Seeing Is Believing: An Infographic Series on the Fundamentals of Financing the Systems of Care for Children and Youth with Special Health Care Needs

March 10, 2019

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Julia Kantner, MSW – Program Manager, CISWH, The Catalyst Center
Workshop Outline

- About Children and Youth with Special Health Care Needs (CYSHCN)
- About the Catalyst Center
- The Infographic Project
- Acknowledgements
- Infographic Topic Overview
- Practical Applications
- Questions and Discussion
Definition of CYSHCN

“Children who have or are at increased risk for a chronic, physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”

Maternal and Child Health Bureau Core Outcomes

- Families of CYSHCN partner in decision-making regarding their child’s health.
- CYSHCN receive coordinated, ongoing, comprehensive care within a medical home.
- **Families of CYSHCN have adequate private and/or public insurance to pay for needed services.**
- Children are screened early and continuously for special health care needs.
- Community-based services are organized so families can use them easily.
- Youth with special health care needs receive the services necessary to make transitions to adult health care.
CYSHCN Prevalence

18.8% of children age 0-17

**CYSHCN Demographics, National Survey for Children’s Health, 2016-2017 combined data**

![Bar chart showing percentages of CYSHCN and Non-CYSHCN by race/ethnicity]

- **Hispanic**: 16.8% CYSHCN, 83.2% Non-CYSHCN
- **White, non-Hispanic**: 18.7% CYSHCN, 81.3% Non-CYSHCN
- **Black, non-Hispanic**: 25.6% CYSHCN, 74.4% Non-CYSHCN
- **Other, non-Hispanic**: 15.3% CYSHCN, 84.7% Non-CYSHCN

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CYSHCN Type of Health Insurance, National Survey for Children’s Health, 2016-2017 combined data

<table>
<thead>
<tr>
<th>Type of Health Insurance</th>
<th>CYSHCN</th>
<th>Non-CYSHCN</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public only</td>
<td>40</td>
<td>29.6</td>
</tr>
<tr>
<td>Private only</td>
<td>47.9</td>
<td>59.9</td>
</tr>
<tr>
<td>Public and Private</td>
<td>7.9</td>
<td>3.9</td>
</tr>
<tr>
<td>Uninsured</td>
<td>4.1</td>
<td>6.7</td>
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</table>
CYSHCN Family-Provider Partnerships, National Survey for Children’s Health, 2016-2017 combined data

How often provider and family decide care and treatment choices together

<table>
<thead>
<tr>
<th></th>
<th>CYSHCN</th>
<th>Non-CYSHCN</th>
</tr>
</thead>
<tbody>
<tr>
<td>Always</td>
<td>66.7</td>
<td>76.1</td>
</tr>
<tr>
<td>Usually</td>
<td>22.9</td>
<td>17.1</td>
</tr>
<tr>
<td>Sometimes or Never</td>
<td>10.3</td>
<td>6.8</td>
</tr>
</tbody>
</table>

CYSHCN Effective Care Coordination, National Survey for Children’s Health, 2016-2017 combined data

- Did not need care coordination: 22.7%
- Received needed care coordination: 47.8%
- Did not receive needed care coordination: 29.5%

The Catalyst Center

• Focuses on coverage and financing of services and supports for CYSHCN
• Provides technical assistance about health care financing policy, practice, and implementation
• Conducts policy research to identify and evaluate financing innovations
• Creates resources such as our State-at-a-Glance Chartbook, value-based purchasing primer, Medicaid and CHIP tutorial, Inequities Tutorial, webinars, and more
• Connects those interested in working together to address complex financing issues
The National Network for Advancing Systems of Care for CYSHCN

ADVANCING SYSTEMS OF SERVICES FOR CYSHCN NETWORK ORGANIZATIONAL CHART

United States Health Resources and Services Administration

Funder
Maternal and Child Health Bureau

Advancing Systems of Services for CYSHCN Network (Network)

1 American Academy of Pediatrics (AAP)
2 National Alliance to Advance Adolescent Health (NAAAH)
3 Boston University (BU)

National Resource Centers

AAP
National Resource Center for Patient/Family-Centered Medical Home (NRC-PFCMCH)

NAAAH
Got Transition

BU
Catalyst Center

Additional Components of the NRC-PFCMCH

AAP
Healthy Tomorrows Resource Center

NAAAH
Early Hearing Detection Intervention Program

Network Email: cyshcnnetwork@aap.org

Context for the Infographic Project

- The system of financing and delivery of services for CYSHCN is complex.

- Disseminating information and increasing knowledge about key issues within this system is a crucial component in affecting better outcomes for CYSHCN.

