# Improving Care for Children and Families with Complex Needs:

## Enhancing Care Coordination in Connecticut

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Ideas and Information

to Promote the Health of

Connecticut's Children

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## About the Child Health and Development Institute of Connecticut:

The Child Health and Development Institute of Connecticut (CHDI), a subsidiary of the Children's Fund of Connecticut, is a not-for-profit organization established to promote and maximize the healthy physical, behavioral, emotional, cognitive, and social development of children throughout Connecticut. CHDI works to ensure that children in Connecticut, particularly those who are disadvantaged, will have access to and make use of a comprehensive, effective, community-based health and mental health care system.

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# Executive Summary

This IMPACT articulates the need for care coordination to help children and families navigate complex health systems, reviews the evolution of care coordination in the physical and behavioral health fields nationally, provides an overview of existing care coordination programs in Connecticut, and makes recommendations to improve policies, systems, and practices.

## The promise of coordinated care

There are nearly 140,000 children in Connecticut who have complex physical, developmental, or behavioral health needs that require frequent and more intensive services. Their families find themselves working with multiple providers and often serve as the primary source of communication between them. These families want help coordinating services, but 40% report not receiving help. As care systems have grown more complex, care coordination has been put forth as a strategy to not only help families, but also to benefit providers and systems through integration and enhanced communication that can improve outcomes and reduce costs.

There is no single definition of care coordination, and programs that identify as providing the service vary greatly in how they operate and the outcomes on which they focus. In some ways, this reflects the flexibility needed to use care coordination as a strategy across multiple settings and varied situations, but the lack of consensus on what care coordination is makes it difficult to identify best practices that can be implemented widely and consistently. If care coordination is to deliver better experiences and improved outcomes for families, greater precision and consideration of what it is and how it should work is needed.

## Care coordination can improve outcomes by broadening the view of health

Care coordination grew out of health navigation in primary care and case management in behavioral health. This parallel development has resulted in similar conversations split across the two fields. There is growing recognition that behavioral health is an important component of overall health in individuals; while the systems delivering services are often separate, the health needs of individuals are intertwined and overlapping. Aligning efforts across physical and behavioral health systems, recognizing the importance of each domain, can improve experiences for children and families.

Care coordination, with its focus on the needs of the family, is well-positioned to address the social, economic, and environmental factors that influence an individual's health. Research on these social determinants of health has increased in recent years and it is estimated that they account for 50% of health outcomes. In addition to these social determinants, racism and trauma exposure negatively impact health. Racism, a component of social and community context, impacts health on multiple levels, with both structural and interpersonal racism resulting in health inequities.

## Connecticut has strong examples of care coordination programs

Connecticut has multiple care coordination initiatives, both within and across the primary and behavioral health care systems. Compared to other states, Connecticut has a robust system of care. System level initiatives include the state's Connecticut Network of Care Transformation (CONNECT) Initiative, which, along with the Children's Behavioral Health Plan and its Implementation Advisory Board, works to develop and sustain a network of care across primary care, behavioral health, education, social services, and other child-serving systems.

The Department of Public Health's Medical Home Initiative for Children and Youth with Special Health Care Needs collaborates with the Connecticut Children's Center for Care Coordination, the United Way Child Development Infoline, and others to improve systems-level care, convene regional collaboratives, and provide direct care coordination to children and families. Other examples of programs in Connecticut providing direct care coordination services to children and families with demonstrated positive outcomes are Help Me Grow and WrapCT.

Though Connecticut benefits from these and other strong programs, there are opportunities to enhance care coordination in the state. Care coordination programs are well-positioned to help systems deliver care that is more family-centered, integrated across physical and behavioral health, and able to address the social determinants of health to improve outcomes for children and families.

## Recommendations for aligning, expanding, and strengthening care coordination

This IMPACT includes recommendations at the policy, system, and program levels to expand and improve care coordination services in the state, including:

- **Promote policies that directly address the conditions that lead to poor health and health disparities, particularly racial and ethnic health disparities.**
- **Ensure that care coordination services address social determinants of health.**
- **Remove barriers to integrating primary and behavioral health care.**
- **Use Wraparound principles to implement a family-driven approach to care coordination**

# Introduction

For most families, balancing the demands of work, school, daily living, and extracurricular activities can be difficult. Keeping up with medical visits such as well-child visits, annual vaccines, dental exams, and other recommended appointments can also be challenging. For the families of children needing a higher level of physical or behavioral health care than the average child, all of these logistics and challenges are even more difficult. Underlying social and economic conditions and individual experiences, such as racism, trauma, and financial insecurity, can create or exacerbate health needs or create barriers to accessing services. Accessing care is further complicated by the current pandemic and the need to use telehealth platforms. Care coordination plays a critical role in supporting families with multiple physical or behavioral health needs and is shown to reduce costs associated with care.

In Connecticut, approximately one in five children has complex health, developmental, or behavioral needs requiring more frequent or more intensive care than a child in the general population typically uses.[1] These families work with multiple providers, and are often faced with navigating a fragmented care system, negotiating insurance coverage, advocating for education accommodations, ensuring critical communication across providers, and accommodating frequent but often uncoordinated appointments. Financial stressors from out-of-pocket expenses and the emotional strain of caring for and worrying about their child with complex needs[2] can also be overwhelming.

Families deserve coordinated care that is centered on meeting their needs and promoting child well-being. Research-supported strategies for care coordination help systems reduce the burden on families, strengthen logistics and communication, promote health equity and culturally competent care, and improve outcomes and care experiences for children and families.

