

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



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Overview

Federal and state program approaches to defining children and youth with special health care needs (CYSHCN) can impact how these programs determine eligibility for health care services and supports (e.g., care coordination), evaluate services and their impact, and measure outcomes. Medicaid and state Title V programs serving CYSHCN often define the population differently, using different definitions for different purposes. As states make changes to their health care delivery systems to improve quality, reduce costs, and improve outcomes, they may look to definitions as a critical first step to ensure CYSHCN are identified and provided needed services.

This issue brief describes how states define CYSHCN within Medicaid and Title V CYSHCN programs and explores the policy implications of these definitions. This analysis also includes state considerations for establishing and implementing definitions of CYSHCN and the potential impact of aligning definitions across these two programs. This brief presents an analysis of administrative and interview data from seven states: Arizona, Florida, New York, Ohio, Oregon, Utah, and Virginia. Data sources included state Medicaid managed care (MMC) contracts, Medicaid state plan amendments, state Title V MCH Services Block Grant applications and annual reports, and state Title V CYSHCN program websites, as well as key informant interviews with state Medicaid and Title V CYSHCN program officials.

Background

Nearly 20% of US children ages birth to 18 years (14.6 million children) have a chronic and/or complex health care need (e.g., asthma, diabetes, spina bifida, or autism) that requires physical and behavioral health care services and supports beyond what children require generally.¹ Children with medical complexity, a subpopulation of CYSHCN, comprise less than 1% of US children and are even more likely to require additional services and supports.² Children with medical complexity have multiple significant chronic health problems that affect multiple organ systems and result in functional limitations, high health care need or utilization, and often the need for or use of medical technology.³

Medicaid and the Children's Health Insurance Program (CHIP) play a prominent role in financing care and providing coverage for CYSHCN, insuring about 46% of all CYSHCN either partially or in full.⁴ CYSHCN are eligible for Medicaid through a variety of coverage pathways, such as meeting income guidelines, disability, receiving Supplemental Security Income (SSI) or adoption assistance, or enrollment in foster care. The Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit for children requires that state Medicaid programs cover "necessary health care, diagnostic services, treatment, and other measures...to correct or ameliorate defects along with physical and mental illnesses and conditions discovered by the screening services, whether or not such services are covered under the State plan."⁵ This benefit is particularly critical for CYSHCN enrolled in Medicaid as it covers all services and supports that are deemed medically necessary.

Medicaid programs that serve children and adults with chronic and complex health care conditions have shifted over time from fee-for-service to primarily managed care and have placed a focus on quality of care. As of 2017, 47 states and Washington DC all enroll at least some or all of the CYSHCN population into some type of Medicaid managed care delivery system.⁶ As more CYSHCN are served by Medicaid managed care, how CYSHCN are defined in Medicaid managed care contracts can play an essential role in connecting children to services, and fulfilling federal requirements for managed care programs to have a mechanism for identifying enrollees with special health care needs.⁷ In many cases, the primary function of many of these specific definitions is to establish eligibility for care coordination services or targeted services and supports by Medicaid managed care organizations.⁸

State Title V CYSHCN programs are mandated by federal statute to provide services and address the needs of CYSHCN. At least 30% of Title V MCH Services Block Grant funding must be directed to address the

needs of CYSHCN.⁹ According to the federal Maternal and Child Health Bureau, Health Resources and Services Administration (MCHB/HRSA), which administers the federal Title V block grant, CYSHCN are defined as children and youth who “have or are at increased risk for chronic physical, developmental, behavioral or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.”¹⁰ The MCHB HRSA definition is broad by design to ensure that the full range of needs experienced by CYSHCN is represented in the population and to align with the overall MCHB goal of working to ensure optimal health and quality of life for all CYSHCN and their families.

How State Medicaid and Title V Programs Define CYSHCN

Definitions in state Medicaid programs, particularly in managed care contracts, are typically used to identify specific populations and sub-populations of CYSHCN, such as children with medical complexity, foster care, or homeless youth that may need additional services or care coordination. State Title V CYSHCN programs use definitions to establish eligibility for CYSHCN services in states where Title V programs still provide direct care, and as a guiding principle for the work of their program. How state Medicaid and Title V programs define CYSHCN can have implications for the provision of services for CYSHCN by these two programs, the structure of health care delivery systems, and partnerships.

