Medicaid Policy Matters Webinar Series

Building an Integrated System of Care for Children and Youth With Special Health Care Needs

September 18, 2025

Aims for Today's Presentation

1. Understand the elements and overarching vision behind an effective System of Care for children and youth with special health care needs (CYSHCN)

2. Identify tools available within Medicaid to help build that system

3. See examples of how states are integrating programs, funding, and services to care for CYSHCN

4. Profile the needs and experiences of CYSHCN in Oregon using the Oregon Child Integrated Dataset (OCID)

Executive Summary

- Medicaid covers a large percentage of CYSHCN, and agencies are currently navigating an uncertain federal policy landscape

- These children often require care across multiple providers and sectors—while a System of Care model envisions integrated services and cross-system coordination, families often experience a more fragmented reality

- Medicaid tools can help states design programs that align with integrated care principles, ranging from coordination mechanisms to specific care services

- States are actively using and combining tools to build out services and system-level structures for CYSHCN—often with direct links to Medicaid

- Integrated, cross-program data can support a more holistic system-level approach

About the Center for Evidence-based Policy

About Our Work

Rigorous and **neutral** research and technical assistance services to support state policymakers

- Evidence review and synthesis

- Data analytics including administrative data integration, management, and analysis

- Policy analysis

- Technical assistance (operational and process-related)

- Trainings and workshops on evidence-based decision making

40 States Served Since 2003

States served
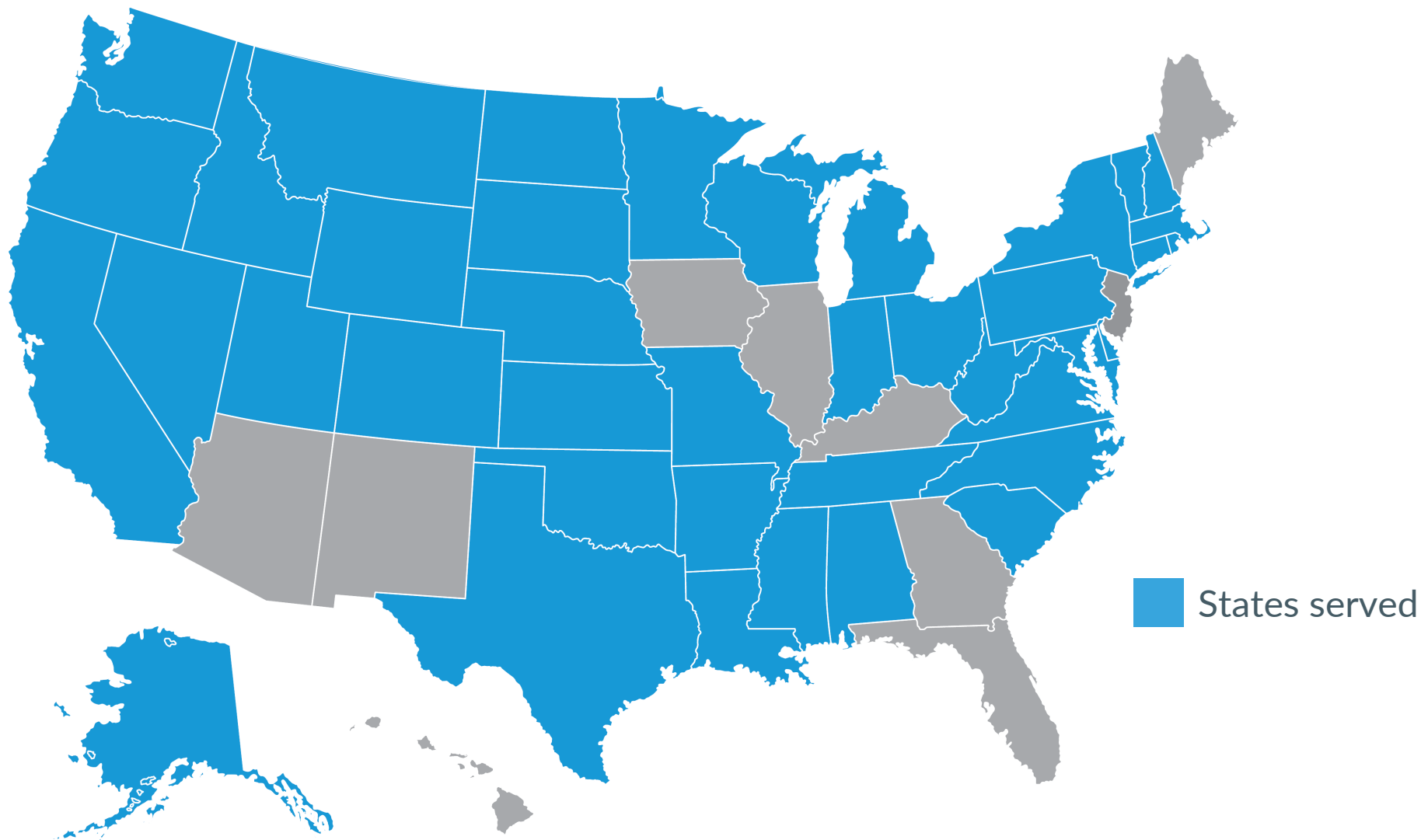
About Our Organization

- Established in 2003 at Oregon Health & Science University

- Our work is driven by states, 90% in Medicaid

- We are not funded by industry or associations

- We are nonpartisan and we do not lobby

- Our work is typically proprietary

Who Are We?

OUR STAFF

- Systematic reviewers
- Policy analysts
- Physicians
- Pharmacists
- Nurses
- Genetics professionals
- Epidemiologists
- Librarians
- Data scientists
- Technical editors
- Researchers

OUR WORK IN 2024

- Produced 50 evidence reports
- Researched 40 topics
- Screened over 30,000 titles and abstracts
- Reviewed in detail more than 3,000 research articles
- Graded 600 articles for quality

TODAY

- **Jesse Baumgartner**
  Policy Analyst

- **Caitlin Burbank**
  Research Associate

- **Valerie King**
  Director of Research

- **Pam Curtis**
  Director

- **Kelsey Platt**
  Project Coordinator

Medicaid Policy Matters Webinar Series

Building an Integrated System of Care for Children and Youth With Special Health Care Needs

September 18, 2025

centerforevidencebasedpolicy.org

Agenda Overview

1 **Background**
Overview of CYSHCN

2 **Building a System of Care**
Understanding the vision and tools for developing a high-functioning system

3 **Strategies in Action**
Reviewing how states are leveraging these tools to build system-level structures

4 **Exploring the OCID Project**
Profiling CYSHCN using a linked, cross-program dataset

5 **Conclusion and Discussion**

Research Approach

- Review of academic and policy literature

- More than 15 key informant interviews with subject matter experts and state agency staff from Medicaid, Title V, early childhood, and additional child-focused programs

