

# The Care Coordination Conundrum and Children and Youth with Special Health Care Needs

What Is Care Coordination?

Who Should Receive It?

Who Should Provide It?

How Should It Be Financed?

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The Catalyst Center: Improving Coverage and Financing of Care for Children and Youth with Special Health Care Needs

at  
Health & Disability Working Group,  
Boston University School of Public Health

with support from  
Lucile Packard Foundation for Children's Health

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## ABOUT THE FOUNDATION

The Lucile Packard Foundation for Children's Health is a public charity, founded in 1997. Its mission is to elevate the priority of children's health, and to increase the quality and accessibility of children's health care through leadership and direct investment. Through its Program for Children with Special Health Care Needs, the Foundation supports development of a high-quality health care system that results in better health outcomes for children and enhanced quality of life of families. The Foundation works in alignment with Lucile Packard Children's Hospital and the child health programs of Stanford University.

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## ABOUT THE CATALYST CENTER

The Catalyst Center is the National Center for Health Insurance and Financing of Care for Children and Youth with Special Health Care Needs, funded by the Division of Services for Children with Special Health Needs, Maternal and Child Health Bureau, Health Resources and Services Administration, US Department of Health and Human Services. The Catalyst Center is a project of the Health & Disability Working Group at the Boston University School of Public Health, providing technical assistance and educational resources on health insurance and financing to states and stakeholders, policy research to identify and evaluate financing innovations, and connections among those interested in working together to promote solutions to complex coverage and financing issues for children and youth with special health care needs.

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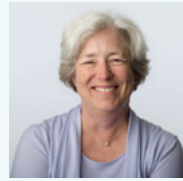
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## ACKNOWLEDGEMENTS

The Catalyst Center is grateful to the Lucile Packard Foundation for Children's Health for the generous funding that supported this project. We especially appreciate the helpful contributions of Edward Schor, Senior Vice President, Programs and Partnerships and Eileen Walsh, Vice President, Programs and Partnerships. We are also indebted to the many experts across the country who informed and improved this work by generously sharing their time, knowledge and insights with us. A list of these talented and thoughtful individuals is provided in Appendix B.

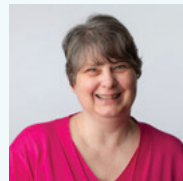
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# Executive Summary

**Children and youth with special health care needs (CYSHCN) generally require services from a broad range of providers and systems. As a result, they and their families have a greater-than-average need for high-quality care coordination. While the definition of care coordination is much debated, it generally involves an interdisciplinary approach to ensuring access to health care and social support services, in which a care coordinator manages and monitors an individual's needs, goals, and preferences based on a comprehensive plan.**

Support is nearly unanimous for care coordination as an essential benefit for CYSHCN.

**However, current care coordination payment methods have resulted in:**

- Poorly structured payment mechanisms
- Low reimbursement rates
- Insufficient incentives to pay for care coordination
- Lack of clarity about who is responsible for financing, providing and reimbursing for care coordination
- Overall limits on funding for services for CYSHCN, among others

Consequently, CYSHCN and their families experience gaps in services, inefficient patterns of care, and additional caregiving burden, all of which have a negative impact on child and family health and well being. In this paper we provide a comprehensive analysis of these issues as well as recommendations for moving the field forward.

Through a literature review, stakeholder interviews and policy analysis we examined various definitions and models of care coordination—including eligibility criteria and types of providers—and identified persistent barriers to adequate financing and reimbursement.

We concluded that broad financing and payment reform to support care coordination is imperative to ensure that all CYSHCN who need care coordination get it at the right time, in the right amount, by the right providers, and at the right cost.

Care coordination models must move away from narrowly focused programs and FFS financing and reimbursement in order to achieve long-term financial stability. Ultimately, payment for care coordination in the context of a risk-adjusted global budget is optimal. Pooling resources and sharing savings should help reduce financial risk and incentivize practice change. Linking care coordination to improved outcomes, increased quality, and greater accountability through the establishment of standardized process and outcome measures will assist in evaluating return on investment (ROI). Maximizing these strategies will help move the field closer to an adequate payment structure that benefits all stakeholders.

**We recommend that stakeholders work in partnership to:**

- 1 Develop a new care coordination paradigm grounded in pooled resources and broad population-based financing and reimbursement models that include CYSHCN as well as other population groups such as adults with chronic illnesses and frail elders.
- 2 Establish the evidence base for care coordination for children, and develop specific metrics and outcomes for the service, including return on investment (ROI) from multiple stakeholder perspectives, including payers, providers and families.
- 3 Develop risk-adjustment models for CYSHCN to level the playing field and encourage health plans and providers to enroll and serve high-need groups.
- 4 Identify the care coordination services that should be part of a bundled/capitated payment.
- 5 Link bundled or capitated payments to improved quality indicators and health outcomes.
- 6 Provide care coordination in teams that include licensed and non-licensed staff with shared responsibility for clinical and non-clinical coordination tasks. Include peer parents on these teams to increase appropriate family involvement, promote communication with family members and aid in quality improvement efforts.