Almost half of states (23 states) include a definition of CYSHCN in their Medicaid managed care contracts. These definitions range from a direct alignment with the MCHB/HRSA definition of CYSHCN, to 10 states that use CYSHCN definitions that rely on condition-specific diagnoses and Medicaid enrollment categories.¹¹ All state Title V CYSHCN programs use some version of the MCHB/HRSA definition to guide their CYSHCN programs.¹²

Specific CYSHCN Populations Included in Medicaid and Title V Definitions

When defining CYSHCN, states may reference specific subpopulations of CYSHCN or other state and federal programs that serve CYSHCN in their definition. State Medicaid programs have used eligibility criteria from SSI, Home and Community Based Service (HCBS) waivers, state foster care programs, Part C of the Individuals with Disabilities Education Act (IDEA) Early Intervention (EI) programs, and Title V CYSHCN programs to inform their CYSHCN definitions. For example, Virginia Medicaid includes the following in their managed care definition of CYSHCN:

1. Children and youth in foster care and those receiving adoption assistance,
2. Children identified as Early Intervention (EI) participants,
3. Medicaid enrollees experiencing childhood obesity,
4. Any child participating in home and community-based services (HCBS) waivers, and
5. Others identified through the health plan’s assessment or by the State Medicaid Agency.

Some state Title V programs, such as those in Ohio, Arizona, and Florida, expand on the MCHB/HRSA definition by specifying 21 as the age limit for services to assist with efforts to transition CYSHCN from pediatric to adult health systems. New York State, meanwhile, defines a list of conditions eligible for Title V services. (See Appendix A for specific definitions used by state Medicaid and Title V CYSHCN programs featured in this brief.)

Selected Federal Program Definitions of CYSHCN

- [Federal MCHB/HRSA](#): Children and youth with special health care needs (CYSHCN) have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.
- [Supplemental Security Income \(SSI\)](#): A child under age 18 will be considered disabled if he or she has a medically determinable physical or mental impairment or combination of impairments that causes marked and severe functional limitations, and that can be expected to cause death or that has lasted or can be expected to last for a continuous period of not less than 12 months.
- [Home and Community-Based Services \(HCBS\) 1915\(c\) Waivers](#): Medicaid HCBS waivers allow states to tailor services to meet the needs of a particular group (e.g., autism, epilepsy, etc.). Eligible individuals must demonstrate the need for a Level of Care that would meet the state’s eligibility requirement for services in an institutional setting.
- [Part C Individuals with Disabilities Education Act \(IDEA\)](#): This federal program provides early intervention services to infants and toddlers under age 3 “who would be at risk of experiencing a substantial developmental delay if early intervention services were not provided to the individual.” The Act defines an infant or toddler with a disability, although states have flexibility in how they design eligibility for services under their Part C funded programs.

Alignment of Definitions Between Medicaid and Title V CYSHCN Programs

States use different approaches to align definitions of CYSHCN between Medicaid and state Title V CYSHCN programs. Some states have a total alignment of definitions across these two programs, while others have no alignment. When exploring the role that coordination of definitions plays in these states, it is essential to note that definitions are only one aspect of the policies and procedures that states put in place to serve CYSHCN in their Medicaid and Title V programs. Alignment and collaboration across these agencies for care coordination services, policies regarding transition of care, and quality measurement can all provide valuable opportunities to improve systems of services for CYSHCN.¹³ When establishing definitions—whether the goal is alignment or not—regular communication and strong partnerships with other agencies are critical to successfully serving CYSHCN and their families.