- Center analysis of data from the OCID dataset

State Medicaid agencies that are part of the MED collaborative have access to the full report

Background

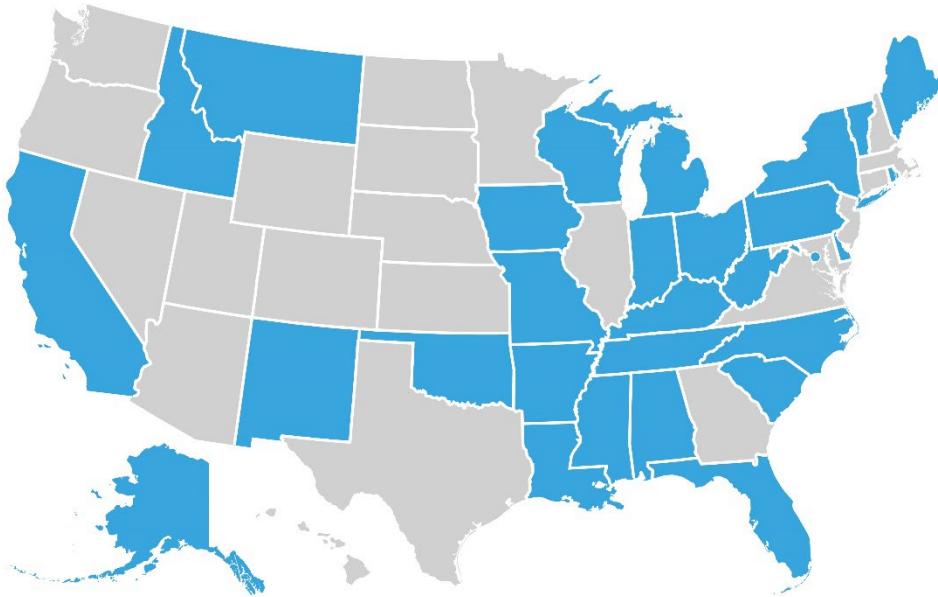# Children and Youth With Special Health Care Needs
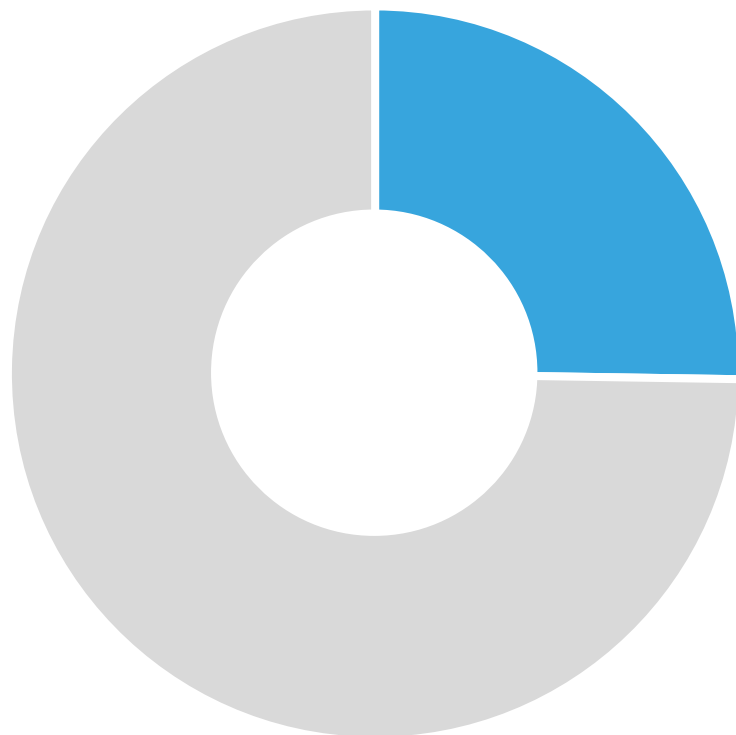
26% of children in the United States meet the definition of having special health care needs

Source. KFF (2025).

Medicaid plays a significant role in the care of children with special needs.

States where at least 41% of CYSHCN are covered by Medicaid or CHIP

Source. KFF (2025).

- Medicaid and the Children's Health Insurance Program (CHIP) provide coverage for at least 41% of children with high needs in 28 states

- Medicaid eligibility can be available through multiple pathways

- Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit often more generous than private insurance
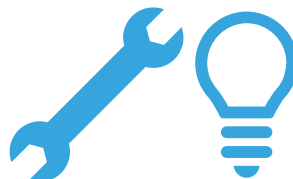
Current Policy Landscape

1 Federal policy environment has shifted significantly

2 Agencies are looking at large program changes after H.R. 1 passage

3 Federal funding availability, priorities, and operations are in flux

Connection to Today's Presentation

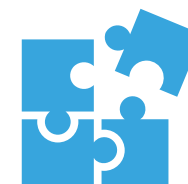## REMAINING HIGH NEED

Children with complex medical conditions must be served

TOOLS AND IDEAS

Opportunities and creative mechanisms may present themselves under new policy landscape

PUTTING THE PIECES TOGETHER

Examples today can serve as a conceptual template for a broader connective approach

Building a System of Care

The vision, elements, and tools for developing a high-functioning system

CYSHCN require integrated care that often spans many systems, providers, and regulatory authorities.

- A "System of Care" model merges higher-level values with system-level infrastructure and service delivery

- CYSHCN often require services in multiple care settings and experience additional social and economic challenges

- The vision for a holistic and connected care system often falls short

Key Components of a System of Care
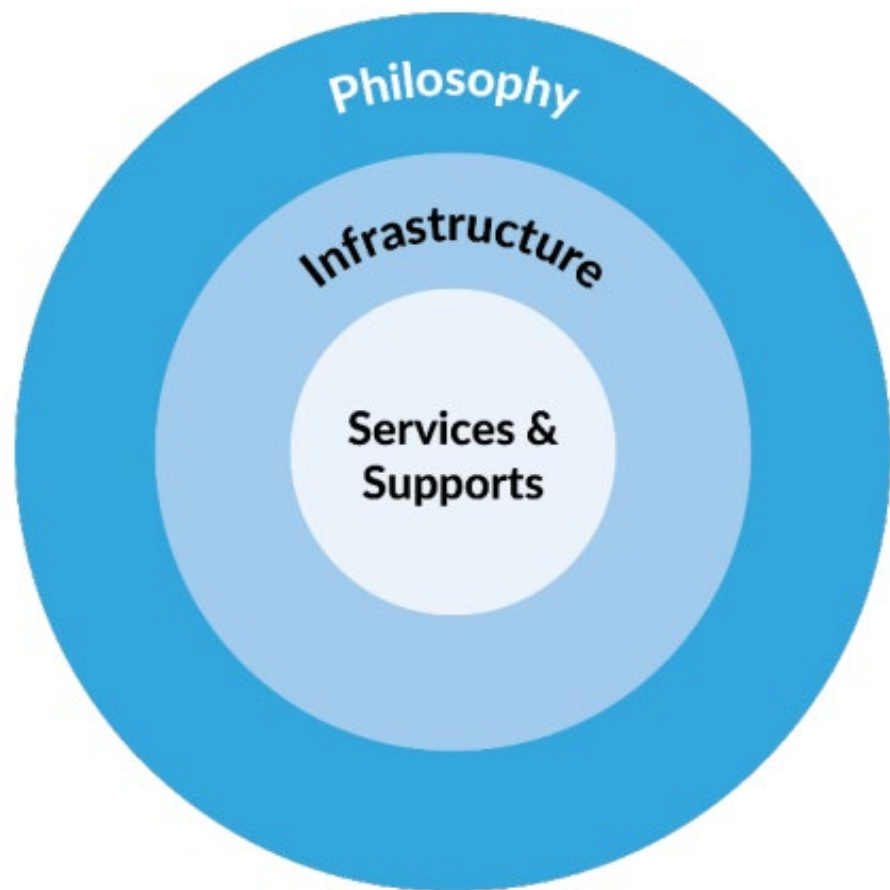
Philosophy of core values and principles