# Introduction

**Care coordination is a team- and family-driven process that aims to facilitate access to services by children and adolescents, improve health care outcomes, increase satisfaction for families and health care practitioners, and reduce costs associated with health care fragmentation, which can lead to under- and over-utilization of care.<sup>1</sup>**

According to the federal Maternal and Child Health Bureau, children and youth with special health care needs (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>2,3</sup> CYSHCN and their families have a greater-than-average need for care coordination in part because they utilize services from a broader range of providers and systems than do children who are developing typically and their families.

Although the benefits of care coordination are generally well accepted, most of the evidence available to date has focused on adults and elders with chronic illnesses, not the pediatric population.

**As a result, barriers to sustainable financing and reimbursement for this service persist for CYSHCN and their families, including:**

- Poorly structured payment mechanisms
- Low reimbursement rates
- Insufficient incentives to pay for care coordination
- Lack of clarity about who is responsible for financing, providing and reimbursing for care coordination
- Overall limits on funding for services for CYSHCN, among others

Without an adequate payment structure to support their efforts, providers are challenged to sustain the costs of care coordination initiatives for CYSHCN.

Drawing on a robust array of stakeholder perspectives—including those of clinicians, payers, policymakers, and families—and a literature review and analysis, this report provides current information about barriers to financing and reimbursement of care coordination.

**Key questions that impact financing and reimbursement are addressed, including:**

- What is care coordination?
- Who is eligible to receive care coordination as a health benefit?
- Who provides care coordination?
- How is care coordination financed?
- How is care coordination reimbursed?

The report discusses key implications of our findings and presents recommendations and implementation strategies. Project methods are described in the Appendices.

## What Is Care Coordination?

Definitions of care coordination abound, operationalized differently in a variety of settings (see Appendix D). Care coordination is difficult to standardize due to differences in the way it is provided. Decisions on the target population, definition of the service, provider criteria and setting all have implications for which of the limited financing and reimbursement strategies currently available can be applied.

**Key attributes of care coordination as a benefit may include:**

- Active engagement of patients/families in needs assessment, planning, delivery and monitoring of care coordination
- Collaborative relationships with primary and specialty care providers in the geographic region
- System accountability
- Physician leadership
- Standardized protocols for care delivery and decision support tools
- Evidence-based screening tools to identify needs, including mental health problems in children
- Consideration of the social determinants of health

**Care coordination often comprises specific tasks such as:**

- Comprehensive needs assessment
- Care plan development
- Management of external referral processes and follow-up communication
- “Huddles” to discuss care needs and decide on strategies to address them
- Use of information technology tools such as emails and secure video conferencing, telephone, telehealth, online coaching and health promotion, electronic medical records, etc.
- Discharge planning and follow-up after hospitalization to prevent readmission

Some experts distinguish between care coordination and other related activities such as care management. These variations in care coordination activities have implications for reimbursement and financing. For example, according to the Safety Net Medical Home Initiative, care coordination includes non-clinical referral or transition management functions, while care management is more intensive clinical management provided by nurses or other health workers to high risk patients.<sup>4</sup> Thus, care management is both more likely to be billable and higher cost than care coordination due to the higher professional status, pay rate, and skill set of nurses or other licensed health care workers who provide care management.

## Who Is Eligible to Receive Care Coordination as a Health Benefit?

As with other health services, eligibility for care coordination depends on the service being covered as a health benefit. Thus health insurance payers often determine eligibility for care coordination. Loss of access to a particular payer can result in loss of access to care coordination, regardless of need. As shown in Table 1, a range of considerations is used to determine eligibility for care coordination.

Often CYSHCN are not specifically identified as a target population to receive care coordination as a benefit if it is offered, in part because of the lower-prevalence conditions CYSHCN experience. Some argue that it is more difficult to identify a well-defined list of conditions or diagnoses for children than for adults.

**TABLE 1 Who is eligible to receive care coordination?**

Eligibility Criteria	Considerations	
<b>Diagnosis- or condition-specific</b>	<p>Child must have specific diagnosis or condition</p> <p>Diagnostic or condition-specific criteria are influenced by a variety of factors, such as state/federal requirements, payer interests, advocacy efforts, and clinical judgment</p>	<p>As a result, children have access to care coordination based on varying criteria, which are not necessarily linked to whether they would benefit from care coordination</p>
<b>Medicaid eligibility</b>	<p>Child must be enrolled in Medicaid</p> <p>Medicaid-sponsored care coordination/case management activities vary across states, programs and eligibility categories</p>	<p>Access to care coordination financed by Medicaid is limited and variable both within and among states</p>
<b>Age</b>	<p>Age criteria may be influenced by a variety of factors, such as state/federal requirements, payer interests, advocacy efforts, and clinical judgment.</p>	<p>Age criteria force transition issues when a child ages out of eligibility for the program providing care coordination</p> <p>Age criteria will inevitably result in some children/young adults being excluded</p>
<b>Utilization or cost to payer</b>	<p>Care coordination eligibility is limited to children with high health care use and/or cost</p> <p>Payers may identify the need for care coordination through the utilization of “unnecessary” or “avoidable” services (Emergency Department use, for example), even though these services are not avoidable for some CYSHCN and may not necessarily indicate the need for care coordination. Conversely, CYSHCN who need care coordination but do not utilize these services may be missed</p>	<p>Cost savings may be anticipated although return on investment (ROI) has not yet been consistently demonstrated</p> <p>Given budget constraints and the need for ROI, eligibility criteria based on cost may be set without best-practice evidence</p>
<b>High risk</b>	<p>Eligibility for care coordination may be determined by risk, defined by:</p> <ul style="list-style-type: none"> <li>• High cost to payers</li> <li>• Poor health or health care quality outcomes</li> <li>• Medical and/or social complexity, including family functioning</li> <li>• Involvement with programs such as foster care/child welfare</li> <li>• Mental/behavioral health concerns</li> </ul>	<p>Eligibility based on risk fragments the population of CYSHCN into limited categories. It can be driven by the needs of organizations rather than by the needs of individual children and families. Gaps or redundancy can result when children qualify under more than one risk category</p>



