01

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

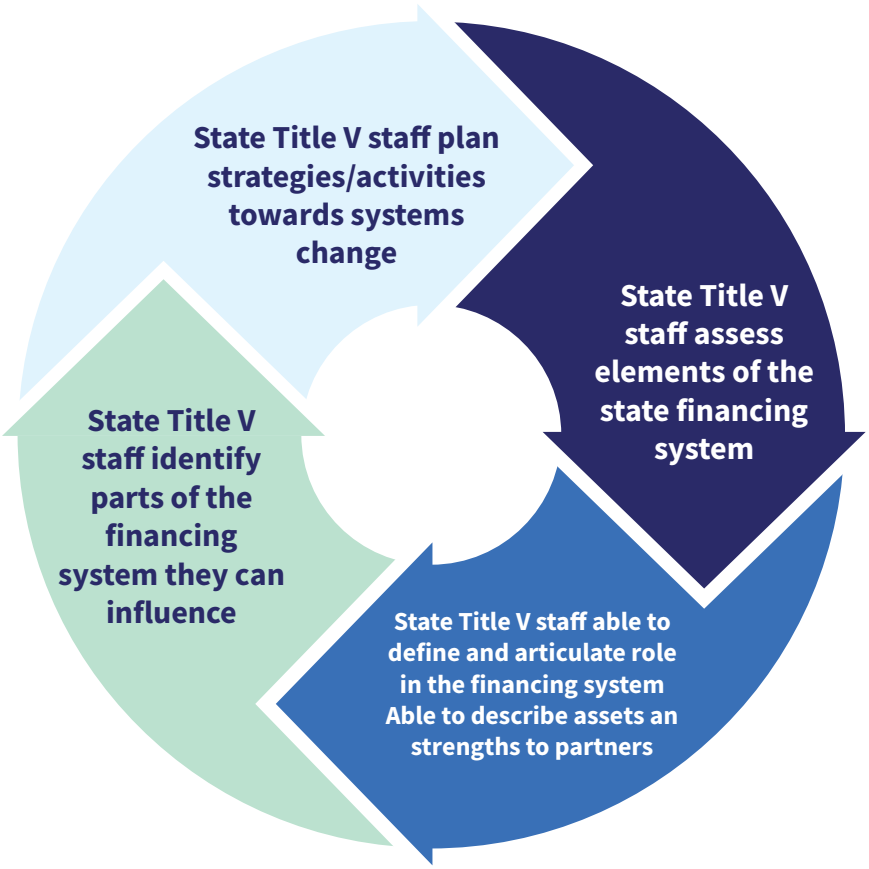

Figure 1: Purpose of the Workbook

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

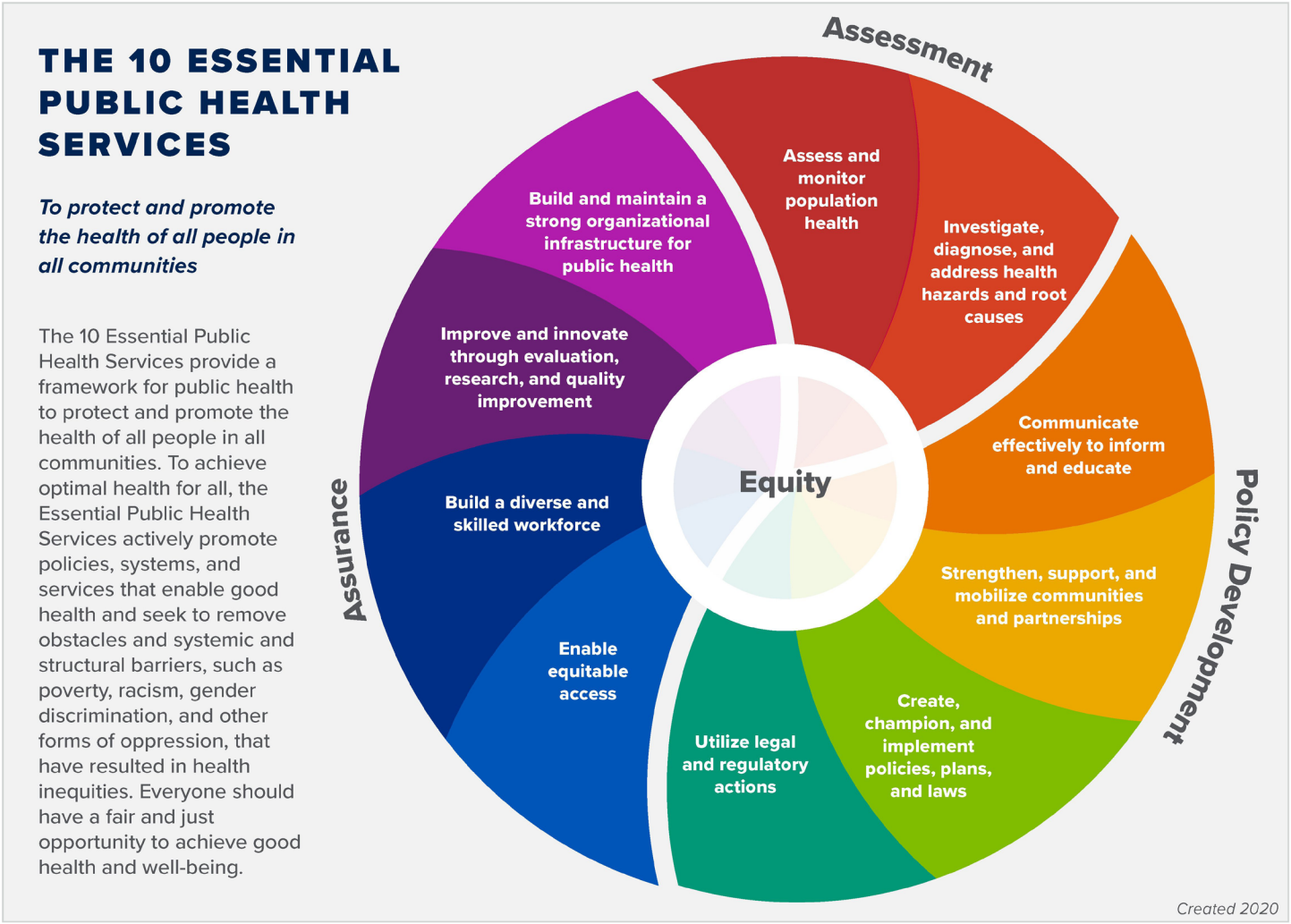

Image source: Centers for Disease Control and Prevention. (2020). 10 Essential Public Health Services. https://www.cdc.gov/publichealthgateway/publichealthservices/essentialhealthservices.html

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.