Infrastructure and processes to meet aspirations

Comprehensive services and supports to deliver care

Source. Stroul, Blau, and Larson (2021).

Dimensions of a System of Care

System of Care Dimensions:
- Early childhood services
- Mental health services
- Substance use services
- Health services
- Social and child welfare services
- Education services
- Juvenile justice services
- Recreational services
- Vocational services
- Transition services
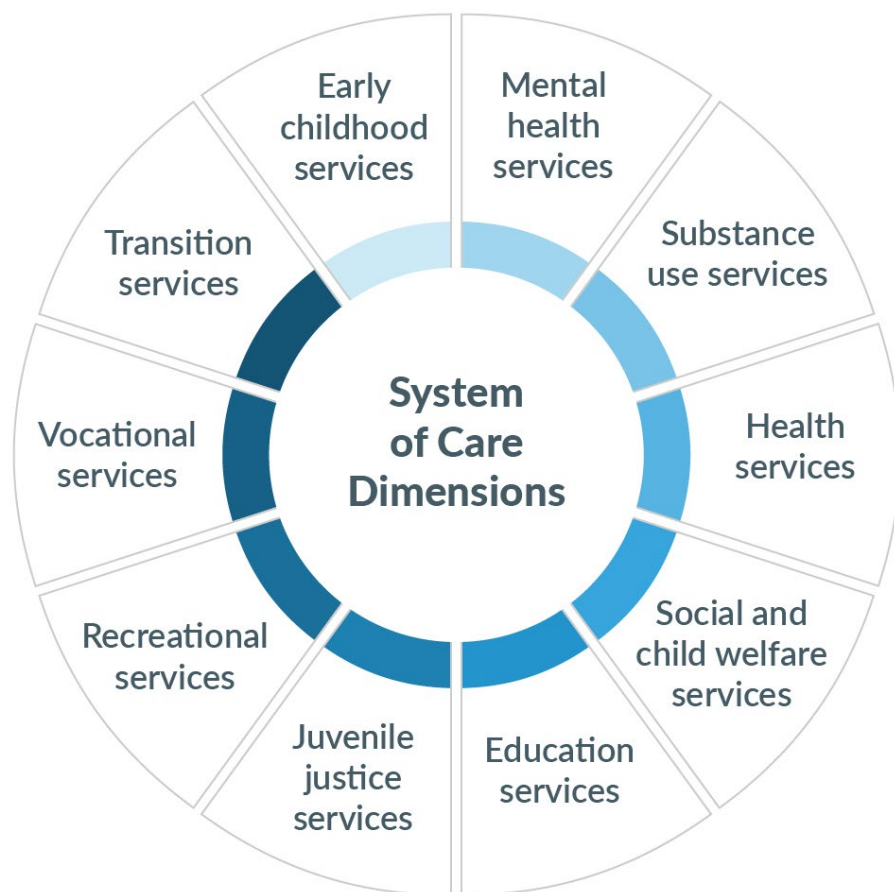
CYSHCN often require health services from multiple providers.

These health needs may be occurring alongside significant social and economic challenges.

Source. Stroul, Blau, and Larson (2021).

Care Mapping for A Child With Complex Medical Needs

Health System
Local pediatrician
Specialty care at children's hospital

Home Health
Home health caregiver services
Meetings and at-home visits with state staff

Title V CYSHCN Program
Care coordination
Specialty care pop-up clinics in local area

Individualized Education Program
Transportation to nonlocal district
Nurse supervision
Care plan team meetings

Early Intervention
Speech, occupational, physical therapy
Additional services at specialized school

Private Insurance
Employment-based primary health insurance plan

Out-of-State Care
Out-of-state trips to see specialty care
Financial support for out-of-state travel

Medicaid 1915(c) Waiver
HCBS care not covered by private insurance
Monthly meetings with Medicaid
Yearly care level assessments

Abbreviation. HCBS: home- and community-based services.

The Reality and Vision for a High-Functioning System of Care

REALITY

- Focus on individual services
- Fragmentation
- Confusion
- Administrative barriers
- Inadequate service levels
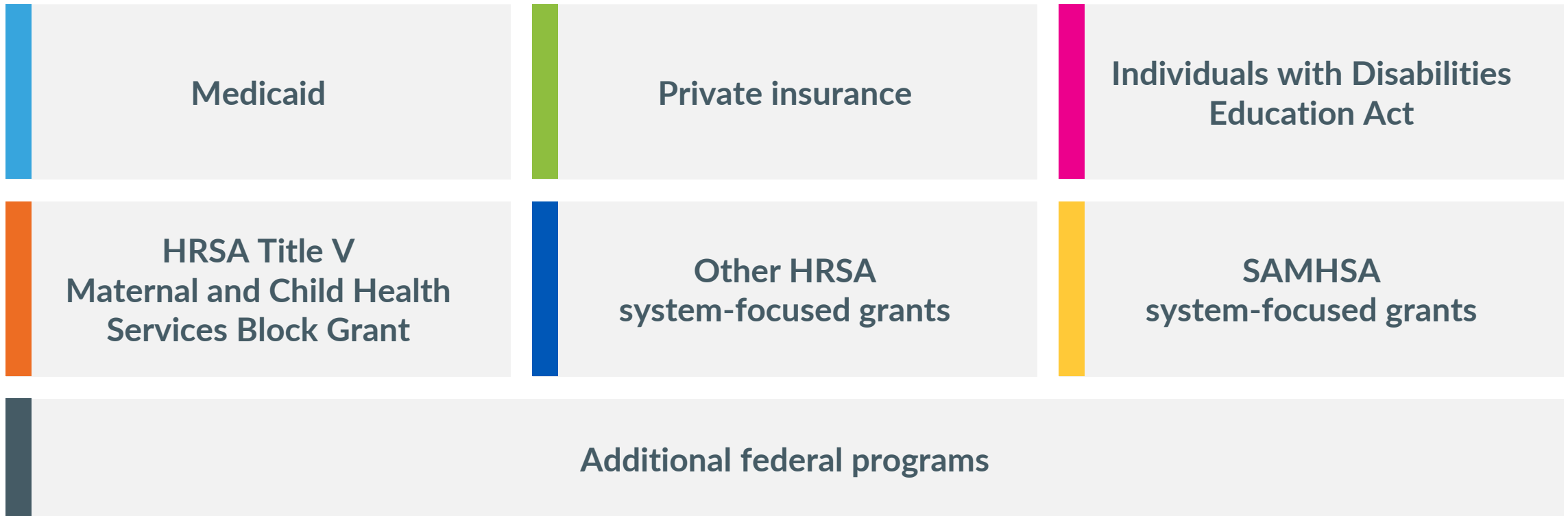- Caregiver health and economic burden