**TABLE 2 Who provides care coordination services and supports?**

Provider	Considerations
Paid staff, including physicians, nurses, school nurses, social workers, administrative staff or paraprofessionals	<p>Different levels of care coordination are provided at different sites by different staff</p> <p>Each type of model has implications for what is provided:</p> <ul style="list-style-type: none"> <li>• Medical practices often provide information and referral-related services</li> <li>• Payers often offer disease- or condition-specific case management</li> <li>• Public agencies typically offer care coordination activities specific to their area of focus</li> <li>• Some communities offer collaborative care coordination across agencies/programs</li> </ul> <p>Reimbursement options are limited by provider’s professional practice (license, activity, etc.)</p>
Family members of CYSHCN	<p>Very little opportunity for funding or reimbursement for family members</p> <p>Families have ultimate accountability with little financial support for care coordination activities</p>

**Who Provides Care Coordination?**

A range of professional and/or administrative staff provide care coordination, with various implications for financing and reimbursement (see Table 2). In some settings, such as large, multidisciplinary community health centers, it may be impossible to know all the staff who provide elements of care coordination, and the responsibility is often distributed among team members in a practice.

Care coordination models vary widely. Care coordination can be integrated into the “work flow” of clinical or administrative teams, performed by a separate department or contracted out to a vendor. In some cases, a hybrid of these options may be used to coordinate care.

The choice of model affects financing and reimbursement possibilities. For example, non-clinical or non-licensed staff cannot easily bill for reimbursement, and payers may impose limits on the amount that can be billed for care coordination services. For programs that use licensed or credentialed staff, variability exists regarding required professional credentials, but typically they include registered nurses or social workers. “Licensed clinician” might include anyone with a license appropriate for a particular child’s needs, including mental health or behavioral health providers.

Individual families play a critical role in care coordination, providing labor-intensive and uncompensated work that in turn props up dysfunctional and fragmented systems. Some small-scale efforts have been made to compensate families for their care coordination activities on behalf of their children. Compensating family members for care coordination activities could save money, though fraud may become a concern. Family involvement helps keep care coordination activities accountable and promotes communication, given that the child and family are the locus of the service.

An ongoing systemic problem is the confusion that results when families are assigned multiple, program-specific care coordinators. These program- or benefit-dedicated care coordinators are not responsible for all care coordination required by an individual child, and as a result families must coordinate all of the various care coordinators who are assigned to their child.<sup>5</sup> One interviewee suggested that care coordination tools and training could be developed to empower families to more effectively and efficiently manage their role as informal but essential care coordinators.

**How Is Care Coordination Financed?**

Care coordination may be financed through a range of public and private sources (see Table 3).<sup>6</sup>

Sometimes, there is collaboration between public and private funding sources. For example, Vermont’s Blueprint for Health funds community health teams through a multi-payer model that includes Medicare, Medicaid, and three large commercial insurers to pay providers based on Patient-Centered Medical Home (PCMH) status through a per-member- per-month (PMPM) payment. Multidisciplinary Community Care Teams (CCTs), designed to increase care coordination for patients with chronic conditions as well as promote prevention and health-maintenance efforts, are financed by payments made from all payers involved in the initiative.<sup>7</sup>

