

# FUNDAMENTALS OF FINANCING THE SYSTEM OF CARE FOR CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS<sup>1</sup> (CYSHCN)



**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.<sup>1</sup>

## CITATIONS

1. McPherson, M., Arango, P., Fox, H., Lauver, C., McManus, M., Newacheck, P., Perrin, J., Shonkoff, J., & Strickland, B. (1998). A new definition of children with special health care needs. *Pediatrics*, 102(1):137-140.
2. The Catalyst Center. (2018). Financing Strategies. <http://cahpp.org/projects/the-catalyst-center/financing-strategies/>

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## 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<sup>1</sup> (CYSHCN). It plays an important role for many privately insured CYSHCN by paying for copays, deductibles, and uncovered services.<sup>2</sup>



### 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.



### 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.



### 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.



## 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.

<http://cahpp.org/projects/the-catalyst-center/state-data-chartbook/>



### 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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2. Rosenthal, J., Henderson, M., Dolatshahi, J., Hess, C., Tobias, C., Bachman, S., & Comeau, M. (2016). *Public insurance programs and children with special health care needs: A tutorial on the basics of Medicaid and the Children's Health Insurance Program (CHIP)*. Boston.

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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)<sup>1</sup>, 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.<sup>2</sup> 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.<sup>3</sup>

## 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>



### 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.

<https://ciswh.org/projects/the-catalyst-center/financing-strategies/>



### 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.

<https://ciswh.org/wp-content/uploads/2016/02/TEFRA-policy-brief.pdf>

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2. Child and Adolescent Health Measurement Initiative. 2016-2017 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by Cooperative Agreement U59MC27866 from the U.S. Department of Health and Human Services, Health Resources and Services Administration's Maternal and Child Health Bureau (HRSA MCHB). Retrieved [2/14/19] from [www.childhealthdata.org](http://www.childhealthdata.org). CAHMI: [www.cahmi.org](http://www.cahmi.org).

3. American Academy of Pediatrics, District II Task Force on Health Care for Children in Foster Care. (2005). *Fostering Health: Health care for children and adolescents in foster care*. 2nd Ed. Retrieved from: <https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/healthy-foster-care-america/Pages/Fostering-Health.aspx>

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## 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.<sup>1</sup>



### CYSHCN

Each Medicaid state plan specifies the federally mandatory and optional state services that a state covers for its enrollees.<sup>1</sup> 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).<sup>1</sup>

### PAYERS & POLICYMAKERS

By law, EPSDT covers all medically necessary services.<sup>1</sup> 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.<sup>3</sup>



### 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.<sup>2</sup>

### 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.



## CATALYST CENTER RESOURCES



### Medicaid Tutorial: EPSDT

This tutorial module examines the history of EPSDT, the importance of EPSDT in coverage for CYSHCN, and types of services covered by EPSDT.

<https://ciswh.org/wp-content/uploads/2017/10/Medicaid-Tutorial-Section12-2017.pdf>



### State Financing Strategies

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

<https://ciswh.org/project/the-catalyst-center/financing-strategy/epsdt/>



### Glossary of Health Care Financing Terms

The glossary is designed to clarify terms and concepts used in health care financing, such as EPSDT.

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

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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<sup>1</sup> (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.<sup>2</sup>



### 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.<sup>2</sup>



### 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.<sup>2</sup> 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>



### 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.

<http://cahpp.org/projects/the-catalyst-center/state-data-chartbook/>



### Webinar: Addressing Health Coverage Inequities among CSHCN 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 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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## 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<sup>1</sup> (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.



### 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.



### 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.<sup>2</sup>



### 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).

## 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.

<http://cahpp.org/resources/breaking-the-link-between-special-health-care-needs-and-financial-hardship/>



### 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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2. Dworetzky, B., Wilson, K., Koppelman, E., Comeau, M., Charmchi, P., Ablavsky, E., ... Bachman, S. (2017). *Breaking the link between special health care needs and financial hardship (2nd ed.)*. Boston. Retrieved from [http://cahpp.org/wp-content/uploads/2017/04/Catalyst\\_Center\\_Breaking\\_The\\_Link-2nd-ed.pdf](http://cahpp.org/wp-content/uploads/2017/04/Catalyst_Center_Breaking_The_Link-2nd-ed.pdf)

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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<sup>1</sup> (CYSHCN), Title V programs must partner with a broad range of stakeholders including providers and systems.

### 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.



### 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.



### 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.

<http://cahpp.org/wp-content/uploads/2017/06/Partnerships-to-Advance-NPM15.pdf>



### Tutorial: Building Partnerships

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

<http://cahpp.org/wp-content/uploads/2017/10/Medicaid-Tutorial-Section3-2017.pdf>



### 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>



### 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.

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

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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.<sup>1</sup> 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.<sup>3</sup> 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.<sup>3</sup>

### 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.<sup>3</sup> 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 and outcomes.<sup>4</sup>



## 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.

<http://cahpp.org/resources/dancing-with-data-using-data-to-support-your-message/>



### 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<sup>1</sup> (CYSHCN); VBP's financial incentives to reduce costs must be evaluated and associated quality outcomes developed.<sup>2</sup>



### 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.



### 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

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.



### 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.



## 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/>



### Innovative Health Care Financing Strategies for Children and Youth with Special Health Care Needs. A Supplement to Pediatrics.

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](http://pediatrics.aappublications.org/content/139/Supplement_2/S89)



### Webinar: Innovative Health Care Financing Strategies for CYSHCN

In this webinar, AMCHP and state Title V programs helped define the role of Title V programs in VBP, discussed program examples, and shared lessons learned.

<http://cahpp.org/resources/webinar-innovative-health-care-financing-strategies-children-youth-special-health-care-needs-supplement-may-2017-issue-pediatrics/>

**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.<sup>1</sup>

## CITATIONS

1. McPherson, M., Arango, P., Fox, H., Lauver, C., McManus, M., Newacheck, P., Perrin, J., Shonkoff, J., & Strickland, B. (1998). A new definition of children with special health care needs. *Pediatrics*, 102(1):137-140.

2. Bachman, S., Comeau, M., & Long, T. (2017). Statement of the problem: Health reform, value-based purchasing, alternative payment strategies, and children and youth with special health care needs. *Pediatrics*, 139(Supplement 2), S89-S98. [http://pediatrics.aappublications.org/content/139/Supplement\\_2/S89](http://pediatrics.aappublications.org/content/139/Supplement_2/S89)

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.

## 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.<sup>1</sup>

Care coordination is crucial for children and youth with special health care needs<sup>2</sup> (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.



## 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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## CITATIONS

1. Bachman, S.S., Comeau, M. & Jankovsky, K.\* (2015). *The Care Coordination Conundrum and Children with Special Health Care Needs. What Is Care Coordination? Who Should Receive It? Who Should Provide It? How Should It Be Financed?* Lucile Packard Foundation for Children's Health. Palo Alto, California.

2. McPherson, M., Arango, P., Fox, H., Lauver, C., McManus, M., Newacheck, P., Perrin, J., Shonkoff, J., & Strickland, B. (1998). A new definition of children with special health care needs. *Pediatrics*, 102(1):137-140.

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