the links between the topics and the priority need.*
Need 3:	☐ State Plan Amendments *Notes:* ☐ Waivers (including HCBS Waivers) *Notes:* ☐ Medicaid Eligibility *Notes:* ☐ Medicaid Enrollment *Notes:* ☐ TEFRA *Notes:* ☐ Health Homes *Notes:* ☐ Medicaid Managed Care *Notes:* ☐ Medical Necessity/Prior Authorizations *Notes:* ☐ EPSDT *Notes:*

Need identified from needs assessment	**Topic from this workbook** *Check boxes for topics relevant in your state that relate to the need. Revisit your responses to questions throughout previous chapters to remind yourself of ways that your work may intersect with these elements of Medicaid, and include notes about the links between the topics and the priority need.*
Need 4:	☐ State Plan Amendments *Notes:* ☐ Waivers (including HCBS Waivers) *Notes:* ☐ Medicaid Eligibility *Notes:* ☐ Medicaid Enrollment *Notes:* ☐ TEFRA *Notes:* ☐ Health Homes *Notes:* ☐ Medicaid Managed Care *Notes:* ☐ Medical Necessity/Prior Authorizations *Notes:* ☐ EPSDT *Notes:*

Reflection Questions:	
What do you notice about the financing topics that the needs of CYSHCN in your state align with? Are they clustered around a few topics or related to completely different topics?	

3. ASSESS YOUR CAPACITY

Understanding the assets your Title V Program has, what assets you may be able to access by making a change or initiating a relationship, and the challenges your program faces is important for effective strategic planning.

A SWOT analysis is a tool to assess the assets a team can draw on and challenges they may face when pursuing a new strategy or initiative. The acronym SWOT stands for Strengths, Weaknesses, Opportunities, and Threats.

Figure 2. Elements of a SWOT Analysis

STRENGTHS	WEAKNESSES
Internal factors that support or help a project or team accomplish its goals[120] Examples: • Team member skills and knowledge • Agency supports • Effective internal processes	Internal factors that hinder a project or team in accomplishing its goals Examples: • Gaps in knowledge or skills • Inefficient processes • Staff turnover
OPPORTUNITIES	**THREATS**
External factors that facilitate a team's work Examples: • Environmental factors, including the political environment • Cross-sector/agency relationships (including those with community-based organizations)	External factors that hinder a team's work Examples: • Environmental factors, including the political environment • Lack of external partnerships

[120] Definitions adapted from:
- Minnesota Department of Health. (n.d.). *SWOT analysis*. https://www.health.state.mn.us/communities/practice/resources/phqitoolbox/swot.html
- Centers for Disease Control and Prevention. (n.d.). *Do a SWOT analysis*. https://www.cdc.gov/publichealthgateway/phcommunities/resourcekit/evaluate/do-a-swot-analysis.html

Figure 3. Sample SWOT Analysis

Example Need: Increase access to quality care coordination for CYSHCN	
STRENGTHS	**WEAKNESSES**
• *Staff expertise in care coordination best practices* • *Consensus within the division about care coordination as a priority* • *Internal data analysis capacity*	• *Gaps in knowledge of financing for care coordination* • *Lack of existing workflows that facilitate collaboration*
OPPORTUNITIES	**THREATS**
• *Existing partnership with state Family to Family Health Information Center to inform strategic planning and ensure care coordination meets families' needs*	• *Difficulty connecting with MCOs in the state, two of which provide care coordination services to enrolled CYSHCN*

For at least two of the needs listed in the table in Section 1, complete a SWOT analysis. You may choose to consider needs that you are already working on, or ones that you have not yet developed an activity to address.

Seleted Need:	
STRENGTHS	**WEAKNESSES**
OPPORTUNITIES	**THREATS**

Seleted Need:	
STRENGTHS	**WEAKNESSES**
OPPORTUNITIES	**THREATS**

Reflection Questions:	
What strengths, weaknesses, opportunities, or threats surprised you?	
Who are your key partners when doing work to support CYSHCN and their families?	
What common threads did you notice in the weaknesses boxes above? What weaknesses do you have the capacity to work to change?	
Which need do you have the most strengths at hand to address?	
Which need has the largest number of opportunity factors?	
Which needs have the most significant weaknesses and threats?	
Having completed the SWOT analyses and considered the questions above, select a priority for CYSHCN that would be most feasible to focus on and write it in the space to the right.	