**TABLE 3 How is care coordination financed?**

Financing Mechanism	Considerations	
<p><b>Medicaid/Children's Health Insurance Program (CHIP)</b></p>	<p>Medicaid/CHIP programs have no single, uniform care coordination model</p> <p>Medicaid/CHIP financing mechanisms include: EPSDT, Targeted Case Management, Section 2703 Health Homes, Home and Community-based Service waivers, and managed care organizations</p> <p>As a result, there is wide variability in care coordination models among states and within programs</p>	<p>Funds are limited</p> <p>Medicaid Managed Care programs have specific contractual obligations that may or may not include care coordination</p> <p>Section 2703 Health Homes receive 90% federal funding, but only for two years</p> <p>Eligibility for enrollment in Medicaid/CHIP is limited</p>
<p><b>Title V MCH/CYSHCN programs</b></p>	<p>Financing for Title V care coordination may come from different sources:</p> <ul style="list-style-type: none"> <li>• Title V alone: Block Grant, general funds, pilots/ grants</li> <li>• Blended funding for specific groups of CYSHCN (for example, funding for Medicaid-enrolled CYSHCN involved with Title V)</li> </ul>	<p>Wide variability exists among states in what is provided, how it is paid for, and eligibility criteria</p> <p>Financing is limited, and there is no state Title V program that offers care coordination to <i>all</i> the CYSHCN in the state</p> <p>Title V care coordination typically includes only Information and Referral services</p>
<p><b>Part C of the Individuals with Disabilities Education Act (also known as Early Intervention/ Birth to Age 3)</b></p>	<p>Part C is limited to children ages 0 to 3 years</p> <p>Specific legislative definition of service coordination under Part C also includes the mandate that an Individual Family Service Plan (IFSP) be created, carried out, and monitored</p>	<p>Unlike an Individual Education Plan (IEP) under special education law, the IFSP must include family needs as well as the child's needs</p> <p>Services are provided in the natural environment (home, day care, etc.)</p> <p>Blended funding (billing private insurers for part of the cost of care and care coordination) is a state option</p>
<p><b>Other state agencies (Mental Health, Child Welfare, Developmental Disabilities, etc.)</b></p>	<p>State agencies are often siloed and care coordination activities are not integrated across agencies</p> <p>Blending funds across agencies can stretch limited care coordination dollars to benefit children served by multiple agencies</p>	<p>Other state agency funding may be linked to Medicaid enrollment, so that children will only receive services from other state agencies if they are Medicaid eligible.</p> <p>Services may be limited by diagnosis/condition or other agency criteria (involvement with child welfare, for example)</p>
<p><b>Commercial insurers</b></p>	<p>Purchased benefit through an employer-sponsored insurance package</p> <p>Often based on adult disease management rather than care coordination</p>	<p>Wide variability among payers</p> <p>Increasing prevalence of high-deductible health plans may limit care coordination</p>
<p><b>Publicly and privately financed grants/pilots</b></p>	<p>Time-limited; sustainability an important issue</p> <p>Program design dependent on requirements/ interests of funder (not necessarily the needs of consumers/providers)</p>	<p>Eligibility limited to specific target populations</p>
<p><b>Other</b></p>	<p>Care coordination activities may be provided in some programs, but may not be labeled as such, e.g., home visiting, home health care, visiting nurse services, school-based services, etc.</p>	<p>Other sources of care coordination funding include Tobacco Settlement Trust Funds, hospital fees from newborn screening, and Title XX Social Services Block Grant, among others</p>

## How Is Care Coordination Reimbursed?

Reimbursement for care coordination happens through a limited set of mechanisms as shown in Table 4.

Fee-for-service (FFS) care coordination billing does not promote team or person-centered care.<sup>9</sup> Specific requirements accompany use of the codes, and additional work is attached to learning the new codes and the rules for implementing them. Sustainable FFS care coordination models are lacking, in part because there has not been an accompanying analysis of the longer term ROI for care coordination. Physician practices would bill more routinely for care coordination if they thought it was worth it to do so (interview data).

Using CPT coding as a payment methodology for non-face-to-face services such as care coordination has associated problems. For example, there is a serious need for payment for telehealth services. However, billing for these services requires additional documentation and administrative work, and the rates for the codes are often seen as inadequate. Further, providers may lack systems to bill for the codes.

McClanahan and Weismuller (2014) highlight recurring themes around the financing of care coordination provided by school nurses, including “lack of adequate funding and reimbursement for providing care coordination” which could be ameliorated through

structural changes designed to provide “adequate reimbursement for non-physician-delivered care coordination, [and] reimbursement for non-face-to-face activities.”<sup>10</sup>

Rather than fee-for-service reimbursement, risk-adjusted payments based on a capitated payment that includes care coordination are being used, especially in “closed system” health plans. To extend the use of capitation, additional work is needed to identify the services that are part of a bundled/capitated payment as well as methods for risk sharing and shared savings opportunities to promote quality and accountability.

Pay-for-performance (P4P) can also be used in conjunction with other reimbursement models to pay for care coordination. Landon (2014) argues, however, that continuing the current FFS payment system, even when blended with fixed PMPM, pay-for-performance, or shared savings payments, does not incentivize behavior change, because the system still favors reimbursement for billable, face-to-face visits.<sup>11</sup>

Even when FFS codes exist for non-face-to-face interactions such as care coordination, and other types of payment reform such as pay-for performance are used, there is little evidence to suggest that these models are increasing care quality or decreasing care costs.