Care coordination is central to many health reform efforts, since it is shown to reduce costs and improve health outcomes for children with complex conditions. The Institute of Medicine identified care coordination as a priority area to focus on in transforming health care, one that cuts across the continuum of care and is relevant across the lifespan.[3] In the United States, care coordination was subsequently adopted as one of six national priority areas identified to advance health care improvement efforts.[4] Care coordination has also been identified as a "building block of high-performing primary care."[5] However, while there is widespread enthusiasm for care coordination across both the physical and behavioral health fields, the lack of consensus on its definition, agreement on effective approaches and strategies, and inconsistent and uncoordinated funding approaches has kept it from having the full impact that many envision and hope it can have.

This IMPACT provides an overview of care coordination approaches, reviews the landscape of care coordination programs in Connecticut, and outlines a roadmap for enhancing and expanding care coordination to improve outcomes for children and families.

The IMPACT provides guidance for policymakers, systems, and providers to improve care coordination for children in ways that

- integrate physical and behavioral health;
- clearly identify the family as the driver of their care coordination needs;
- acknowledge and address social determinants of health, trauma, and racism as underlying barriers to health; and
- recognize that promoting well-being goes beyond addressing an individual illness or disorder.

## The Need for Coordinated Care

Children with special health care needs are those who "have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."[6] This broad definition acknowledges children who are "at risk" even if they do not currently have a diagnosis. It also recognizes that the population of children in need of services goes beyond those with physical health problems. In Connecticut, there are nearly 140,000 children with complex physical, developmental, or behavioral health needs requiring more frequent or more intensive care than the general child population typically uses.[7] This equates to roughly 19% of Connecticut's child population.[a] These are the families that find themselves working with multiple providers, duplicating efforts, and navigating siloed systems of care.

Families whose children require more frequent or intensive services often want help in managing that care. However, too often they do not get the support they need. According to results from the National Survey for Children's Health, among the 74% of parents of children with special health care needs who needed care coordination, only 60% received effective coordination services.[8] Percentages were lower among children of color and those with behavioral health care needs.[9,10] Higher rates of parenting stress, lower income, and having public insurance or no insurance were associated with higher levels of unmet care coordination needs. These findings show disparities based on race and economic factors and illustrate the importance of considering the social and economic context when looking at health services and outcomes. These are gaps between families and clinical care that could be bridged through coordination of services that effectively and intentionally address social determinants of health.

For those children who have both physical and behavioral health[b] concerns or diagnoses, access to effective coordination is even more challenging. Research has documented numerous barriers to accessing mental health care for families seeking services, including cost, difficulty scheduling, inconvenient locations, the belief that problems are not serious enough to warrant treatment, and uncertainty about where to go for help.[12] Pediatricians also face barriers in referring children to mental health professionals.[13] Unfortunately, this means children with behavioral health disorders often do not get behavioral health treatment. Rates of participation in treatment vary by condition, but it is estimated that up to two-thirds of children with a diagnosed behavioral

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[a] Based upon the US Census 2018 One Year Estimate for individuals in Connecticut under the age of 18.

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[b] Note that the term "behavioral health" encompasses promotion of mental health and well-being as well as substance abuse support and treatment (see SAMHSA Behavioral Health Integration, https://www.samhsa.gov/sites/default/files/samhsa-behavioral-health-integration.pdf). For the purposes of this report, "behavioral health" is used throughout the document to be inclusive of mental health as well as other supports for child and family well-being, such as substance abuse services. You will note that "mental health" is used in instances where only mental health is offered, or when referencing literature that is specific to mental health.

### Systems of Care

The term system of care is used in this report to refer to the various child-serving systems, inclusive of physical and behavioral health, child welfare, schools, juvenile justice, early childhood, and social services.

Behavioral Health System of Care (SOC), distinguished in this report by being capitalized, refers to the specific framework and philosophy for providing behavioral health care. Specifically, it is defined as: *a spectrum of effective, community-based services and supports for children and youth with or at risk for mental health or other challenges and their families that is organized into a coordinated network, builds meaningful partnerships with families and youth, and addresses their cultural and linguistic needs, in order to help them to function better at home, school, in the community, and throughout life.*[11]

**The core values that underlie the SOC approach are that services are**
- **family-driven;**
- **community-based; and**
- **culturally and linguistically competent.**

The SOC approach is implemented widely by states and other jurisdictions, including Connecticut. More about Connecticut's work in this area is highlighted in the "Wraparound: Principles and Framework for Care Coordination" box on page 23.

health disorder go without treatment,[14] with children of color and children without insurance facing the greatest unmet need.

For those children who *do* receive behavioral health services, many of those with less severe conditions will receive treatment through their pediatricians, and others will receive treatment within schools or juvenile justice settings, not necessarily coordinated with (or communicated to) other ongoing care or a medical home.[15,16] Parents with children receiving services from mental health providers report a desire for collaborative communication between their primary care and mental health providers, but in many cases also report being the main conduit of information between the two.[17] Even if a child receives care coordination for both physical and behavioral needs, they would likely receive separate care coordinators for each, rather than integrated services on a single plan of care. This still puts the burden of communication and coordination on the family, which is contrary to the purpose and ideals of care coordination.

Over the past two decades, care coordination has gained popularity as a strategy to improve outcomes for individuals and their families, bridge fragmented systems of care, facilitate communication across providers, increase efficiency, and reduce costs.[18] In surveys collected by the Healthcare Intelligence Network, a clearinghouse for publishers focused on the business of health care, 92% of responding health care organizations

## Care coordination has potential benefits for children and families, providers, and systems of care

reported having a care coordination program.[19] Care coordination generally organizes patient care activities in ways that are more deliberate and family-focused than earlier iterations of care integration approaches. Care coordination has potential benefits for children and families, providers, and systems of care:

- **For a family,** the use of care coordination to centralize communication can reduce the time and effort needed to bridge care across providers, ease access to behavioral health specialists, connect the family to social services to address social determinants of health, and ultimately improve outcomes for children.[20]

- **For providers,** care coordination can increase knowledge across specialties, improve engagement with families, help ensure follow up on referrals, and facilitate integrated care for complex or co-occurring needs, increasing efficiency within and across practices and services.