4. IDENTIFY A PRIORITY AND WRITE SMART OBJECTIVES

To move from identifying a priority and the tools you have to address it to developing a road map for addressing the need, this section includes a short tutorial on writing goals and objectives that will help you measure progress in addressing your selected priority.

A goal describes the effect you want your program or initiative to have.[121] Objectives are the "stepping stones" that will lead to that effect.[122] When writing objectives, consider what you want to change, for whom, and in what time frame.[123]

There are two types of objectives:

- Process objectives are the "ingredients" of a program.[124] They describe the services, materials, activities, and/or strategies that you will deliver as part of your program, to whom, and over what time period.[125]
- Outcome objectives describe what you'll be making with your "ingredients", that is, the effect you expect from the activities described by your process objectives.[126] Outcome objectives describe "how participants will change as a result of your intervention or services."[127] They can describe change at different ecological levels and changes that will take place across various timeframes.[128]

No matter what type of objective you have identified, it should be SMART. This acronym stands for:

- Specific—the objective describes the "who," "what," "when", and "where."[129]
- Measurable—the objective articulates "how much" change will be achieved.[130] Select items that you have, or will have, the ability to actually measure.[131]
- Achievable—the objective is feasible to accomplish given program resources and other constraints.[132]
- Relevant—the objective will help move you toward the desired effect described in your overall goal.[133]
- Time-Bound—the objective includes a specific date by which you will accomplish it, and can be completed in a time frame that is appropriate to the identified need.[134]

[121] Asian & Pacific Islander American Health Forum. (2011, March 31). *Writing SMART goals and objectives* [Video]. YouTube. https://www.youtube.com/watch?v=MAhs-m6cNzY

[122] Ibid.

[123] Ibid.

[124] Ibid.

[125] Centers for Disease Control & Prevention, Division of STD Prevention (n.d.). *Developing Program Goals and Measurable Objectives*. https://www.cdc.gov/std/program/pupestd/developing%20program%20goals%20and%20objectives.pdf

[126] Ibid.

[127] Asian & Pacific Islander American Health Forum. (2011, March 31). *Writing SMART goals and objectives* [Video]. YouTube. https://www.youtube.com/watch?v=MAhs-m6cNzY

[128] Asian & Pacific Islander American Health Forum. (2011, March 31). *Writing SMART goals and objectives* [Video]. YouTube. https://www.youtube.com/watch?v=MAhs-m6cNzY

[129] Centers for Disease Control & Prevention, Division of STD Prevention (n.d.). *Developing Program Goals and Measurable Objectives*. https://www.cdc.gov/std/program/pupestd/developing%20program%20goals%20and%20objectives.pdf

[130] Ibid.

[131] Asian & Pacific Islander American Health Forum. (2011, March 31). *Writing SMART goals and objectives* [Video]. YouTube. https://www.youtube.com/watch?v=MAhs-m6cNzY

[132] Centers for Disease Control & Prevention, Division of STD Prevention (n.d.). *Developing Program Goals and Measurable Objectives*. https://www.cdc.gov/std/program/pupestd/developing%20program%20goals%20and%20objectives.pdf

[133] Asian & Pacific Islander American Health Forum. (2011, March 31). *Writing SMART goals and objectives* [Video]. YouTube. https://www.youtube.com/watch?v=MAhs-m6cNzY

[134] United States Department of Health and Human Services, Office of Minority Health (2016, November 14). *Using logic models for planning & evaluation*. [Video] YouTube. https://www.youtube.com/watch?v=I4AKaZb3YB8

Use the table below to practice writing SMART objectives related to the topic you identified in the previous section.