**TABLE 4 How is care coordination reimbursed?**

Reimbursement Mechanism	Considerations
<b>Fee-for-service payment using Current Procedural Terminology (CPT) codes</b>  See Appendix E for sample codes <sup>8</sup>	Medicaid care coordination CPT codes (e.g., medical team conferences, complex chronic care coordination services, transitional care-management services)  Medicare is implementing CPT codes for care coordination, supplemented by per member per month (PMPM)  Many other payers have not implemented CPT codes for care coordination  There are strict limits on who can bill through CPT codes
<b>Capitated payment by health plan</b>	Health plan hires care coordinator/case manager  Decision about where care coordinator is based has practice and cost implications for payer and provider
<b>Global or bundled payment to Accountable Care Organization (ACO)</b>	ACO hires care coordinator/case manager  Decision about where care coordinator is based has practice and cost implications for payer and provider
<b>Line item in department, agency or organization budget for salaried staff</b>	Requires commitment to add salaried staff to budget  May be difficult to initiate/sustain in times of fiscal restraint  Hard to demonstrate return on investment



# Key Implications

**Payers, providers, policymakers, families and other stakeholders generally agree that care coordination is a valuable service for CYSHCN and their families. There is also agreement that a positive ROI from care coordination is undetermined to date but likely long-term, perhaps over a child's life course, and thus does not accrue to any single stakeholder in one-year budget cycles. In contrast, no consensus exists about what care coordination is, who should provide it, who should receive it, and how it should be paid for.**

Efforts to define and operationalize care coordination require specific model design choices, primarily by payers. These model design choices are necessarily interrelated, and their effects interact upon implementation. For example, if care coordination is targeted to children who are high utilizers of inpatient hospital services, that will have implications for whether licensed staff are needed to provide the service, due to the complexity of the need, reimbursement rules, health care coverage eligibility requirements, and the setting in which the service is provided. Thus, once a specific program design choice is made, that choice will affect other design aspects of the care coordination model, the program's implementation and take-up in the field.

Without the opportunity to grow to scale, developing the evidence base for care coordination remains challenging. Narrowly defined, targeted models and grant-funded small projects based on the factors described above (payer, provider type, etc.) offer results that are not necessarily generalizable across all CYSHCN and are often dismissed by policymakers as too narrowly focused to "prove" efficacy or cost-effectiveness. The lack of a shared definition of care coordination impedes efforts to measure its outcomes or develop a clear evidence base about its value. Efforts to specify ROI for care coordination from a cost-savings perspective have not been successful. Refocusing this energy on developing pay-for-performance strategies within integrated systems may be more promising.

Fee-for-service reimbursement for care coordination will likely not be successful in achieving the goal of financially supporting a high-quality, sustainable system of care coordination for all CYSHCN. Key stakeholder interviews consistently revealed that CPT codes for care coordination are not catching on, due to low payment levels, strict limits on their use, administrative staff time and attention needed to make systemic use of them, and the fact that care coordination can be successfully provided by non-reimbursable paraprofessionals.

Although some providers are using the codes, this does not necessarily lead to adequate reimbursement for care coordination. Providers are reluctant to bill for care coordination using the codes in part because they do not perceive the reimbursement as worth the time or labor spent in doing so. Perhaps more aggressive advocacy by clinicians will increase reimbursement rates for care coordination, but that seems unlikely, absent more robust evidence regarding ROI and in the current economic environment.

Moreover, care coordination is needed because children receive services from a wide array of providers housed in a variety of siloed systems, and there is no mechanism built into a FFS model to incentivize communication and coordination among these many providers. It also follows, then, that FFS reimbursement for care coordination is unlikely to be as effective as systems that promote integration and pool funding to support that integration.

Further, CYSHCN frequently move among different sources of insurance coverage, especially when covered under income-sensitive options such as Medicaid and CHIP. The Affordable Care Act of 2010 has introduced new opportunities for expanding children's coverage and, as a result, heightened concerns that children will move among these options.<sup>12</sup> Reliance on funding of care coordination by individual payers through FFS reimbursement means continued risk of fragmentation and discontinuity.

Overall, current financing and reimbursement models are inadequate to support a high-quality, sustainable system of care coordination. Absent funding for an *integrated* system of care coordination, based on an individual child and family's needs, access is predicated on other factors (payer, provider type, location of care, diagnosis, program enrollment, etc.) as outlined in Table 1. Available funding determines access to care coordination.

Few interview results and almost no literature were devoted to information on specific strategies to support the important, unreimbursed contribution of individual families and other informal caregivers. Program-design choices, as described above, may mean any particular care coordination model targets a subset of all CYSHCN. Regardless of the specific choices that are made, the fact that the choices are made at all means that the care coordination tasks are pushed onto other, not specifically reimbursed resources, including families. Ultimately, responsibility for coordinating care falls on the child's family, and external supports are needed to ease their burden.

# Recommendations and Next Steps

**The nearly unanimous support for care coordination as an essential benefit for CYSHCN has not been translated into sustainable financing and reimbursement for this service, and as a result CYSHCN and their families experience gaps in services, inefficient patterns of care, and additional caregiving burden.**

To make the transition from the messy status quo to a high-performing system of care for CYSHCN, care coordination strategies must move away from targeted programs and fee-for-service financing and reimbursement to a risk-adjusted global budget that facilitates broad eligibility and provides sustainable, adequate provider reimbursement.