- **On a systems level,** care coordination can support the integration and coordination across multiple service sectors (e.g., social services, primary care, and behavioral health) improving efficiency, reducing costs, and supporting a "whole child" approach to children's health and well-being.[21]

## What is Care Coordination?

While the term "care coordination" has been central in many system reform efforts and is used widely, there is no clear and consistent definition. A recent review identified more than 57 unique definitions for "care coordination."[22] Considering that "care coordination" can be used to describe practices as diverse as a phone-based referral and follow-up system to a family-led meeting with multiple providers and a detailed and shared plan of care, the definitions, in turn, reflect the wide range of functions, activities, settings, and target populations associated with care coordination programs.

Definitions of care coordination are often broad enough to recognize both physical and behavioral health needs, but most of the literature, as well as the programs delivering services, focus on one domain or the other. This separation between fields is a challenge in comprehensively defining and understanding care coordination. As part of ongoing efforts to integrate physical and behavioral health, this IMPACT report covers care coordination from both perspectives.

For the purposes of this report, the Child Health and Development Institute of Connecticut (CHDI) has identified the following working definition of care coordination to serve as a criterion for selection of policies and programs to include for discussion within the report. Consistent with CHDI's mission, this report focuses on care coordination programs that serve children and their families.

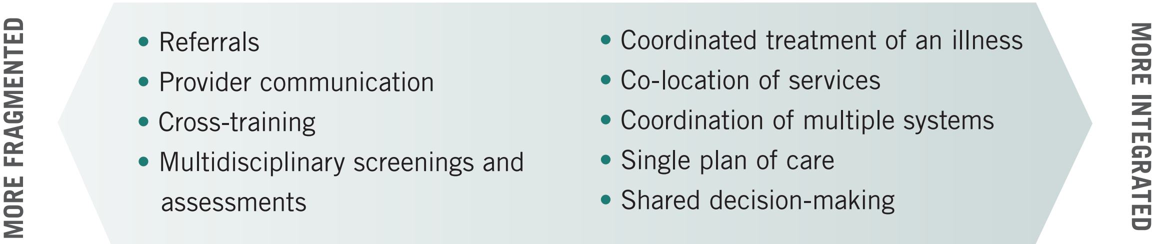
**Working Definition: Care coordination refers to intentional efforts to support communication and organization across health, behavioral health, and social service providers as needed in collaboration with the child and family, to facilitate the delivery of integrated services.**

### From Fragmentation to Integration

While there have been efforts made to distinguish care coordination from other similar strategies, programs, and practices, such as case management, patient navigation, disease management, and others, these strategies often look similar to care coordination, and to one another, in practice. These terms generally include a variety of activities that may also be components of care coordination strategies. For example, case management may include a collaborative approach to communication across providers, and disease management may include guidance on self-management as well as treatment strategies across providers and patient education. Given the inconsistency in the use of the terminology and the growing interest in policy and programs to support care integration strategies, both the primary care and behavioral health fields have developed frameworks that plot the continuum of coordination toward system integration.[23,24,25]

Figure 1 identifies activities that are used in a variety of care management frameworks and places them along a continuum ranging from fragmentation to system integration. While an effective care coordination program may include the strategies identified toward the left portion of the figure, it will need to also include the types of strategies shown on the right side to achieve a more integrated model of coordination. Care coordination should not simply improve connections in a fragmented system; instead, it should move toward integration of those systems, so that children and families experience a unified treatment plan regardless of the systems in which they are involved or the services they need.

**Figure 1: Continuum of Care Integration**



## Variation in Models and Approaches

Care coordination programs vary widely in whom they serve, what they provide, who delivers services, how they are funded, and what values and principles underlie their work.

- **Health focus** – Care coordination programs exist in both physical health and behavioral health settings. While it is increasingly recognized these areas of health are intertwined for individuals, programs tend to focus on one domain or the other. Many of the other variations in care coordination models and approaches stem from their placement in either the physical health or behavioral health system.

- **Target populations** – Some programs are modeled to provide care coordination services to all families, while others target those with the highest needs[26] or triage families across a tiered model of care coordination. Care coordination services are most commonly directed toward individuals with chronic, complex, and/or comorbid conditions and their families or caretakers, as the service is particularly valuable to this population and has been shown to reduce health care costs.

- **Activities –** Care coordinators — that is, those working to support families in managing their child's care and addressing multiple needs — engage in a range of activities, such as conducting screenings (or referring out for them), identifying community resources for families, coordinating delivery of services, communicating with providers, advocating on behalf of families, educating families, and supporting families during crises.[27]

- **The care coordinator's role and qualifications** – Some care coordinators are required to be licensed medical or behavioral health providers, while others have requirements focused on their social service or family engagement backgrounds, such as community health workers. There is support for a range of qualifications and skills in the care coordinator role as long as the qualifications are aligned with the expectations of the program model (see "Who are Care Coordinators?" on page 14 for more information).

- **Funding** – Care coordination programs are funded by a variety of sources, sometimes braided from multiple funders, including private nonprofits and foundations, as well as government agencies, and in some cases programs are paid for directly by states' Medicaid programs.[28] In the physical health model, some care coordination activities are funded, but many activities remain unreimbursed. Traditional payment models especially fall short in paying for care coordination services. Traditional fee-for-service models of reimbursement are challenged to effectively incentivize the use of care coordination to the extent value-based care (VBC) models can. VBC payment approaches, such as capitated per member per month and high-performance networks, are designed to reward efficiency and quality in care, and therefore incentivize use of care coordination as a strategy to improve cost-effectiveness of care as well as wellness outcomes for the patient.