In states where there is alignment among definitions, state Medicaid and Title V CYSHCN leaders report that having a shared understanding of who falls under the term CYSHCN makes it easier to work together to serve them. These states also report strong connections between Medicaid and Title V agencies. For example, Florida, New York, Oregon, Utah, and Ohio all use the MCHB/HRSA definition in both their Medicaid and state Title V CYSHCN programs to define CYSHCN. These states report that having alignment of definitions across programs can help partners—including managed care organizations and community-based CYSHCN providers—understand the population they are serving. Utah also established the shared definition of CYSHCN in its recently renewed Memorandum of Understanding between the state Title V CYSHCN and Medicaid programs. In Ohio, the majority of CYSHCN are served through the Children with Medical Handicaps (CMH) program, which is administered by the Ohio Department of Health (ODH) and Title V CYSHCN programs. The CMH program and ODH work closely with the Ohio Department of Medicaid to ensure access to care and assist families with any

challenges and barriers they experience. State health officials in Ohio indicated that working closely on the program has helped facilitate a successful relationship between the two agencies. Additionally, the state Title V CYSHCN program has been able to foster stronger relationships with Medicaid during the transition of CYSHCN to a managed care delivery system.

In contrast, officials in several states, including Arizona, report strong interagency collaboration in serving CYSHCN even though they do not have shared CYSHCN definitions across their Medicaid and Title V programs. For example, the Arizona Health Care Cost Containment System (AHCCCS) administers the Medicaid program and the Children's Rehabilitative Services Program (CRS) for CYSHCN, which is the state's Title V CYSHCN programs. The AZ Title V program and the AHCCCS both reported having an open dialogue and communication around serving the CYSHCN populations. In an interview with program staff, they explained they had not perceived a need to align a definition across agencies.

The Role of CYSHCN Definitions in Medicaid Managed Care

Given that more states are serving populations with chronic and complex conditions in Medicaid managed care delivery systems, having a specific definition of CYSHCN in these programs, and in managed care contracts, can be important. Managed care contract definitions of CYSHCN can help state Medicaid programs emphasize to their MCO the importance of this population and aid in requiring MCOs to target specific services and supports to CYSHCN. Intentionally defining CYSHCN in managed care contracts and including subpopulations of CYSHCN in contract language allows for a greater ability to serve children and youth who may not typically be eligible for specialty care and services.

In Oregon, for example, Coordinated Care Organizations (CCOs), which are regionally based Medicaid accountable care organizations that bring together different types of providers and community organizations to share financial responsibility for providing coordinated care,¹⁴ are working closely with the state Title V CYSHCN program to examine social complexity factors when serving subpopulations of CYSHCN who experience chronic disease. The CCOs are working to address social determinants of health, such as homelessness, when defining the subpopulations of CYSHCN enrolled in the state's health plans. Oregon's Medicaid managed care contract definition also targets children and youth with substance use disorders.

Florida's state Title V CYSHCN program has intentionally included and focused on adolescents as part of the CYSHCN definition in their managed care program. The specific mention of adolescents is intended to underscore the importance of adolescents with special health care needs and their unique needs, including support for transitioning from pediatric to adult health care services. Virginia Medicaid includes youth who are aging out of foster care in their definition of CYSHCN in contracts with MCOs. This population is a priority in the state, and naming them in contracts makes it easier for the state to require MCOs to implement targeted services and ensure MCOs have transition plans in place for this population of children.

CYSHCN Definitions in State Statute or Regulations

Some states include a definition of CYSHCN in state law or regulations, which can help codify the definition and create an overarching, shared understanding of the CYSHCN population. This codified definition may make it easier for state agencies, legislators, families, and community partners to have a common understanding of identifying CYSHCN and how to design approaches to serve this population of children and youth. For example, the Children's Rehabilitative Services (CRS) program in Arizona serves CYSHCN that are eligible for Medicaid. The definition for CYSHCN and the list of eligible conditions for the CRS program is defined in state law.¹⁵ Florida has a definition of CYSHCN in statute.¹⁶ The Ohio CMH program has specific eligible conditions in state law, but no overall definition of CYSHCN is mandated. Virginia's definition of CYSHCN exists in administrative code.¹⁷ Examples of states with definitions of CYSHCN in statute or code can be found in Appendix A.