VISION

- Family and whole-child perspective
- Data integration
- Single entry points for multiprogram enrollment
- Predictable cross-sector care pathways and coordination
- Mechanisms to troubleshoot cross-system issues
- Enhanced insurance coverage, funding, and service capacity

Many funding streams support the delivery of CYSHCN services, and Medicaid programs have a variety of tools available to help build the care system.

- States are often leveraging and blending federal funding sources

- Federal agencies have historically supported system-building efforts for CYSHCN, though current landscape is uncertain

- Medicaid agencies have opportunities to design programs, benefits, and eligibility criteria that align with integrated care principles

Many Funding Sources Support Systems of Care for CYSHCN, but Federal Landscape in Flux

Medicaid	**Private insurance**	**Individuals with Disabilities Education Act**
HRSA Title V Maternal and Child Health Services Block Grant	**Other HRSA system-focused grants**	**SAMHSA system-focused grants**
Additional federal programs		

Abbreviations. HRSA: US Health Resources and Services Administration; SAMHSA: Substance Abuse and Mental Health Services Administration.

Title V Maternal and Child Health Services Block Grant

- Federal-state partnership, with states and localities contributing at least a $3 match for every $4 of federal Title V funds

- States must spend at least 30% of federal funds on primary and preventive care for children, and 30% on CYSHCN services program

- Title V agencies and the Medicaid program must have an interagency agreement to increase partnership and coordination

- Title V CYSHCN programs have evolved from direct service roles to care-enabling and system-building roles, in some cases with direct funding and operational ties to Medicaid programs

Medicaid Agencies Can Design Programs and Benefits That Align With Vision for System of Care

- Building focal organizational and coordination structures that work across systems

- Addressing health care workforce concerns

- Lowering financial burden for CYSHCN families

- Supporting the role of the education system for CYSHCN care

- Ensuring access to core and specialty health care services

- Improving the breadth of covered services

Medicaid Levers

1. Leveraging EPSDT benefits and standards

2. Expanding Medicaid eligibility pathways

3. Health Homes and care coordination

4. School-based services

5. Paying family caregivers

6. Leveraging telehealth

7. Tailored CYSHCN plans and benefits
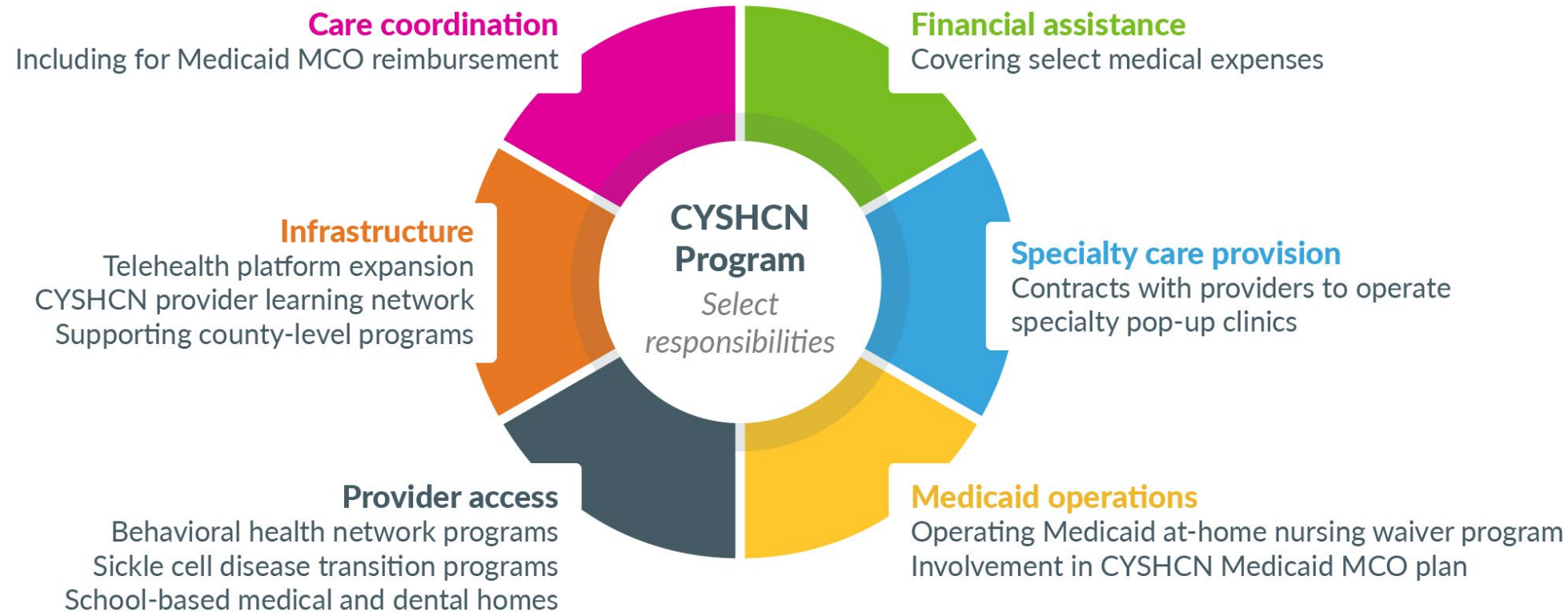
8. Whole Child Medicaid models

Strategies in Action

How states are leveraging these tools to build system-level structures

States are actively integrating programs, funding sources, and service areas to care for CYSHCN—with consistent Medicaid links.