- The Catalyst Center has created over a decade’s worth of content from research, technical assistance and policy analysis.
Question:
How can we make financing literature more accessible?

Answer:
Infographics
Infographics are…

- Visual
- Manageable with limited amounts of information
- Popular / Shareable
  - Easy to share electronically or on paper
- Effective tools for promoting processing, learning, and recalling dense information
- Able to show relationships & structure

Infographic Design
MEDICAID AND CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS

Medicaid is a public benefit program that pays for health care and related services for vulnerable populations (including low income families with children, and people with disabilities) who meet certain federal and state eligibility criteria.

**Payers & Policymakers**

CYSCHN need to access Medicaid’s benefits through a broad range of providers. Access to providers is important because by definition, CYSCHN need more health care services and supports than children typically do for age-appropriate things such as vaccinations, therapies, medications, and more.

**Families**

There are many pathways to Medicaid coverage for CYSCHN: eligibility based on income only, income and functional level of disability, severe disability, or engagement with the foster care system. Medicaid can help families ensure their CYSCHN has health care coverage for the services they need.

**Providers**

The causes and consequences of financial hardship for families raising CYSCHN are mitigated by the design elements of Medicaid: adequate benefits in the form of EPSDT, cost-sharing limits, and rules around access to providers.

**Catalyst Center Resources**

Public Insurance Programs and CSHCN: A Tutorial on the Basics of Medicaid and the Children’s Health Insurance Program (CHIP)

This tutorial gives an overview of Medicaid/CHIP, the population these programs serve, and details to help think about ways to improve access to coverage for CYSCHN.

[http://catalyst.bu.edu/resources/Medicaid-CHIP-tutorial](http://catalyst.bu.edu/resources/Medicaid-CHIP-tutorial)

Infographic: Medicaid & CHIP: What's the Difference?

This infographic explains the important differences between Medicaid and CHIP.

[http://catalyst.bu.edu/resources/medicaid-big-difference/](http://catalyst.bu.edu/resources/medicaid-big-difference/)

State-at-a-glance Chartbook

The Chartbook provides state and national data. It is a valuable tool for learning about health care and financing care and for advocating for improved coverage.


State Financing Strategies

This page links to examples of the innovative strategies states are using to improve and finance care for CYSCHN, such as EPSDT, TEFRA, and more.


**Defining CYSCHN**

According to the federal Maternal and Child Health Bureau, CYSCHN are those 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.
MEDICAID AND CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS

Medicaid is a public benefit program that pays for health care and related services for vulnerable populations (including low income families with children, and people with disabilities) who meet certain federal and state eligibility criteria.

Title & Overview

Icons Represent A Few Key Stakeholders
**Title & Overview**

Medicaid and Children and Youth with Special Health Care Needs

**Further Resources**

- Catalyst Center Resources
  - Public Insurance Programs and CHIP: A Tutorial on the Basics of Medicaid and the Children's Health Insurance Program (CHIP)
  - Infographic: Medicaid & CHIP: What's the Difference?

**Definition of CYSHCN**

- CYSHCN: According to the federal Maternal and Child Health Bureau, CYSHCN are those who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions, and who require health and related services of a type or amount beyond that required by children generally.

**Icons Represent A Few Key Stakeholders**

- CYSHCN
- Families
- Providers
- Payers & Policymakers

**Citations**


This project is supported by HRSA of the U.S. Department of Health and Human Services (HHS) under grant number U58/CS11087. This information content and conclusions are those of the author and should not be construed as the official position or policy of HHS or any of its agencies.
Infographic Topic Overview

- The Cover Page
- Medicaid & CYSHCN
- Pathways to Medicaid Coverage For CYSHCN
- EPSDT & CYSHCN
- Inequities In Coverage And Financing Of Care & CYSHCN
- Financial Hardship In Families Raising CYSHCN
- The Importance Of Partnerships In Advancing Financing And Coverage
- Family Engagement And CYSHCN
- Value-Based Purchasing For CYSHCN
- Care Coordination For CYSHCN
Acknowledgements

We want to thank our partners and colleagues for their expert input and comments

- **State Title V Colleagues**: Sandra Broughton, Elizabeth Collins, Elaine Gabovitch, Alison Martin, Meredith Pyle, Shirley Payne

- **Family Leaders**: Cara Coleman, Nora Wells, Donene Feist, Rylin Rodgers, and Janis Guerney

- **Catalyst’s HRSA/MCHB Project Officer (2014-2018)**: Leticia Manning, MPH - LCDR, U. S. Public Health Service

- **Former Catalyst PI**: Sally Bachman, PhD
FUNDAMENTALS OF FINANCING THE SYSTEM OF CARE FOR CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS (CYSHCN)

WHAT SHOULD YOU KNOW ABOUT FINANCING THE SYSTEM OF CARE FOR CYSHCN?