Key State Considerations in Defining CYSHCN

There are many considerations for states that have an interest in establishing or refining their definitions of CYSHCN. States will want to consider a range of decisions and strategies, including engaging key partners in definition development, considering alignment of definitions, and fully understanding the role that the definition can play in service delivery system design. Additionally, effective administration and coordination between agencies and programs will be important as states may face budget challenges or revenue shortfalls due to local, national, or global events (e.g., COVID-19, economic recession, natural disasters, etc.). The following strategies may be helpful for states seeking to define CYSHCN in their state programs more fully:

- **Medicaid managed care contracts present an opportunity for states to focus efforts on specific populations within CYSHCN.** States can use MMC to make specific subpopulations of CYSHCN a top priority for providers and Medicaid Managed Care Organizations (MCOs). For example, states can specify subpopulations, such as homeless children, children in foster care, children with medical complexity, medically fragile children, adolescents with Substance Use Disorder, or children with obesity, to help target services.
- **Determining how other state programs or partners define CYSHCN may be helpful when establishing new programs or determining priorities for funding of existing programs.** To support effective communication and partnerships, state agencies may want to seek out and analyze definitions of CYSHCN used by other programs in their state. When state programs look to establish or update their definition of CYSHCN, it may be helpful to review how other programs and partners define this population to guide program development and policymaking. Understanding how state programs define CYSHCN can facilitate communication about the planning, development, and implementation of new programs or procedures.
- **Engaging external partners in defining CYSHCN can also help ensure that state programs are considering all of the aspects of this population that are important to families and to the services the program is trying to deliver.** Understanding the definitions of CYSHCN used by other state agencies and programs can help build effective partnerships and target limited resources for vulnerable populations. Programs and partners to consider in establishing a CYSHCN definition include special education programs, foster care support services, child disability advocates, families, and other social service programs.
- **Alignment of definitions across programs may be an important first step to build partnerships and a shared understanding among programs when serving CYSHCN.** Alignment of CYSHCN definitions may help states that are looking to collaborate across agencies or programs or establish these partnerships. The Title V/Medicaid memorandum of understanding could be a mechanism for formalizing definitions of CYSHCN. For states that do not currently have strong collaborative relationships between Medicaid and Title V, discussing each program's current definitions of CYSHCN and understanding the roles and implications of those definitions can be an important first step to building future collaborations around serving CYSHCN.
- **Standardizing definitions in state regulations or law can help with interagency coordination and understanding of the CYSHCN population.** A definition in legislation or code can help create a standard for agencies and programs. This allows for agencies to have a guide when further defining the population for specific programs and services. A codified definition also allows for agencies, advocates, and families to align over a common message when working to serve this population. However, it is important to have the flexibility to adapt and change definitions as systems evolve to support CYSHCN. Having a standard definition of CYSHCN in state regulations allows

for state agencies to efficiently build out programs and services for populations, creates a shared understanding of who is eligible for services, and can act as a roadmap for legislative bodies if further clarification or expansion is needed.

- **Additional detail and context to CYSHCN definitions can allow states to prioritize sub-populations of CYSHCN and target needed services.** State CYSHCN definitions are critical to identifying and serving children in need of services and delivering services effectively. Some states use program definitions that include a targeted focus on specific conditions, include a list of covered services or conditions, or highlight specific conditions that are state priorities, such as childhood obesity or autism. States may also want to specifically include children on Medicaid waivers and transition-age youth to ensure these subpopulations are considered part of the broader CYSHCN population. As states grapple with limited resources and a desire to target those with the highest need, defining CYSHCN more specifically can help with resource allocation.
- **There is no one-size-fits-all approach to defining CYSHCN.** States will want to consider what definitions work best for their agencies when deciding to adopt a definition of CYSHCN. State Medicaid and state Title V agencies that are looking to establish close interagency collaborations to serve CYSHCN better may want to consider aligning or partnering on defining CYSHCN as an important way to establish or build on this partnership. Definitions can also serve as a way to highlight state priorities or populations for increased attention and supports.

Conclusion

State Title V programs rely heavily on the MCHB/HRSA definition of children and youth with special health care needs, because they are in part driven by the federal program priority for assuring the health of all children, including CYSHCN. This definition is broad and allows states to use and operationalize the definition to fit their needs. State Medicaid agencies can use Medicaid managed care contracts to define CYSHCN and target specific subpopulations of CYSHCN. Officials in state Medicaid and Title V agree that collaboration and strong partnerships are critical to define and serve this population. Definitions of CYSHCN can help states implement programs and design systems of care, create a shared message around CYSHCN, and strengthen cross-agency collaboration. Defining this population can be an important first step in establishing a coordinated and successful system of care for CYSHCN.