- Strategic roles for Title V CYSHCN programs

- Behavioral health integration opportunities

- Creation of CYSHCN-specific system and provider models

- Leveraging interagency relationships and collaboration

Title V CYSHCN Programs Can Play Strategic Roles and Connect Directly to State Medicaid Programs

Care coordination
Including for Medicaid MCO reimbursement

Financial assistance
Covering select medical expenses

Infrastructure
Telehealth platform expansion
CYSHCN provider learning network
Supporting county-level programs

CYSHCN Program
Select responsibilities

Specialty care provision
Contracts with providers to operate specialty pop-up clinics

Provider access
Behavioral health network programs
Sickle cell disease transition programs
School-based medical and dental homes

Medicaid operations
Operating Medicaid at-home nursing waiver program
Involvement in CYSHCN Medicaid MCO plan

Abbreviation. MCO: managed care organization.

State Efforts to Address Behavioral Health Care Integration for CYSHCN

1 **Medicaid Health Homes**
Better integrating physical and behavioral health

2 **Medicaid targeted case management**
Identifying high-need children for behavioral health coordination

3 **Specialized Medicaid managed care organization (MCO) entities**
Focusing on pediatric behavioral health

4 **Provider networks and consultation hubs**
Using federal grants to set up pediatric behavioral health networks and teleconsultation platforms

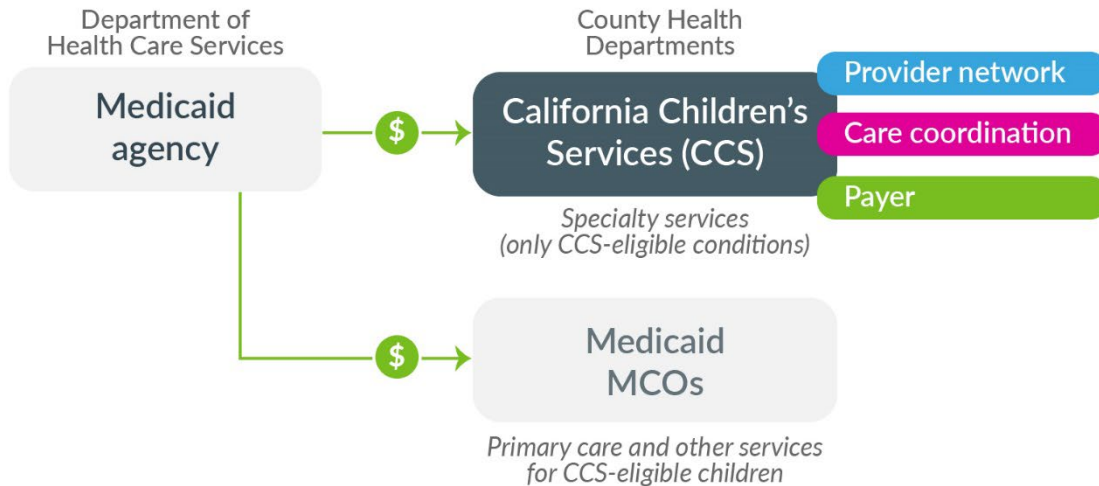**5** **High-fidelity wraparound services**
Piloting through federal grant funding, moving to full Medicaid benefit
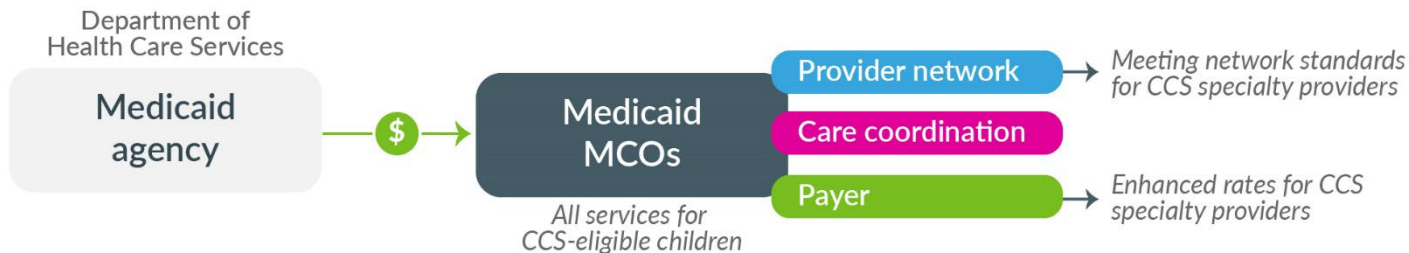
California Children's Services
State System Model

California Children's Services Model for Medicaid-Eligible Kids
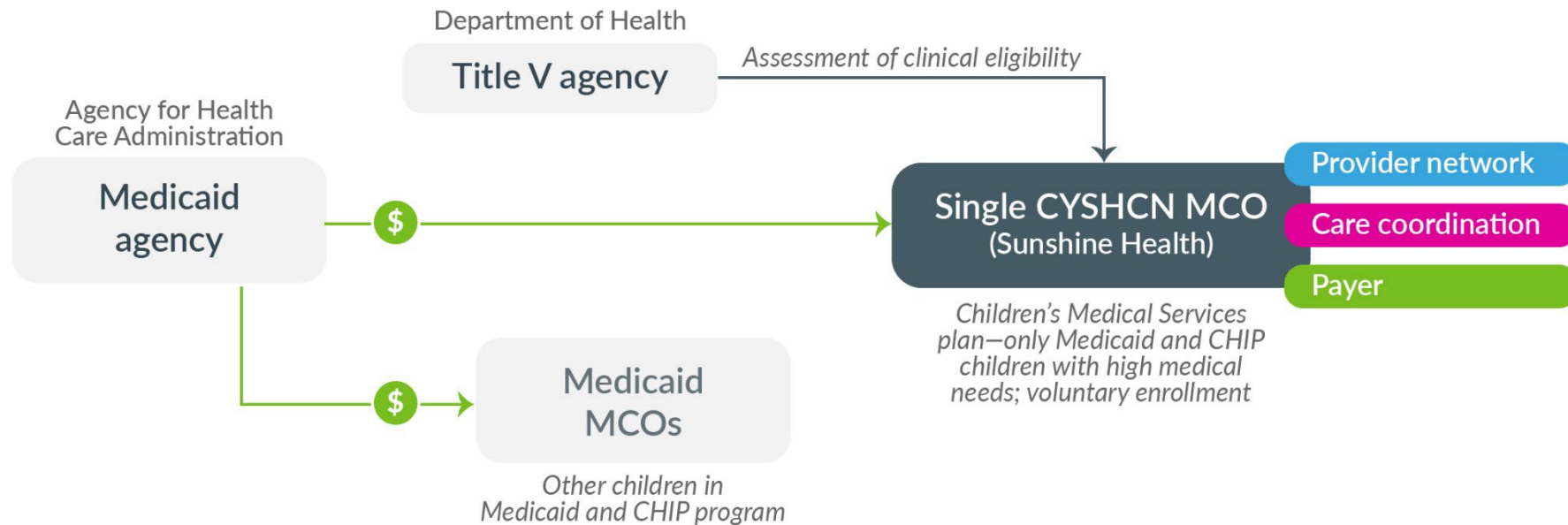
California Whole Child Model