The system of financing and delivery of services for CYSHCN is complex.

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, limits opportunities for family/professional partnerships, and thus impedes improved outcomes for CYSHCN and their families, while undermining efforts at increasing value in health care.  

DEFINING CYSHCN: According to the federal Maternal and Child Health Bureau, CYSHCN are those 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.

CITATIONS
MEDICAID AND CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS

Medicaid is a public benefit program that pays for health care and related services for vulnerable populations (including low-income families with children, and people with disabilities) who meet certain federal and state eligibility criteria.

CYSHCN
Medicaid is the largest single payer for children and youth with special health care needs\(^1\) (CYSHCN). It plays an important role for many privately insured CYSHCN by paying for copays, deductibles, and uncovered services.\(^2\)

FAMILIES
There are many pathways to Medicaid coverage for CYSHCN: eligibility based on income only, income and functional level of disability, severe disability, or engagement with the foster care system. Medicaid can help families ensure their CYSHCN has health care coverage for the services they need.

PAYERS & POLICYMAKERS
CYSHCN need to access Medicaid's benefits through a broad range of providers. Access to providers is important because by definition, CYSHCN require more health care services and supports than children typically do for expensive things such as wheelchairs, therapies, medications, and more.

PROVIDERS
The causes and consequences of financial hardship for families raising CYSHCN are mitigated by the design elements of Medicaid: adequate benefits in the form of EPSDT, cost-sharing limits, and rules around access to providers.

*Full infographic available at: [catalystctr.org](http://catalystctr.org)
PATHWAYS TO MEDICAID COVERAGE FOR CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS

Medicaid is a public benefit program that pays for health care and related services for vulnerable populations who meet certain federal and state eligibility criteria. For children and youth with special health care needs (CYSHCN), there are four main pathways to Medicaid coverage.

**CYSHCN**
One pathway is eligibility based on severe disability requiring an institutional level of care. When a child receives extended care in an institutional setting, Medicaid disregards household income as an eligibility requirement. For a child that requires an institutional level of care but can safely be cared for at home, some states offer coverage under the TEFRA State Plan Option or waivers.

**PAYERS & POLICYMAKERS**
About 48% of CYSHCN are insured fully or partially by public insurance. The most common pathway to Medicaid coverage is eligibility based on income, not health status. Regardless of how a child comes to be enrolled, Medicaid is a critically important source of adequate and affordable health care coverage for CYSHCN.

**FAMILIES**
Another pathway is eligibility based on income and functional level of disability. For low-income families in most states, a child receiving supplemental security income (SSI) is eligible for Medicaid. For middle-income families of CYSHCN with high health-related expenses, states with Medicaid buy-in programs allow access to Medicaid to supplement private insurance or for primary coverage.

**PROVIDERS**
All children in foster care are eligible for Medicaid. Children in foster care are vulnerable in many ways and should be considered important members of the population of CYSHCN because of their increased risk for and prevalence of poor physical, developmental and mental health status and outcomes.

*Full infographic available at: catalystctr.org*
EPSDT AND CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS

EPSDT stands for Early and Periodic Screening, Diagnostic and Treatment. It is a federally required Medicaid benefit that ensures all children under 21, who are enrolled in Medicaid, receive preventive screenings and comprehensive health services in the amount, scope, and duration they need to develop and thrive.¹

**CYSHCN**

Each Medicaid state plan specifies the federally mandatory and optional state services that a state covers for its enrollees.² However, EPSDT requires Medicaid programs to cover any service that is deemed medically necessary for an enrollee under age 21, whether or not it is included in the Medicaid state plan. EPSDT is a way to ensure adequacy of coverage for children and youth with special health care needs (CYSHCN).³

**Payers & Policy Makers**

By law, EPSDT covers all medically necessary services.³ The law does not define medical necessity, however, and the definition varies by state. In general, medically necessary services are those that: improve health or lessen the impact of a condition, prevent a condition, or cure/restore health. The comprehensive and individualized nature of EPSDT is critical for CYSHCN, who, by definition, use more health care services than children typically do.³

**Families**

In addition to covering a broad array of health care services, EPSDT requires Medicaid programs to provide parent education regarding the EPSDT benefit. Parents are also entitled to receive help in accessing services that are covered under EPSDT, like transportation, assistance with scheduling appointments, as well as assistance in securing uncovered services.²

**Providers**

Under EPSDT, Medicaid must pay for physical, mental, developmental, dental, hearing, vision, and other tests to screen for and identify potential health problems. Follow-up diagnostic tests to rule out or confirm a diagnosis, and treatments to control, correct, or reduce identified health problems should also be covered.