- **Philosophy or guiding principles** – Many care coordination programs focus on coordination across providers with limited communication with the families. Other programs employ a family-driven philosophy, with the setting and activities determined primarily by the family, and driven around a single plan of care that emphasizes the family's strengths, needs, vision, and goals (see "Wraparound: Principles and Framework for Care Coordination" on p. 23 an example).

### Who are Care Coordinators?

The role and qualifications of care coordinators vary widely. Some programs have employed community health workers as care coordinators to utilize the workers' strengths in connecting with and relating to patients' health, socio-cultural, and community experiences, and have achieved demonstrable outcomes with this approach.[29] One program leveraged the interpersonal skills and cultural knowledge of community health workers to improve patient engagement across providers as well as to engage patients directly in health education and ownership over maintenance of their chronic conditions. This model was found to improve outcomes, including reduced hospitalization, emergency department visits, and a $2.30 return on investment for every dollar spent.[30] Other research suggests there is benefit in having care coordinators with more health expertise, such as advanced practice nurses, who can offer families with children and youth with special health care needs (CYSHCN) the clinical knowledge across specialties most apt to address their complex needs.[31] *Who* provides care coordination services should be determined by the needs of the target population and the context within which services are delivered.[32,33]

## The Need for Consensus

The lack of precision in the definition and components of care coordination limits its potential to be widely and consistently implemented. This, in turn, makes it difficult to establish best practices and demonstrate how care coordination improves outcomes for children and families. This is compounded by literature and conversations around care coordination focusing on physical health or behavioral health, with little emphasis on integrating across the two domains. Care coordination must be flexible enough to serve families with diverse needs across varied settings, but there should be common core elements and a shared guiding philosophy. If care coordination is to truly transform care for children and families, a clear understanding of what it is (and is not), how it works, and how to measure its effectiveness is needed.

### What Can We Learn from COVID-19?

The COVID-19 pandemic and the resulting widespread use of telehealth presents an opportunity to examine the effectiveness of this technology for delivering care coordination services. While surely more evaluations of remote care coordination efforts are needed, the existing literature suggests the use of telehealth may be beneficial, but more as one component in a broader strategy for service delivery. One analysis found that while telehealth may be used as an ongoing mechanism for care coordination delivery, it is important that there be some amount of in-person relationship building between the family and the care coordinator.[34] Given the widespread use of telehealth during 2020, new analyses will be informative.

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## Care Coordination Improves Outcomes for Children, Families, Providers, and Systems

Coordinated services are beneficial for children with multiple needs who are served by a fragmented system. In fact, research demonstrates that a lack of coordinated care for CYSHCN can produce detrimental outcomes, including medication discrepancies, appointments missed or treatment delayed, and poor communication across providers.[35] Given the variability of care coordination definitions and design, research on outcomes of care coordination efforts, especially those serving children, is still underway.

The most extensive literature on outcomes is available for care coordination services provided to older adult populations; however, literature on outcomes for children is growing. Published evaluations of care coordination programs generally demonstrate beneficial outcomes at the individual, family, provider, and/or system levels; however, because care coordination encompasses such wide-ranging strategies and multiple intended outcomes, many of the studies find positive results in one or more outcome areas and not in others. For example, a review of a home-based care coordination program designed to reduce incidence of low birth weight found success in the ultimate outcomes of healthy birth weights and cost-savings, but did not achieve the intended short-term outcome of increasing numbers of prenatal visits.[36] A review of a program coordinating care for pregnant women with substance use disorders found lower foster care placement rates and lower incidence of child maltreatment, but not outcomes related to healthy birth weight.[37]

A collective understanding of which design elements of care coordination programs achieve which outcomes is underdeveloped, with a need for future evaluations to further inform the field regarding effective strategies. There is, however, evidence from existing evaluations that care coordination can benefit children's health outcomes, families' financial and emotional outcomes, providers' knowledge, costs, and relationships with families, and better integrated care at the systems level.

**Examples of these outcomes are identified below.**

- Positive outcomes associated with care coordination include reduced unnecessary use of emergency departments and fewer days missed at school.[38,39] These not only directly benefit the individual child and family, but also help improve systems and decrease costs, as well.

## Care coordination must take a broad and holistic view of the child and family if it is to achieve its intended goals of improving care quality and outcomes

- The parents and caregivers of children receiving care coordination services also benefit. A survey of families with CYSHCN identified outcomes among families receiving self-reported "adequate" (i.e., of sufficient quality) care coordination services to address their needs. These families were more likely to report receiving family-centered care, having improved relationships with providers, fewer out-of-pocket expenses, less time spent on coordinating care, and fewer days missed at school and work.[40]

- Care coordination has also demonstrated outcomes for providers and systems. Examples include North Carolina's documented cost savings from the implementation of a care coordination model in their state. The model connects patients to medical homes, while also providing case management for high need individuals, and utilizing system-level data to improve quality. The program saves the state an estimated $160 million annually through reductions in the use of emergency departments, outpatient care, and pharmacy services.[41]

While outcomes from care coordination programs are promising for all stakeholders, as referenced earlier, as referenced earlier, gaps remain across measures, outcomes, and data related to care coordination services.[42] The majority of the respondents to the Healthcare Intelligence Network reported not yet knowing if they were attaining return on investment from their care coordination efforts.[43] This points to a need for additional work to identify best practices, outcomes, and measures, especially as funding for and implementation of care coordination continue to expand.