**While we move toward financing reform for care coordination, payment strategies that can be implemented in the interim include:**

- Primary Care Case Management (PCCM)
- Pay for Performance (P4P) schemes
- Per-Member Per-Month (PMPM) payments provided within the context of a patient-centered medical home

**Stakeholders can draw on practices already implemented as described above, such as:**

- Care coordination provided within a state-wide system of non-clinical services that facilitate access to health care, such as the Title V MCH/CSHCN program
- Payer-sponsored care coordination or case-management programs, such as those in Managed Care Organizations (MCOs)
- Section 2703 Health Homes for Medicaid enrollees under the Affordable Care Act

While these strategies can be implemented as interim financing and payment methods, they will not lead to a sustainable model of financing and reimbursing care coordination that is broadly available to all CYSHCN who require care coordination and their families. For this transformation, broader financing and payment reform is necessary.

**Our analysis leads us to recommend that stakeholders work in partnership to:**

- 1** Develop a new care coordination paradigm grounded in pooled resources and broad population-based financing and reimbursement models that include CYSHCN as well as other population groups such as adults with chronic illnesses and frail elders.
- 2** Establish the evidence base for care coordination for children and develop specific metrics and outcomes for the service, including return on investment (ROI) from multiple stakeholder perspectives, including payers, providers and families.
- 3** Develop risk-adjustment models for CYSHCN to level the playing field and encourage health plans and providers to enroll and serve high-need groups.
- 4** Identify the care coordination services that should be part of a bundled/capitated payment.
- 5** Link bundled or capitated payments to improved quality indicators and health outcomes.
- 6** Provide care coordination in teams that include licensed and non-licensed staff with shared responsibility for clinical and non-clinical coordination tasks. Including peer parents on these teams will increase appropriate family involvement, promote communication with family members and aid in quality improvement efforts.

Providers have been challenged to meet the care coordination needs of CYSHCN and their families due to unsustainable models of financing and reimbursement. Ultimately, payment for care coordination in the context of a risk-adjusted global budget is optimal; pooling resources and sharing savings should help reduce financial risk and incentivize practice change. Linking care coordination to improved outcomes, increased quality, and greater accountability through the establishment of standardized process and outcome measures will assist in evaluating return on investment (ROI). Maximizing these strategies will help move the field closer to ensuring that all CYSHCN who need care coordination get it at the right time, in the right amount, by the right providers, and at the right cost.

## Appendix A: Methods

**We conducted a literature review, stakeholder interviews, and policy analysis to gather and analyze relevant data and identify options for financing and reimbursement of care coordination for CYSHCN. We included literature on reimbursement for care coordination mechanisms that have been implemented with adult populations such as Medicare beneficiaries.**

In addition, we conducted and analyzed the results of key informant interviews with stakeholders, including nationally recognized experts in financing care coordination and related areas such as medical-home implementation, payment reform, integrated care systems, coding and reimbursement policy, family-professional collaboration and communication, and health care quality initiatives (*see Appendix B for a list of interviewees*).

Interviews were conducted over the telephone, directed by a semi-structured interview guide (*see Appendix C for a copy of the guide*). The interviews focused on specific care coordination financing and reimbursement strategies and barriers to implementing these strategies. We took detailed notes during the interviews, wrote a summary following each interview, and sent the notes to the key informant to review and edit. We analyzed the data using qualitative methods to identify themes, focusing on concrete and specific barriers and evidence-based practices that successfully pay for care coordination.

In addition to key informant interviews, we drew on data gathered from the Catalyst Center 2014/15 structured interview project on health care financing initiatives with Title V Maternal and Child Health (MCH) and Children with Special Health Care Needs (CSHCN) directors, as well as historical data gathered from Medicaid staff and family leaders (all 50 states, Puerto Rico and the District of Columbia) to identify mechanisms currently used to pay for care coordination. We have categorized prior interview results into relevant themes for analysis, including care coordination.<sup>13</sup> Our methods were reviewed and approved by the Boston University Medical Campus Institutional Review Board.

## Appendix B: Key Informants

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# Appendix C: Semi-structured Interview Guide

## Options For Financing Care Coordination For Children And Youth With Special Health Care Needs: Key Stakeholder Interview Guide



According to the American Academy of Pediatrics (AAP), care coordination is a team- and family-driven process that improves family and health care practitioner satisfaction, facilitates children's and youth's access to services, improves health care outcomes, and reduces costs associated with health care fragmentation, which can lead to under- and overutilization of care. In this interview, we are specifically focused on reimbursement mechanisms for care coordination, with the *a priori* understanding that care coordination is an essential service for CYSHCN.

### 1. CAN YOU IDENTIFY A LOCATION OR A MODEL WHERE CARE COORDINATION IS REIMBURSED AS A HEALTH BENEFIT?

- a. If so, how does this work in terms of the service itself: level, frequency, intensity?
- b. Is there any measurement or evaluation of the program that you are aware of? If so, please describe.