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- ¹⁶ [Florida law Chapter 391.021\(2\)](#)
- ¹⁷ [12VAC5-191-10. Definitions.](#)

Appendix A: Table: Summary of Select State CYSHCN Definitions in Medicaid and Title V CYSHCN Programs

State	Definition of CYSHCN that Guides Title V	Medicaid Program Definition of CYSHCN	Medicaid Managed Care Contract Language	State Code and/or Regulations
AZ	MCHB/HRSA definition ¹	No Medicaid program definition of CYSHCN ²	No definition of CYSHCN included in Medicaid managed care contracts.	Title 36-261 "Children who have a chronic illness or physical disability; program"
FL	MCHB/HRSA definition	No Medicaid program definition of CYSHCN ³	No definition of CYSHCN included in Medicaid managed care contracts.	Florida law Chapter 391.021(2) and 64C-2.002, Florida Administrative Code ⁴
NY	MCHB/HRSA definition	MCHB/HRSA definition ⁵	"Children and youth with special health care needs are those who have or are suspected of having a serious or chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."	N/A
OH	MCHB/HRSA definition ⁶	MCHB/HRSA definition	No definition of CYSHCN included in Medicaid managed care contracts.	N/A
OR	MCHB/HRSA definition	No Medicaid program definition of CYSHCN ⁷	No definition of CYSHCN included in Medicaid managed care contracts.	N/A
UT	MCHB/HRSA definition	No Medicaid program definition of CYSHCN ⁸	"Child with Special Health Care Needs means a child under 21 years of age who has or is at increased risk for chronic physical, developmental, behavioral, or emotional conditions and requires health and related services of a type or amount beyond that required by children generally, including a child who, consistent with Section 1932(a) (2) (A) of the Social Security Act, 42 U.S.C.1396u-2(a) (2) (A): 1. is blind or disabled or in a related population (eligible for SSI under Title XVI of the Social Security Act); 2. is in Foster Care or other out-of-home placement; 3. is receiving Foster Care or adoption assistance; or 4. is receiving services through a family-centered, community-based co-ordinated care system that receives grant funds described in Section 501(a) (1)(D) of Title V of the Social Security Act."	N/A
VA	MCHB/HRSA definition ⁹	No Medicaid program definition of CYSHCN ¹⁰	"Children with Special Health Care Needs (CSHCN) - Children and youth with special needs that have or are at increased risk for a chronic physical, developmental, behavioral or emotional condition(s) and may need health and related services of a type or amount over and above those usually expected for the child's age. These include, but are not limited to, the children in the eligibility categories of foster care and adoption assistance (aid category 076 and 072), youth who have aged out of the foster care system (Aid Category 70), children identified as Early Intervention (EI) participants, members identified as experiencing childhood obesity and others as identified through the Contractor's assessment or by the Department."	12VAC5-191-10. Definitions

¹ The definition used by the Children Rehabilitative Services is legislatively mandated [36-261. Children who have a chronic illness or physical disability](#)

² [Section A: Contract Amendment](#) - While contracts do not have a specific CSHCN definition, it does define "Special Health Care Needs".

³ [Attachment II - Scope of Service Core Provisions](#) (p22) - While contracts do not have a specific CSHCN definition, it does define "Special Health Care Needs."

⁴ Definition is in legislation ([Florida law Chapter 391.021\(2\)](#)) and codified in administrative code ([64C-2.002, Florida Administrative Code](#)).

⁵ [Medicaid Managed Care/Family Health Plus/HIV Special Needs Plan/Health and Recovery Plan Model Contract](#) (p92)

⁶ While the MCHB definition is used broadly within the Title V program, specific programs may have other definitions that focus on a specific condition. These specific definitions are often legislatively mandated.

⁷ [Coordinated Care Organization Contract](#) (p43) - While CCO contracts do not have a specific CSHCN definition, it does define "Special Health Care Needs".

⁸ [Accountable Care Organization Contract](#) (p4)

⁹ Virginia defines CYSHCN in administrative code - [12VAC5-191-10. Definitions](#).

¹⁰ [Medallion 4.0 MCO Contract](#) (p23)