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

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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 populations these programs serve, and details to help think about ways to improve access to coverage for CYSHCN.
http://cahpp.org/resources/Medicaid-CHIP-tutorial

Infographic: Medicaid & CHIP: What’s the Difference?
This infographic explains the important differences between Medicaid and CHIP.
http://cahpp.org/resources/medicaid-chip-difference/

State-at-a-glance Chartbook
The Chartbook provides state and national data. It is a valuable tool for learning about health insurance and financing of 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 CYSHCN, such as EPSDT, TEFRA, and more.
http://cahpp.org/projects/the-catalyst-center/financing-strategies/

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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.

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**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 populations these programs serve, and details to help think about ways to improve access to coverage for CYSHCN.
  - [http://cahpp.org/resources/Medicaid-CHIP-tutorial](http://cahpp.org/resources/Medicaid-CHIP-tutorial)

- **Expanding Access to Medicaid Coverage: The TEFRA Option and Children with Disabilities**
  This policy brief explains what TEFRA means for pathways to Medicaid for children, a comparison of TEFRA and HCBS waivers, how TEFRA affects CYSHCN, and suggests improvements.

- **State Financing Strategies**
  This page links to examples of the innovative strategies states are using to improve and finance care for CYSHCN, such as Medicaid Buy-ins, TEFRA, foster care and more.

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EPSTD AND CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS

EPSTD 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.1 However, EPSTD 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. EPSTD is a way to ensure adequacy of coverage for children and youth with special health care needs (CYSHCN).1

Payers & PolicyMakers
By law, EPSTD covers all medically necessary services.1 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 EPSTD 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, EPSTD requires Medicaid programs to provide parent education regarding the EPSTD benefit. Parents are also entitled to receive help in accessing services that are covered under EPSTD, like transportation, assistance with scheduling appointments, as well as assistance in securing uncovered services.2

Providers
Under EPSTD, 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.

Catalyst Center Resources

Medicaid Tutorial: EPSTD
This tutorial module examines the history of EPSTD, the importance of EPSTD in coverage for CYSHCN, and types of services covered by EPSTD.


Glossary of Health Care Financing Terms
The glossary is designed to clarify terms and concepts used in health care financing, such as EPSTD.

https://ciswh.org/projects/the-catalyst-center/glossary/

State Financing Strategies
This page links to examples of innovative strategies states are using to improve and finance care for CYSHCN, like state EPSTD coordinators.

https://ciswh.org/project/the-catalyst-center/financing-strategy/epstd/

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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.

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.

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.

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.

CATALYST CENTER RESOURCES

Health Care Coverage and Financing for Children with Special Health Care Needs: A Tutorial to Address Inequities

This tutorial clarifies the language used to describe these inequities and provides tools and examples of policies, programs, and partnerships.

http://cahpp.org/resources/inequities-tutorial

Webinar: Addressing Health Coverage Inequities among CYSHCN in Your State

A webinar to get acquainted with the Inequities Tutorial. MCH staff from Alaska and Michigan shared strategies for working towards health equity for CYSHCN.

http://cahpp.org/resources/webinar-addressing-inequities

State-at-a-glance Chartbook

Understanding data is helpful in shaping policies and programs to address inequities. Learn what inequities look like in your state using the Chartbook.


State Financing Strategies

This page links to examples of the innovative strategies states are using to reduce health inequities and finance care for all CYSHCN.

http://cahpp.org/project/the-catalyst-center/financing-strategy/inequities/

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CITATIONS


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).

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**CATALYST CENTER RESOURCES**

**Breaking the Link Between Special Health Care Needs and Financial Hardship**
This report examines the impact that health care financing and coverage gaps have on the lives of families and highlights innovative policy solutions that can improve care for CYSHCN.


**Information for Families**
This directory provides links to a range of national and state-based direct service organizations and to information related to Title V Maternal and Child Health programs.

http://cahpp.org/projects/the-catalyst-center/info/

**Family Stories**
These personal stories help illustrate the challenges families face raising CYSHCN and demonstrate what is possible when additional financing and services are available.

http://cahpp.org/projects/the-catalyst-center/stories/

**State Financing Strategies**
This page links to examples of the innovative strategies states are using to improve and finance care for CYSHCN, like relief funds, benefits counseling, and more.

http://cahpp.org/projects/the-catalyst-center/financing-strategies/

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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.

CATALYST CENTER RESOURCES

**Leveraging Title V Partnerships to Advance National Performance Measure # 15:**

This brief highlights collaborative Title V partnerships that hold promise for advancing the Title V NPM #15: Adequate Insurance Coverage.


**Webinar on Addressing Inequities Through Partnerships**

This webinar is a companion to our Tutorial to address inequities. MCH staff from Alaska and Michigan share strategies and partnerships for working towards health equity for CYSHCN.

- [http://cahpp.org/resources/webinar-addressing-inequities](http://cahpp.org/resources/webinar-addressing-inequities)

**Tutorial: Building Partnerships**

This tutorial module examines the types of partnerships between Title V and Medicaid/CHIP that are required and feasible to build.


**Information for Families**

This directory, which is organized by state, provides links to a wide range of direct service organizations, and to important information related to Title V Maternal and Child Health programs.


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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 lead to better health outcomes and better resource allocation.

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.

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.

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 outcomes.

RESOURCES
State Financing Strategies
This page links to examples of the innovative strategies states are using to support family partnership, such as partnerships with family-run organizations.

http://cahpp.org/project/the-catalyst-center/financing-strategy/family-supports/

Health Care Coverage and Financing for Children with Special Health Care Needs: A Tutorial to Address Inequities
This tutorial clarifies the language used to describe these inequities and provides tools and examples of policies, programs, and partnerships.

http://cahpp.org/resources/inequities-tutorial

Dancing with Data: Using Data to Support Your Message
This guide exhibits the benefits of using data and stories in efforts made on behalf of CYSHCN, and provides tips for using these tools effectively.


Family Voices
Family Voices is a national family-led organization of families and friends of CYSHCN. They connect a network of family organizations across the United States that provide support to families of CYSHCN.

http://familyvoices.org/

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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 (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.

PARENTS & 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.

PAYERS & POLICYMAKERS

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.

Catalyst Center Resources

A Primer on Value-Based Strategies for Improving Financing of Care for CYSHCN

This primer focuses on opportunities to increase value in spending on services for CYSHCN through alternative payment mechanisms and delivery innovations. http://cahpp.org/resources/primer-value-based-strategies-improving-financing-care-children-youth-special-health-care-needs/


This special supplement to Pediatrics on VBP and value-based insurance design addresses their potential implications for CYSHCN. http://pediatrics.aappublications.org/content/139/Supplement_2/S89

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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.

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.

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.

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.

CATALYST CENTER RESOURCES

Care Coordination Conundrum Report

This report discusses why care coordination has been insufficiently financed to date, and what can be done to address these challenges.

http://cahpp.org/resources/care-coordination-conundrum

State Financing Strategies

This page links to examples of the innovative strategies states are using to promote care coordination for CYSHCN.

http://cahpp.org/project/the-catalyst-center/financing-strategy/care-coordination/

Webinar Series on Care Coordination for Children with Complex Health Care Needs

This webinar series focuses on coordinating care for children with “social complexity”.

http://cahpp.org/resources/webinar-series-on-care-coordination/

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