- Statewide provider network and coverage program delivering specialty treatment to low-income CYSHCN

- Recent integration of program into Medicaid MCOs (Whole Child model)

Information sources. California Department of Health Care Services program overview (2025); Okumura et al. (2022).
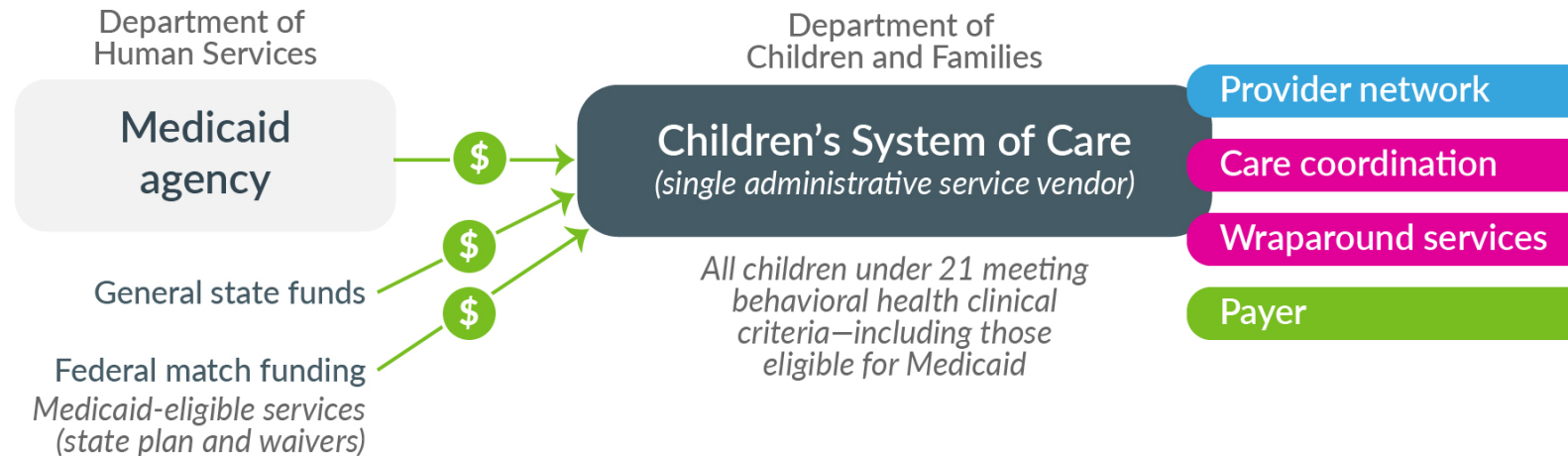
Florida CYSHCN Medicaid MCO Plan

State System Model

Department of Health

Title V agency — *Assessment of clinical eligibility*

Agency for Health Care Administration

Medicaid agency

Single CYSHCN MCO (Sunshine Health)
- Provider network
- Care coordination
- Payer

Children's Medical Services plan—only Medicaid and CHIP children with high medical needs; voluntary enrollment

Medicaid MCOs

Other children in Medicaid and CHIP program

Information sources. Florida State Legislature (2025); Florida Department of Health (2025); McCarthy and Waugh (2022).

- MCO specifically designed for CYSHCN eligible for Medicaid and CHIP

- Strong historical ties between Title V agency and Medicaid agency

New Jersey Children's System of Care

State System Model

Department of Human Services

Department of Children and Families

Medicaid agency

$

$

General state funds

$

Federal match funding

Medicaid-eligible services (state plan and waivers)

Children's System of Care
(single administrative service vendor)

All children under 21 meeting behavioral health clinical criteria—including those eligible for Medicaid

Provider network

Care coordination

Wraparound services

Payer

Information sources. New Jersey Department of Children and Families overview (2023); Center for Health Care Strategies and Casey Family Programs (2025).

- State public behavioral health system and provider network for all children—mental health, substance use, intellectual and developmental disabilities

- Integrated Medicaid financing design

Ohio Partners for Kids Medicaid Accountable Care Organization

State System Model

Department of
Medicaid

Created by Nationwide
Children's Hospital

**Medicaid
agency** → $ → **Medicaid
MCOs** → $ → **ACO
(Partners for Kids)**

*Most children on
Medicaid in central
and western Ohio*

- Provider network
- Care coordination
- Payer
- Capacity building

Information source. Partners for Kids overview (2024)
Abbreviation. ACO: accountable care organization.

- Based out of Nationwide Children's Hospital in Columbus

- Receives capitation funding from MCOs

- Responsible for organizing, delivering, and paying for care services for >470,000 children on Medicaid

Examples of Interagency Relationships and Action

1 Medicaid–Title V CYSHCN program collaboration

2 Consolidating Medicaid 1915(c) waivers for CYSHCN under Medicaid agency

3 Cross-agency collaborative bodies (e.g., Children's Cabinets)

4 Pursuing data and eligibility integration projects

5 Coordinating operations for jointly delivered services (e.g., medical foster care programs)
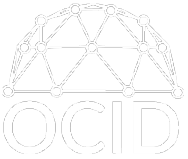
The Oregon Child Integrated Dataset

Profiling CYSHCN using linked, cross-program data

OCID

The Oregon Child Integrated Dataset
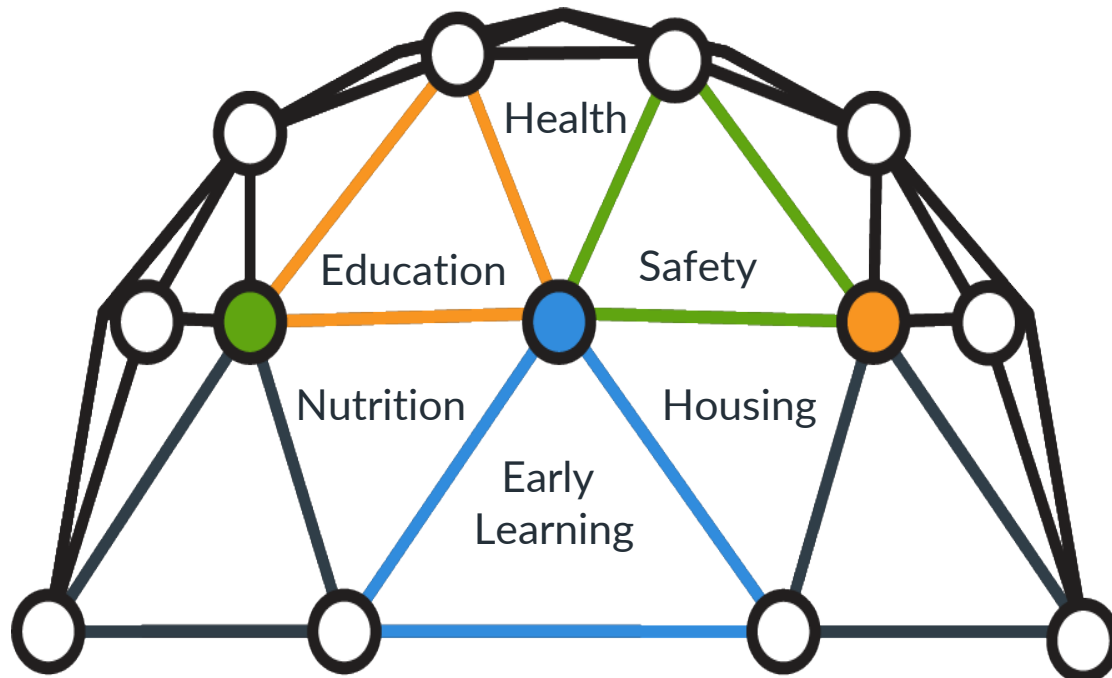
- Nonpartisan, objective resource to improve the well-being of all children in Oregon