Priority you identified in the previous section:	
Consider what would need to change in order to improve that priority need. Write the effect that would be required:	
Next, re-phrase that effect as a SMART goal:	
Let's write a first objective.	
What's something you will do to advance your goal?	
Among whom will you do the activity above?	
When will you do this activity?	
Put it all together. Objective 1:	
Objective 1 is:	☐ Process Objective ☐ Outcome Objective
Now make sure it's SMART.	
Is it specific?	*For your objective, name the* *Who:* *What:* *When:* *Where:*
Is it measurable?	*How much change do you expect to see?* *What data source will you use to measure that change?*
Is it achievable?	*Is this objective feasible? What strengths or resources will you draw on to accomplish this objective?*
Is it relevant?	*Describe how your objective helps you move toward the goal identified above.*
Is it time-bound?	*What's your target end date?*

Time for another one.	
What's something you will do to advance your goal?	
Among whom will you do the activity above?	
When will you do this activity?	
Put it all together. Objective 2:	
Objective 2 is:	☐ Process Objective ☐ Outcome Objective
Now make sure it's SMART.	
Is it specific?	*For your objective, name the* *Who:* *What:* *When:* *Where:*
Is it measurable?	*How much change do you expect to see?* *What data source will you use to measure that change?*
Is it achievable?	*Is this objective feasible? What strengths or resources will you draw on to accomplish this objective?*
Is it relevant?	*Describe how your objective helps you move toward the goal identified above.*
Is it time-bound?	*What's your target end date?*

Keep going! Write at least one more objective that will help move towards your goal.	
What's something you will do to advance your goal?	
Among whom will you do the activity above?	
When will you do this activity?	
Put it all together. Objective 3:	
Objective 3 is:	☐ Process Objective ☐ Outcome Objective
Now make sure it's SMART.	
Is it specific?	*For your objective, name the* *Who:* *What:* *When:* *Where:*
Is it measurable?	*How much change do you expect to see?* *What data source will you use to measure that change?*
Is it achievable?	*Is this objective feasible? What strengths or resources will you draw on to accomplish this objective?*
Is it relevant?	*Describe how your objective helps you move toward the goal identified above.*
Is it time-bound?	*What's your target end date?*

You're on a roll. Just one more.	
What's something you will do to advance your goal?	
Among whom will you do the activity above?	
Where will you do this activity?	
Put it all together. Objective 4:	
Objective 4 is:	☐ Process Objective ☐ Outcome Objective
Now make sure it's SMART.	
Is it specific?	*For your objective, name the* *Who:* *What:* *When:* *Where:*
Is it measurable?	*How much change do you expect to see?* *What data source will you use to measure that change?*
Is it achievable?	*Is this objective feasible? What strengths or resources will you draw on to accomplish this objective?*
Is it relevant?	*Describe how your objective helps you move toward the goal identified above.*
Is it time-bound?	*What's your target end date?*

Two additional dimensions of goals to consider are Inclusivity and Equity (expanding the acronym to SMARTIE goals).[135]	
Inclusivity: When you consider the goals you identified above, whose voices informed your thinking? What interested parties would you want to involve in the process of affirming that this is an important goal and implementing programs to work toward this goal?	
Equity: Consider the goals you identified through the lens of health equity. How would achieving these goals advance health equity for CYSHCN?	
Finally, identify the objective that must be met first. What is the first step you can take toward your first objective?	
By what date will you complete this first activity?	

[135] National Center for Education in Maternal and Child Health. (n.d.). Thinking upstream to plan: "SMARTIE" TA. https://www.mchevidence.org/about/planning.php

BLOCK GRANT TIP:

Consider using the objectives that you have written above to inform your state Action Plan Narrative.

5. NEXT STEPS

Thank you for utilizing The Workbook. Title V plays a vital role in the system of services for CYSHCN. By bringing a focus to financing mechanisms within that system, there is great potential for improving it with the help of Title V's expertise, skills, and relationships.

If you have any questions as you move forward in your strategic planning efforts related to financing, please feel free to reach out to us at the Catalyst Center at cyshcn@bu.edu.