# Effective Care Coordination Addresses All Factors that Relate to Health

Regardless of the setting or specific program model, care coordination must take a broad and holistic view of the child and family if it is to achieve its intended goals of improving care quality and outcomes. Providers have expertise in diagnosis and treatment generally, but services are delivered to each child and family specifically. It is critical to acknowledge that physical and behavioral health are influenced and shaped by the social, economic, and environmental context in which families live, as well as significant or traumatic events individuals might experience. Research on the relationship between these social determinants of health and health outcomes and inequities has grown in recent years.[44] Per the County Health Rankings Model, social and economic conditions combined with the physical environment are estimated to account for 50% of the factors contributing to health outcomes, with health behaviors accounting for another 30%. This is contrasted with the quality of medical care contributing only 20% (at most) to health outcomes.[45,46] With this increased understanding of the drivers of outcomes, those working within systems of care have extended their service delivery approach to include addressing social and economic needs.

## Addressing Social Determinants of Health

Social determinants of health are inclusive of five key areas: economic stability, neighborhood and built environment, education, social and community context, and health and health care.[47] These areas reflect the influence that poverty, living and working conditions, racism and discrimination, and access to health care/health information have on health outcomes. Social, environmental, or economic conditions within a family's life may either directly cause a health condition (e.g., lead in drinking water), or may influence the family's ability to access services (e.g., lack of transportation to attend medical appointments).

Care coordination approaches can be cost-effective and improve wellness outcomes not only through coordination across health care providers, but also in consideration of the social determinants of health. For example, coordinated communication across providers working with a toddler could reduce duplication of developmental screenings and accelerate referral and delivery of needed speech services. Likewise, linking a family with transportation or housing services could reduce barriers to accessing timely care and reduce the need for more intensive services later. It is easy to see, therefore, why health plans, such as HUSKY,[c] Connecticut's Medicaid program, would invest in direct reimbursement, incentives, or shared savings programs to promote care coordination to reduce costs and improve outcomes.

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[c] In Connecticut "HUSKY Health" encompasses health insurance coverage through both Medicaid and the Children's Health Insurance Program (CHIP). The state's Department of Social Services administers the program.

## Care coordination, as a strategy for integrating services for children and families, will obtain greater outcomes if it incorporates screening for trauma and social determinants of health

Racism itself impacts health outcomes on multiple levels, intersecting with each of the other key areas of the social determinants of health to compound inequity. Research has demonstrated the impact of both structural or systemic racism, as well as individual or interpersonal racism in physical and behavioral health inequity.[48,49] Disparities in health outcomes are wide-ranging, including access to, receipt of, and quality of health care,[50] rates of heart disease and diabetes,[51] maternal and infant mortality,[52] and, most recently, are present in the rates of hospitalization and death from COVID-19.[53,54]

### Recognizing Trauma

In addition to the social determinants of health, childhood trauma can have long-term impacts on the health of children and families. It is estimated that 71% of individuals experience a traumatic event before turning 18 (including abuse, exposure to violence, or serious accidents).[55] Research has linked these experiences to lifelong health outcomes, including psychiatric diagnoses, substance use, and a variety of physical health conditions. Research over the past couple of decades has exposed the extensive impact of trauma, and, as a result, trauma-informed approaches to care across systems working with children and families have become more common.

Care coordination programs, too, should use a trauma-informed approach in order to improve outcomes for children and families. Care coordination services, therefore, should integrate trauma screening to identify trauma exposure and sequelae, trauma training for staff to understand the potential effects of trauma and how to address them, knowledge of existing trauma-focused resources (assessment and treatment options) for children and families, and protocols for sharing information on families' trauma experiences and symptoms across providers and/or agencies.

Without recognizing and addressing past or ongoing trauma, as well as social, environmental, and economic barriers to wellness, it is unlikely that services will meet the family's needs or that programs will attain their desired health outcomes. Therefore, care coordination, as a strategy for integrating services for children and families, will obtain greater outcomes if it incorporates screening for trauma and social determinants of health and refers to appropriate community services (e.g., housing, legal aid, food services, evidence-based treatment for trauma), as needed.

### What are the Social Determinants of Health?

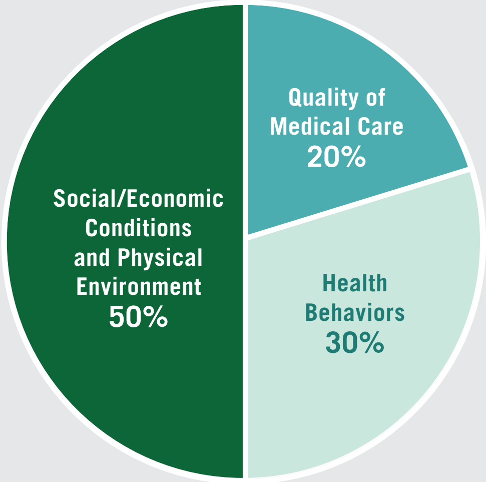
Social determinants of health (SDOH) are defined as "conditions in the environments in which people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks."

SDOH comprise five domains:[56]

1. Economic stability (e.g., employment and poverty)
2. Neighborhood and built environment (e.g., housing quality and environmental conditions)
3. Education (e.g., language and literacy, and enrollment in higher education)
4. Social and community context (e.g., discrimination, racism, and social cohesion)
5. Health and health care (e.g., access to health care and health literacy)

It is estimated that up to half of health outcomes are attributed to SDOH.[57] If care coordination services are to improve outcomes for children and families, they must recognize and address the importance of these factors in contributing to health and well-being.