### 2. WHAT ARE THE ELIGIBILITY GUIDELINES FOR CARE COORDINATION? HOW ARE PRIORITY POPULATIONS IDENTIFIED? IS THERE TIERING OF THE ELIGIBLE POPULATION? WHO MAKES ELIGIBILITY DECISIONS? PROMPTS:

- a. Program participation (Part C of IDEA; payer enrollee, etc.)
- b. Medical complexity
- c. High utilization/cost
- d. Family income
- e. Age of child
- f. Geography
- g. Setting (hospital admission, Accountable Care Organization, managed care enrollee)
- h. Psychosocial risk (impact of social determinates of health)

### 3. WHO PROVIDES CARE COORDINATION? PROMPTS:

- a. Practice-based care coordinators
- b. Practice-based health care team
- c. Care coordinators external to practices (hospital-based; health plan employees);
- d. Community care teams
- e. Statewide, Title V care coordination systems
- f. Others



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**4. DESCRIBE SOURCES OF PAYMENT FOR CARE COORDINATION IN THIS MODEL: PRIVATE INSURANCE, MEDICAID, CHIP, TITLE V, IDEA PART B & C, BLENDED FUNDING, SECTION 2703 HEALTH HOMES UNDER THE AFFORDABLE CARE ACT, OUT-OF-POCKET.**

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**5. WHAT MECHANISM IS USED TO REIMBURSE PROVIDERS? DOES THIS MECHANISM VARY BY PROVIDER TYPE? WHAT REIMBURSEMENT RATES ARE USED? IS THERE TIERING OR RISK-ADJUSTING OF PAYMENT? IF SO, WHAT FACTORS ARE CONSIDERED (MEDICAL COMPLEXITY, PSYCHOSOCIAL RISK, ETC.) PROMPTS:**

- a. Fee For Service based on CPT codes (99636-00638) and may be linked to time devoted to service;
- b. Capitated PMPM;
- c. Contract for services;
- d. Billing for consultation;
- e. Administrative services;
- f. Telehealth;
- g. Home visiting programs;
- h. External Quality Review Organization practice improvement projects;
- i. Section 2703 Health Homes (state option under the Affordable Care Act);
- j. Pilot/grant funded projects;
- k. Targeted case management through Medicaid reimbursement;
- l. Shared resource supported by independent practices
- m. Other

**In addition to reimbursement, what are the other financial implications of these models? Prompts:**

- a. Start-up costs Sustainability
- b. Unreimbursable administrative costs
- c. Demand for services

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**6. WHERE DO THE UNCOMPENSATED CONTRIBUTIONS OF FAMILIES FIT IN? ARE THEY BEING MONITORED OR MEASURED? IF SO, HOW?**

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**7. IS CARE COORDINATION PAID FOR IN OTHER SERVICE SYSTEMS SUCH AS EDUCATION? IF SO, HOW?**

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**8. IS THERE ANY INTEGRATION OR COORDINATION BETWEEN DIFFERENT AGENCIES/ORGANIZATIONS PROVIDING CARE COORDINATION TO CYSHCN? IS THERE ANY POOLING OR BLENDING OF FUNDING FOR CARE COORDINATION BETWEEN AGENCIES/ ORGANIZATIONS?**

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**9. WHAT IS THE MOST IMPORTANT IMPEDIMENT TO CARE COORDINATION REIMBURSEMENT?**

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## Appendix D: Care Coordination Definitions

Source	Definition or key attributes
American Academy of Pediatrics (AAP) (2014) <sup>14</sup> Antonelli & Antonelli (2004) <sup>15</sup>	Care coordination should be a team- and family-driven process that improves family and health care practitioner satisfaction, facilitates children's and youth's access to services, improves health care outcomes, and reduces costs associated with health care fragmentation, which can lead to under- and overutilization of care
Antonelli, McAllister & Popp (2009) <sup>16</sup>	Pediatric care coordination is a patient and family centered, assessment driven, team based activity, designed to meet the needs of children and youth while enhancing the caregiving capabilities of families. Care coordination addresses interrelated medical, social, developmental, behavioral, educational and financial needs to achieve optimal health and wellness outcomes.
Au et al. (2011) <sup>17</sup>	Both organizational setting and financing affect care coordination; insurance coverage type (private, public, dual eligible for Medicare and Medicaid, or no insurance at all) influences both the type of care coordination services and when these services are received.
Berenson & Howell (2009) <sup>18</sup>	A person-centered, assessment-based interdisciplinary approach to integrating health care and social support services in which a care coordinator manages and monitors an individual's needs, goals, and preferences based on a comprehensive plan
Safety Net Medical Home Initiative (2013) <sup>19</sup>	Care coordination begins with the thoughtful identification of key service providers in the community followed by the deliberate organization of patient care activities between two or more participants involved in a patient's care to facilitate the appropriate delivery of health care services.
Silow-Carroll & Hagelow (2010) <sup>20</sup>	Essential components of care coordination for children including the importance of early and thorough screening as well as enrollment into effective interventions; the need for not only comprehensive screening, but also "subsequent action" in order to effectively address early childhood developmental delays; and the importance of coordinated care, particularly for families given the complex needs, issues, and social contexts and systems in which families must operate to receive care.
Silow-Carroll et al. (2014) <sup>21</sup>	Care coordination comprises variable components across states and systems of care and can be provided by a great range of professional and non-professional staff supported by various payers and forms of payment

# Appendix E:

## Coordination of care (physician management) CPT codes<sup>22</sup>

### PROLONGED SERVICES (WITH DIRECT PATIENT CONTACT)

These are used when a physician provides prolonged service in an inpatient or outpatient setting that is beyond the usual service provided. They can be billed in addition to the E/M code.