- Oregon-specific, integrated cross-program data following children starting in 2001 from five state agencies

- Responsive and accessible in-depth analyses and interactive data visualizations

- Governed by state policymakers and guided by community leaders

Analysis Overview

○ Profile analysis of Oregon children and youth enrolled in Medicaid or CHIP who had special health care needs in 2021

○ Additional data presented from recently released OCID analysis on complex medical and social needs during early childhood for children born between 2007 and 2011

○ See CYSHCN report appendix for more details

Medicaid Has a Large Role in CYSHCN Care in Oregon

More than one-third of children enrolled in Oregon Medicaid or CHIP had at least 1 chronic condition in 2021

| Complex chronic	Noncomplex chronic	Nonchronic
13%	22%	65%
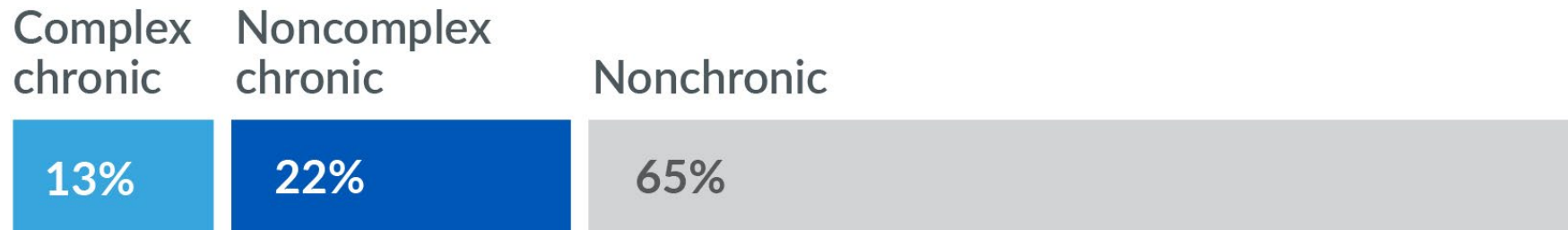
Children with complex chronic conditions have conditions that affect multiple body systems or those that are progressive or malignant

Children with noncomplex chronic conditions have conditions that affect one body system and are not progressive or malignant

Source. MED-OCID Brief: Building an Integrated System of Care for Children and Youth With Special Health Care Needs (2025).

Social and Environmental Experiences of CYSHCN in Oregon in 2021
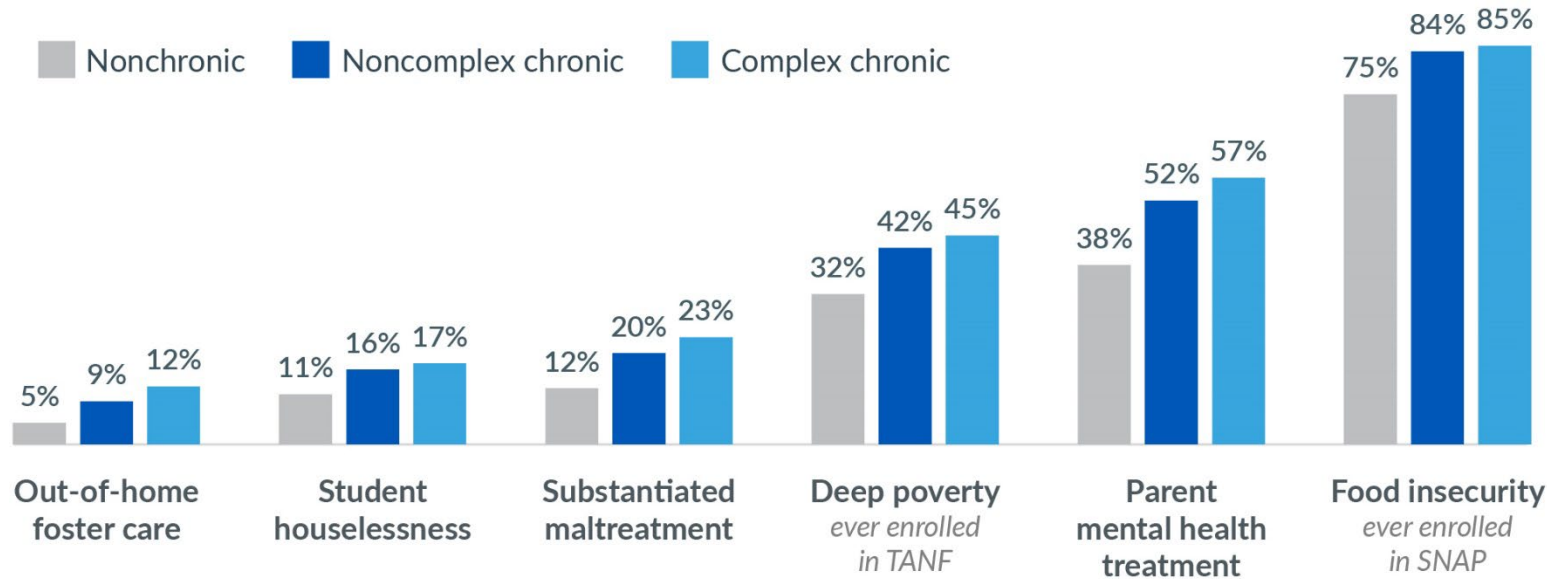
CYSHCN navigate more challenging circumstances at the family and individual level

Note. *Parent-level experiences are those that occurred during the life of the child and are calculated only for youth born in Oregon.
Source. MED-OCID Brief: Building an Integrated System of Care for Children and Youth With Special Health Care Needs (2025).
Abbreviations. SNAP: Supplemental Nutrition Assistance Program; TANF: Temporary Assistance for Needy Families.