*Full infographic available at: catalystctr.org*
INEQUITIES IN COVERAGE AND FINANCING OF CARE FOR CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS

While uninsurance among children and youth with special health care needs (CYSHCN) is generally low, several subgroups are less likely to be adequately insured and face a greater risk for adverse health effects as a result.

CYSHCN

CYSHCN are more likely to be uninsured or underinsured if they are: non-white, from low-income families, from families in which English is not the primary language, immigrants or from mixed-immigration status families, or are more limited in their functional abilities.

Payers & Policymakers

To help ensure health care access equity, some states have partnerships that pool resources to maximize outreach and enrollment for the most vulnerable CYSHCN. Financing is important for Title V programs and family leadership groups to maintain and develop strategies that address inequities.

Families

Family income is a source of inequities. CYSHCN with family incomes of less than 200% of the federal poverty level (FPL) are less likely to be insured and more likely to experience gaps in coverage than those with higher family incomes.

Providers

Non-white CYSHCN are more likely to have an unmet need for health care services or equipment in the past year than white CYSHCN. Providers can help address gaps in services through culturally and linguistically appropriate services and support for outreach and enrollment efforts.

*Full infographic available at: catalystctr.org
**FINANCIAL HARDSHIP IN FAMILIES RAISING CYSHCN**

Inadequate insurance coverage and financing results in significant financial hardship for many families raising children and youth with special health care needs (CYSHCN).

**CYSHCN**

Most CYSHCN have insurance, but having health insurance does not necessarily mean the coverage is adequate or affordable. Being insured is only part of the story. Many families make difficult sacrifices to help ensure adequate care for their CYSHCN.

**FAMILIES**

Inadequate health care coverage is a serious problem for a large percentage of families raising CYSHCN. Not every service or support CYSHCN need is paid for by insurance and as a result, families often incur large out-of-pocket (OOP) costs, resulting in financial hardship and medical debt.

**PAYERS & POLICYMAKERS**

Adequacy is a problem for both publicly and privately insured CYSHCN. Implementing financing strategies aimed at covering more services and reducing families’ OOP expenses could help address higher costs later as the result of absent or delayed care.

**PROVIDERS**

Adequacy is composed of three elements: benefits (what a child needs is covered), access (children can get the services they need by being able to see appropriate providers) and affordability (OOP expenses are reasonable).

*Full infographic available at: catalystctr.org*
THE IMPORTANCE OF PARTNERSHIPS IN ADVANCING FINANCING AND COVERAGE

Title V programs can work in partnership with multiple stakeholders to advance National Performance Measures (NPMs) and improve National Outcome Measures (NOMs) for MCH populations.

**CYSHCN**
To efficiently and effectively meet the varied health and social support needs of children and youth with special health care needs (CYSHCN), Title V programs must partner with a broad range of stakeholders including providers and systems.

**FAMILIES**
Family-to-Family Health Information Centers in every state are valuable partners to ensure families of CYSHCN receive insurance information, application assistance, one-on-one counseling to facilitate enrollment in and use of health insurance benefits.

**PAYERS & POLICYMAKERS**
Partnerships with payers and policymakers help states advance the adequate health insurance measure, and thus decrease the percent of children without health insurance, increase the percent of CYSHCN who receive care in a well-functioning system, and address health inequities.

**PROVIDERS**
Providers, working in partnership with Title V, family leaders and other stakeholders, can help lead system transformations that promote financing and coverage of integrated family centered services and supports for CYSHCN.

*Full infographic available at: catalystctr.org
FAMILY ENGAGEMENT AND CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS

Family engagement means patients, families, their representatives, and health professionals are working in active partnership at various levels across the health care system, from direct care, organizational design and governance, to policy making. It ensures the consumer voice is included to improve care for children and youth with special health care needs (CYSHCN).

**CYSHCN**
Family engagement on the individual level is a key element of family-centered care, proven to enhance the well-being of CYSHCN and families. CYSHCN and families are most directly affected by decision-making, therefore partnerships between families, CYSHCN, and health care providers leads to better health outcomes and better resource allocation.

**FAMILIES**
Active partnership between professionals and families helps ensure that the lived experience of families informs care and support services. It also helps families by providing physical and mental health benefits to caregivers, by building on strengths, supporting families, and reducing stress. Programs that support peer mentoring are critical in supporting families in partnering at all levels.