#### Inpatient

99354 first 74 min  
99355 each additional 30 min

#### Outpatient

99356 first 74 min  
99357 each additional 30 min

### PROLONGED SERVICES (WITHOUT DIRECT PATIENT CONTACT)

This refers to such services as reviewing records, communication with other providers or the patient and/or family.

99358 first 74 min  
99359 each additional 30 min

### CASE MANAGEMENT SERVICES

This refers to Team Conferences needed to coordinate the activities of patient care. They may occur during a hospitalization or after discharge and the patient or family need not be present. *\*\*Each physician present can bill this code separately.*

99361 approximately 30 min

99362 approximately 60 min

### ADDITIONAL SERVICES

There are additional codes for phone calls which involve active management of a problem over the phone, e.g., the after-hours call that prevents an ER visit. They can also be used when management or coordination involves phone communication with a pharmacy, lab, social worker, home care provider, therapist, or other physician.

99371 brief call (< 10 min)

99372 intermediate call (10-20 min)

99373 complex call (> 20 min)

# References

1. American Academy of Pediatrics, Council on Children with Disabilities and Medical Home Implementation Project Advisory Committee. (2014). Patient- and family-centered care coordination: A framework for integrating care for children and youth across multiple systems. *Pediatrics*, Volume 133(5):e1451-60.
2. Health Resources and Services Administration, Maternal and Child Health Bureau. (2015). Title V Maternal and Child Health Services Block Grant Program. Retrieved from <http://mchb.hrsa.gov/programs/titlevgrants/>.
3. 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.
4. Safety Net Medical Home Initiative. Horner K., Schaefer J., Wagner E. (2013). Care Coordination: Reducing care fragmentation in primary care. In K. E. Phillips & V. Weir (Eds.) *Safety Net Medical Home Initiative Implementation Guide Series*. 2nd ed. Seattle, WA: Qualis Health and The MacColl Center for Health Care Innovation at the Group Health Research Institute.
5. Hughes, D., & Lee, P. R. (2014). Reflections and responses: Six models for understanding how families experience the system of care for children with special health care needs (Report). Lucile Packard Foundation for Children's Health.
6. Hong, C. S., Siegel, A. L., & Ferris, T. G. (2014). Caring for high-need, high-cost patients: What makes for a successful care management program? The Commonwealth Fund.
7. Berenson, R., & Howell, J. (2009). Structuring, financing, and paying for effective chronic care coordination: A report commissioned by the National Coalition for Care Coordination (N3C). Urban Institute.
8. American Academy of Pediatrics. (2014). Non-face-to-face Care Options in 2014. *AAP Pediatric Coding Newsletter Online*.
9. Derrett, S., Gunter, K. E., Nocon, R. S., Quinn, M. T., Coleman, K., Daniel, D. M., Wagner, E. H., & Chin, M. H. (2014). How 3 rural safety net clinics integrate care for patients: A qualitative case study. *Medical Care*, 52, S39-S47.
10. McClanahan, R. & Weismuller, P. C. (2014). School nurses and care coordination for children with complex needs: An integrative review. *Journal of School Nursing*, 1-10.
11. Landon, B. E. (2014). Structuring payments to patient-centered medical homes. *JAMA*, 312(16), 1633-34.
12. Sommers B.D., & S. Rosenbaum (2011). Issues in health reform: How changes in eligibility may move millions back and forth between Medicaid and insurance exchanges. *Health Affairs*. 30(2):228-36.
13. Catalyst Center, Health & Disability Working Group at Boston University School of Public Health. (2015). Online State-at-a-glance Chartbook. Retrieved from <http://www.hdwg.org/catalyst/state-data-chartbook>.
14. American Academy of Pediatrics, Council on Children with Disabilities and Medical Home Implementation Project Advisory Committee. (2014). *Op Cit*.
15. Antonelli, R. C., & Antonelli, D. M. (2004). Providing a medical home: The cost of care coordination services in a community-based, general pediatric practice. *Pediatrics*, 133(5), 1522-1528.
16. Antonelli, R. C., McAllister, J. W., & Popp, J. (2009). Making care coordination a critical component of the pediatric health system: A multidisciplinary framework. The Commonwealth Fund.
17. Au, M., Simon, S., Chen, A., Lipson, D., Gimm, G., & Rich, E. (2011). Comparative effectiveness of care coordination for adults with disabilities (research brief). Mathematica Policy Research, Center on Health Care Effectiveness.
18. Berenson, R., & Howell, J. (2009). *Op Cit*.
19. Safety Net Medical Home Initiative. Horner K., Schaefer J., Wagner E. (2013). *Op Cit*.
20. Silow-Carroll, S., & Hagelow, G. (2010). System of care coordination for children: Lessons learned across state models (issue brief). The Commonwealth Fund.
21. Silow-Carroll, S., Ehrenpreis, B., and Rosenstein, S. (2014). Care coordination for California's children and youth with special health care needs: Building blocks from other states. Health Management Associates.
22. American Academy of Pediatrics. (2014). Non-face-to-face Care Options in 2014. *AAP Pediatric Coding Newsletter Online*. *Op Cit*.