**Factors Contributing to Health Outcomes**



**The future direction of care coordination should focus on better alignment across systems so plans of care address a child's needs more holistically**

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## Aligning Physical and Behavioral Health

If a child has both physical and behavioral health needs that require care coordination, he or she is likely to be assigned separate care coordinators in each system. This puts the burden on the family to coordinate the care coordinators, a scenario that is contrary to the intended aims of care coordination. When the Institute of Medicine put forth care coordination as a recommended strategy for health reform, it recognized the role of behavioral health providers;[58] however, in practice, the focus is typically on one domain or the other rather than taking an integrated and comprehensive approach that bridges the two. These distinctions reflect the larger tension between the increasingly common acknowledgment that behavioral health is an important component of overall health for an individual and the reality that the systems delivering the services are separate, each with its own practice cultures and payment structures. While the history to date of care coordination has been split across physical health and behavioral health domains, the future direction of care coordination should focus on better alignment across systems so plans of care address a child's needs more holistically. Care coordination practices with shared values and principles and commitment to engagement across health and behavioral health providers are beneficial to children and families regardless of the system in which they are receiving treatment.

### Physical Health

Programs associated with physical health providers were initiated to support the multiple needs of children and youth with special health care needs (CYSHCN), coordinating between primary and specialty care, including behavioral health, in collaboration with schools and other community-based services. They have since evolved in recognition of the impact of the social determinants of health on physical health outcomes to incorporate social services, trauma treatment, and other child-centered services. As the primary point of access to health care for children, as well as a trusted source of anticipatory guidance for families, pediatricians serve a critical role in initiating coordination of care across both medical and behavioral health providers. Without pediatricians' identification of behavioral health needs and treatment of common diagnoses, and without their efforts to coordinate that care, many children's needs would remain unmet. Care coordination efforts initiated by primary care, therefore, are well-poised to utilize the medical home as the hub, with communication being coordinated across the various providers involved in the child's care.

### Behavioral Health

Care coordination models implemented by the behavioral health system, such as Wraparound (see "Wraparound: Principles and Framework for Care Coordination" on page 23 of this document), tend to be well-poised to utilize the

*family* as the hub of coordination and bring providers and other partners to the family's table (sometimes literally the table in the family's home, and other times figuratively, meeting in a community or provider setting but with the discussion driven by the family). The values and principles that underlie the Behavioral Health System of Care (SOC) (i.e., family-driven, community-based, and culturally and linguistically competent) are implemented widely by states and systems, including Connecticut, and are considered a cornerstone of the field's approach to serving families whose children have behavioral health needs. These values are also embedded within the ten principles that guide the Wraparound process, an intensive care coordination program for children with high level behavioral health needs that works with the family's informal social network as well as professionals to support implementation of the family's plan of care.

These principles can be adapted to support any care coordination program's efforts to serve families, whether within the behavioral health system or not; however, challenges with adaptation of the full model across systems should be acknowledged.[59,60] Behavioral health providers, schools, juvenile justice, and social service providers are more likely to be able to join meetings in a family's home or community setting than are primary care or other medical

**While there are differences in the physical and behavioral health approaches to care coordination, the fields’ underlying philosophies are complementary and compatible**

providers. The limitations of physicians’ time and traditional payment structures create barriers for their ongoing involvement in these types of activities.

## Sharing Best Practices

While there are differences in the physical and behavioral health approaches to care coordination, the fields’ underlying philosophies are complementary and compatible. While the hub of care coordination for primary care providers may be the medical home and not the family’s home, the American Academy of Pediatrics’ definition of medical home, cited below, includes “family-centered, compassionate, and culturally effective,” which are principles that align closely with the values of Wraparound and the Behavioral Health SOC.

> *The [...AAP] believes that the medical care of infants, children, and adolescents ideally should be accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective. It should be delivered or directed by well-trained physicians who provide primary care and help to manage and facilitate essentially all aspects of pediatric care. The physician should be known to the child and family and should be able to develop a partnership of mutual responsibility and trust with them. These characteristics define the “medical home.”*[61]

The physical and behavioral health fields have an opportunity to learn from one another and integrate their approaches to care coordination. Care coordination models centered in a medical home, while already guided by a family-centered philosophy, can learn from models such as Wraparound, that offer a high-fidelity approach with specific strategies for effectively engaging families. In turn, behavioral health models that engage directly through the family can work to identify more effective strategies for engaging and coordinating with the medical home and other physical health providers.

## Wraparound: Principles and Framework for Care Coordination

Wraparound is a national model for partnering with families and children in addressing serious behavioral health challenges. Wraparound takes a comprehensive, holistic, family-driven approach to responding to needs. A Wraparound care coordinator works with the family to build up a support team that includes both professionals providing services and formal supports to the family, as well as the family's natural or informal supports system (e.g., extended family, friends, neighbors, faith leaders). A care coordinator works with the family and team to develop a plan of care, taking a "one family, one plan" approach to avoid duplication of services and simplify families' experiences across systems. Monthly team meetings guide the implementation of the family's plan of care. Over time, the roles of natural supports take a greater responsibility in implementing the plan of care as sustainable supports for the family. Wraparound uses a set of ten principles that guide practice:[62]

1. **Family voice and choice** – family and child perspectives are prioritized.
2. **Team based** – the family agrees on the team, which brings together formal, informal, and other community support.
3. **Natural supports** – full participation from the family's personal network of support is encouraged.
4. **Collaboration** – all team members work cooperatively and share responsibility for the plan of care.
5. **Community based** – team implements strategies that are inclusive, accessible, and in the least restrictive setting.
6. **Culturally competent** – the process demonstrates respect for the family's values, preferences, beliefs, culture, and identity.
7. **Individualized** – strategies, supports, and services are customized to the child and family.
8. **Strengths based** – plans identify, build upon, and enhance the capabilities and assets of the family, their community, and other team members.
9. **Unconditional** – the team does not give up on children and their families; when setbacks occur, the team continues to work toward achieving the family's goals.
10. **Outcome based** – the plan is tied to observable and measurable indicators of success.