**PAYERS & POLICYMAKERS**
Engaging with family leaders moves systems work forward more efficiently and effectively, helping to inform policy improvements. Organizations such as Family Voices can help recruit, support, and connect families from all communities to family leadership opportunities. Family leaders who represent the diversity of a community are effective ambassadors and cultural brokers for underserved populations.

**PROVIDERS**
Family engagement at the organizational level occurs within institutions, for example through hospital advisory committees, which can promote a shift towards family-centered care. Family-centered care has benefits for children, families, and providers. Families who are informed, empowered, and active care partners are more likely to inform, understand, and utilize clinical recommendations, improving care and outcomes.

*Full infographic available at: catalystctr.org*
VALUE-BASED PURCHASING FOR CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS

Little is known about the impact of Value-Based Purchasing (VBP) on children and youth with special health care needs\(^1\) (CYSHCN); VBP’s financial incentives to reduce costs must be evaluated and associated quality outcomes developed.\(^2\)

CYSHCN

The evidence base for VBP strategies is weak, and what does exist targets primarily adult health; little is known about the impact of VBP program development and implementation on children, especially CYSHCN.

Payers & Policymakers

Policymakers must critically analyze the potential impact of VBP for CYSHCN, since this group of children, by definition, uses more health care services than other children and inevitably incurs higher per person costs.

Families

The field needs better targeted outcome measures and comprehensive definitions of value, including family perspectives that may include measures of family financial hardship, family well-being, and other factors that cannot be measured from claims data.

Providers

Providers can help by developing valid and reliable measures of value for critical outcomes such as care integration, care coordination, and integration of mental, developmental, and physical health within the medical home.

*Full infographic available at: [catalystctr.org](http://catalystctr.org)*

Boston University School of Social Work
Center for Innovation in Social Work & Health
**CARE COORDINATION FOR CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS**

Care coordination involves an interdisciplinary approach in which a care coordinator supports access to care according to an individual’s needs, goals, and preferences. Care coordination is crucial for children and youth with special health care needs (CYSHCN).

**CYSHCN**

CYSHCN generally require services from a broad range of providers and systems and thus need cross-system care coordination, for example between schools and health care providers. Without care coordination, CYSHCN often experience gaps in services and fragmented care that can have a negative impact on child and family health and well-being.

**Payers & Policymakers**

Payers and policymakers need to develop new care coordination models that pool resources and use broad population-based financing and reimbursement models for CYSHCN and other population groups such as adults with chronic illnesses and frail elders.

**Families**

Families strongly agree that care coordination is essential for CYSHCN. However, there are inadequate delivery and financing systems in place to assure this benefit for CYSHCN. Families provide much of the care coordination that CYSHCN need, without effective supports.

**Providers**

Working in a variety of settings, providers can deliver cross-system care coordination in teams that include licensed and non-licensed staff with shared responsibility for clinical and non-clinical coordination tasks. Parents are essential members on these teams in order promote communication with families, and improve care quality.

*Full infographic available at: [catalystctr.org](http://catalystctr.org)*
Practical Applications

- Communicating the need for an alternative payment model to a Coordinated Care Organization
- Educating a new staffer or student about the system of care for CYSHCN
- Sharing needs with state policy makers or Medicaid representatives
  - Discussing coordinated care for CYHSCN
  - Discussing state Medicaid benefits
  - Addressing concerns regarding inequities for CYHSCN
Practical Applications Continued…

- Educating families about pathways to Medicaid coverage
- Supporting education and development of new family leaders
- Supporting education of provider to promote better partnership
- Supporting the education and data needs of policymakers in an easily digestible format

How could you imagine using these?
Practical Applications: Using the Infographics

- PDF’s Pre-Loaded Onto Your USB Drives
  - Packaged as a whole & individual infographics
  - PDF of today’s slide deck
  - Introduction to the Network

- All Infographics are also available online
  - [https://ciswh.org/resources/?place=project&project_ref=160](https://ciswh.org/resources/?place=project&project_ref=160)

- Reminder:
  - Images on today’s PowerPoint are just pieces of the infographics used for illustrative purposes. Please only use the complete official pages for distribution.
Questions/Comments?
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Catalyst Center Website: catalystctr.org

Network Email: cyshcnnetwork@aap.org

This project is supported by HRSA of the U.S. Department of Health and Human Services (HHS) under grant number U41MC13618, *Health Insurance and Financing/CSHCN* ($473,000 annually). This information or content and conclusions are those of the authors and should not be construed as the official position or policy of, nor should any endorsements be inferred, by HRSA, HHS or the U.S. Government. LCDR Leticia Manning, MPH, MCHB/HRSA Project Officer.
THANK YOU!