Health Care Use of CYSHCN in Oregon in 2021

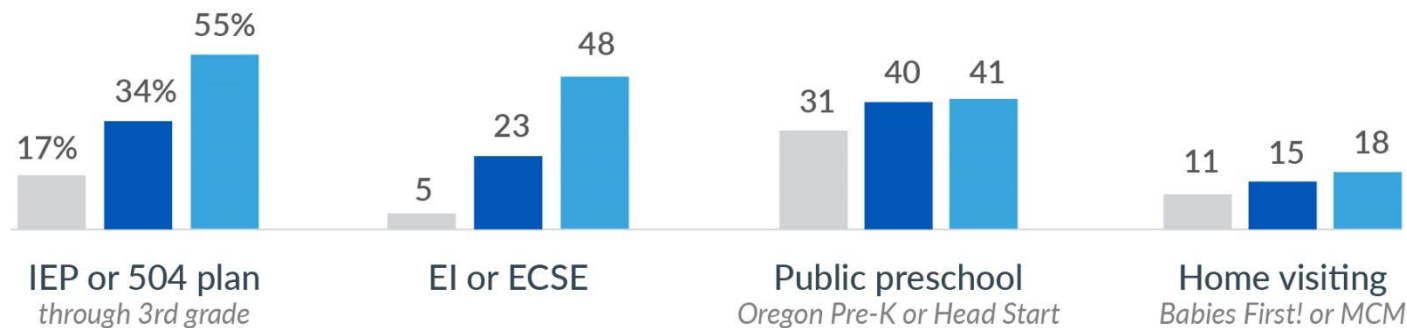|	Well-child visit	≥1 ED visits	≥1 inpatient visits
Nonchronic	53.1%	12.1%	0.7%
Noncomplex chronic	64.5	18.5	1.3
Complex chronic	67.0	25.8	3.8

More children and youth with chronic conditions had recent well-child visits, but they also had higher rates of emergency department visits and inpatient hospital stays.

Connecting the Data: Early Childhood Program Participation of CYSHCN in Oregon

More children with chronic health conditions accessed **early childhood support services**

Legend: Nonchronic, Noncomplex chronic, Complex chronic

IEP or 504 plan *through 3rd grade*: 17%, 34%, 55%

EI or ECSE: 5, 23, 48

Public preschool *Oregon Pre-K or Head Start*: 31, 40, 41

Home visiting *Babies First! or MCM*: 11, 15, 18

Source. OCID Series on Complex Medical and Social Needs in Early Childhood (2024).
*Abbreviations.* ECSE: Early Childhood Special Education; EI: Early Intervention; IEP: Individualized Education Program; MCM: Maternity Case Management.

More CYSHCN between birth and age 5 were enrolled in early childhood programs and received disability support in elementary school through 3rd grade

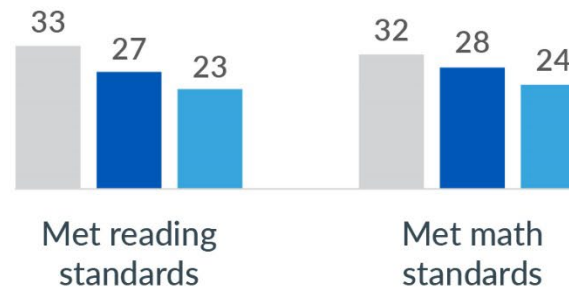# Connecting the Data: Early Educational Experiences

■ Nonchronic   ■ Noncomplex chronic   ■ Complex chronic

More children with chronic health conditions experienced **school disruptions** by 3rd grade
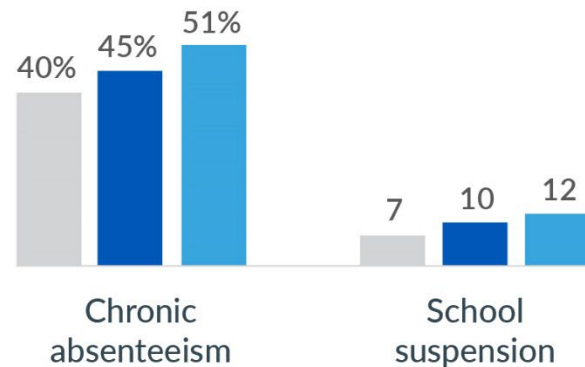
Fewer children with chronic health conditions met **3rd grade standards**

CYSHCN between birth and age 5 went on to have more disruptive educational experiences and fewer met 3rd grade standards

Source. OCID Series on Complex Medical and Social Needs in Early Childhood (2024).

Integrated data unlocks insights.

OCID

- Provides **policymakers** with a cross-program view of circumstances affecting CYSHCN that could be isolated in individual datasets

- Connecting health system and social service data may identify **collaboration** opportunities among agencies commonly touched by CYSHCN

- Enables **innovation** among agencies and policymakers by providing a connected view of the System of Care for CYSHCN

Conclusion and Discussion

State Considerations and Takeaways

1 Exploring ways to use different Medicaid levers

2 Bringing the pieces together

3 Connecting Medicaid and Title V programs

4 Improving data integration across programs

These concepts and goals are particularly applicable to the current environment with ongoing federal funding and policy changes.

Key Points

- Medicaid covers a large percentage of CYSHCN, and agencies are currently navigating an uncertain federal policy landscape

- These children often require care across multiple providers and sectors—while a System of Care model envisions integrated services and cross-system coordination, families often experience a more fragmented reality

- Medicaid tools can help states design programs that align with integrated care principles, ranging from coordination mechanisms to specific care services

- States are actively using and combining tools to build out services and system-level structures for CYSHCN—often with direct links to Medicaid

- Integrated, cross-program data can support a more holistic system-level approach

This report provides a high-level overview of the systems and sectors involved in CYSHCN care, and the roles that Medicaid agencies can play.

- Details how Medicaid programs use tools, programs, funding, and collaboration to build systems and care structures

- Provides foundational ideas and concepts for bringing together care system entities and elements within local contexts

- Demonstrates the potential of cross-system data-sharing between Medicaid and other agencies

Follow-Up Items

- Public brief and appendix PDFs are available on the [Center website](#)

- MED member states have access to the full original policy report
  › Contact Sharon Civil at civils@ohsu.edu if you need help accessing it

- A recording of today's webinar will be available on the Center website

- Attendees are also invited to visit the [OCID project website](#)

Questions and Discussion

Medicaid Policy Matters Webinar Series

Medicaid Policy Matters: Next Webinar

◦ **Title**: Medicaid Management Strategies for Practitioner Administered Drugs (PADs)

◦ **Date and Time:** Tuesday, December 9, 2025, at 11:00am (PT)

Abbreviations

- **ACO:** accountable care organization

- **CHIP**: Children's Health Insurance Program

- **CYSHCN**: children and youth with special health care needs

- **EPSDT:** Early and Periodic Screening, Diagnostic, and Treatment

- **HRSA:** US Health Resources and Services Administration

- **MCO**: managed care organization

- **OCID**: Oregon Child Integrated Dataset

- **SAMHSA**: Substance Abuse and Mental Health Services Administration