Evaluations have demonstrated youth receiving Wraparound improve on functional and residential outcomes, such as lower rates of suspension, greater use of community services, and living in less restrictive environments.[63]

### WrapCT Care Coordination

Within Connecticut, WrapCT utilizes the high-fidelity Wraparound approach and the program serves as the direct care component of the CONNECTing Children and Families to Care initiative. DCF serves as the lead agency for WrapCT Care Coordination, with ten community-based provider agencies offering care coordination services directly to families throughout the state. More than 1,300 children were served in fiscal year 2019. Evaluations of WrapCT have demonstrated improvements in children's functioning and problem severity (as measured by the Ohio Scales) following completion of the service, as well as lessened strain among caregivers. A review of Medicaid claims has also demonstrated cost savings associated with participation in WrapCT.[64]

# Care Coordination in Connecticut

Simultaneous to the expansion of care coordination nationally, both in efforts to leverage federal opportunities and to address local interest, Connecticut has engaged in the funding and implementation of local and statewide care coordination programs. Figure 2 provides a timeline of key national and Connecticut-specific care coordination policies and investments over the last two decades. In the earlier sections of this report, the national literature has been synthesized. The remaining sections seek to apply this research to efforts within Connecticut and identify recommendations that facilitate the best care and outcomes for children and families in Connecticut.

## Integrating Statewide Systems to Better Meet the Needs of Families

**Compared to many states, Connecticut has a robust system of care for children.** While most care coordination programs work directly with families to coordinate care, some initiatives have been designed specifically to improve integration across systems of care. Two examples are cited below.

The **Connecticut Network of Care Transformation (CONNECT)** Initiative is funded by federal grants from 2013 to 2023 to develop, implement, and sustain a vision for a coordinated system of care where there is no wrong door to accessing a full range of child services and supports across the primary care, behavioral health, education, social services, and other child-serving systems. It builds upon the existing Behavioral Health System of Care (consistent with the definition and core values identified in the "System of Care" box on page 9) and care coordination programs to strengthen accessibility and navigability in the larger context of the state's efforts for CONNECTing Children and Families to Care.

The **Connecticut Children's Center for Care Coordination** provides an example of the state's evolving work in addressing the systemic and underlying needs of families. Originally launched in 1996, the program initially began as a care coordination service for families with CYSHCN. Recognizing that the needs of families and children could be better served by improving alignment of systems, the Center developed a model for regional collaboratives to support an organized approach to care coordination within regions, convening care coordinators across child-serving systems to review challenging cases, identify appropriate supports across systems, and identify potential policy-level solutions. The Center also provides training to providers in the community to build their capacity for care coordination and education on addressing the social determinants of health. In addition to its systems-level work, the Center engages in direct care coordination for families, as referenced in Table 1 on page 26 and described in Appendix A.

## Care Coordination Services for Families

Connecticut has multiple care coordination programs both within and across the primary and behavioral health care systems. Table 1 identifies a sample of care coordination services provided in the state. The table categorizes the varying care coordination services and approaches, the primary system of care initiating the service, the potential overlap across target populations, and the possible gaps. Note that the table is intended to demonstrate a range of care coordination services available to children and families in Connecticut, but is not an exhaustive list. Full program descriptions can be found in Appendix A.

Most of the programs included in the table are “care coordination programs”; that is, they are designed with care coordination as the primary or driving service to families. In addition, there are a handful of programs included (and marked within the table) that have a broader intent (e.g., clinic-based health services, parenting support through home visits) but have care coordination services as a key component of the program. Examples of both “care coordination programs” and programs with care coordination as a component of the program are described below.

Several of the state’s care coordination programs (i.e., programs with care coordination as the primary focus) have demonstrated promising outcomes. Two examples include the H.O.M.E. project and WrapCT Care Coordination. The H.O.M.E. project was a care coordination pilot that grew into a statewide program. It was designed for children insured by HUSKY receiving care through the Charter Oak Health Center. The evaluation demonstrated children were more likely to use dental and mental health services, that families were more confident in accessing services for their children, and that they tended to use their primary care provider more often.[65] On the behavioral health side, WrapCT Care Coordination provides high-fidelity Wraparound care coordination services statewide for children who have or would qualify as having a serious emotional disturbance (SED) diagnosis. See “Wraparound: Principles and Framework for Care Coordination” as well as Table 1 and Appendix A for additional information on this program.

Federally Qualified Health Centers (FQHCs) are community-based clinics offering primary care in underserved areas. While their focus is direct health care services, care coordination is a significant component of their services. These providers receive funding from the federal government, and therefore must meet specific requirements relating to access for the population served and quality of the services provided. Effective as of 2017, care coordination services are required for participation in Connecticut’s Person-Centered Medical Home (PCMH) program and more intensive coordination services are available through the PCMH Plus program. Providers receive shares of cost savings based on achievement of benchmarks. These state requirements include a variety of care coordination activities, such as integrating behavioral health, providing culturally and linguistically appropriate services, and planning the transition of necessary services from youth to adulthood.

FQHCs as well as school-based health centers provide care coordination of on-site services (i.e., behavioral health and primary health co-located at the same center). Many such sites also include coordination with community-based services related to social determinants of health.

## Table 1: A Sample of Connecticut's Care Coordination Initiatives and Programs*

| Program Name | Care Coordination Services | | | | | | | | | | | | System of Care Focus | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | *Families* | | | | | *Providers* | | | | | *Systems* | | | |
| | Referrals | Scheduling | Support/Follow Up on Referrals | Education on System Navigation | Care Plans | Case Review | Clinical Consultation/ Co-management | Formal Agreements Between Providers | Provider Education/ Capacity Building | Provider Networking | System Integration | Policy and Advocacy | Primary/Physical Health | Behavioral/ Developmental Health |
| **Autism Care Management Services** | ● | | ● | ● | ● | ● | ● | | ● | | | | | ● |
| **Birth to Three** | ● | ● | ● | ● | ● | | | | | | | | | ● |
| **Community Support for Families** | ● | ● | ● | ● | ● | ● | ● | | | | | | | ● |
| **Connecticut Children's Center for Care Coordination^** | ● | ● | ● | ● | ● | ● | ● | | ● | ● | ● | ● | ● | |
| **Connecticut Home Visiting System+ †** | ● | | ● | ● | ● | | | | | | | | | ● |
| **Enhanced Care Clinic Initiative^+** | ● | ● | ● | | ● | | ● | ● | | | ● | | | ● |
| **Federally Qualified Health Centers+** | ● | ● | ● | | | | | | | | | | ● | |
| **Help Me Grow^** | ● | | ● | ● | | | | | ● | ● | ● | | | ● |
| **Medical Home Initiative for CYSHCN^** | ● | | ● | ● | ● | ● | ● | | ● | ● | ● | ● | ● | |
| **Person-Centered Medical Home Plus^** | ● | ● | ● | ● | ● | | ● | | ● | | | | ● | |
| **School-Based Health Centers+** | ● | | ● | | | | ● | | | | | | ● | |
| **211 Child Development Infoline** | ● | | | | | | | | | | | | | ● |
| **WrapCT** | ● | | ● | ● | ● | | | | | | | | | ● |

* This table is meant to be a sample of care coordination programs and services offered in the state, and is not an exhaustive list.

^ These programs are intentionally designed to bridge care between physical or primary care and behavioral health and/or developmental services.

** The Center for Care Coordination, Autism Management Services and the Medical Home Initiative for CYSHCN are available to youth under the age of 21.

+ The majority of the programs listed in the table are care coordination programs; i.e., care coordination is the primary activity of the program. Those programs noted with (+), however, reflect programs that have a broader scope, e.g., health services, parenting education, etc., but with care coordination as a primary strategy embedded within the program.

† Inclusive of multiple home visiting models. Services/screenings reflect what is offered by at least one model.

| Target Population | | | | | | | | | Setting | | | | | Screening Assessment | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Prenatal | Infants and Young Children | Children 0-18 | Children and Adults | Husky | Private Insurance | Statewide | Specific Towns/ Regions | Specific Needs/ Diagnoses | Phone | Family Home | Medical Home | Clinic | Other | Developmental or Behavioral | Trauma | Social Determinants of Health |
| | | ● | ● | ● | ● | ● | | ● | ● | ● | | | | | | ● |
| | ● | | | ● | ● | ● | | ● | | ● | | | | ● | ● | |
| | | ● | | ● | ● | ● | | ● | | ● | | | | | | ● |
| | | ●** | | ● | ● | ● | | | | | ● | ● | | ● | ● | ● |
| ● | ● | | | ● | ● | | ● | | | ● | | | | ● | ● | ● |
| | | | ● | ● | ● | ● | | ● | | | | ● | | ● | | |
| | | | ● | ● | ● | | ● | | | | | ● | | ● | ● | ● |
| | ● | | | ● | ● | ● | | | ● | | ● | | | ● | | |
| | | ● | | ● | ● | ● | | ● | ● | ● | ● | | | ● | | ● |
| | | | ● | ● | | ● | | | | | ● | | | ● | ● | ● |
| | | ● | | ● | ● | | ● | | | | | ● | | ● | ● | |
| ● | ● | | | ● | ● | ● | | | ● | | | | | ● | | |
| | | ● | | ● | ● | ● | | ● | | ● | | | ● | ● | ● | ● |

## Opportunities for Strengthening Care Coordination in Connecticut

In spite of the strength of Connecticut's care coordination programs, challenges exist. Per the 2017–2018 National Survey of Children's Health, among families in Connecticut with CYSHCN who require care coordination supports, 40% did not receive them. These numbers are comparable to the nationwide figure referenced previously in this report.[66] At the same time, while some families lack the care coordination they are in need of, others may be inundated with multiple or even conflicting care coordination programs. Care coordination programs in the state may have overlapping target populations, resulting in some families being assigned multiple care coordinators from different systems or even different care

**Figure 2: National and State Timeline of Care Coordination Adoption**

**Connecticut**

- **Connecticut Children's Center for Care Coordination (1996)** Launched to serve CYSHCN and later expands its scope
- **Connecticut Community KidCare Initiative (2000)** The legislation expands behavioral health access and services for children.
- **WrapCT (2006)** Funding is provided for care coordination services using the Wraparound approach.

1996 2000 2001 2002 2006

**National**

- **Public Health Services Act (2000)** Care coordination services for CYSHCN is added to Title V of the Social Security Act.
- **Institute of Medicine Recommendation for Care Coordination (2001)** Care coordination is identified as a key strategy to advance the US health care system.
- **New Freedom Commission on Mental Health (2002)** The presidential commission and national report identifies care coordination across providers within its recommendations.

coordination programs within the same system. When multiple care coordination programs exist without a strategy for weaving them together, and in the absence of a single plan of care that cuts across child-serving systems, this creates duplications and inefficiencies in the system and confusion for families.

**In recognition that all families benefit from having coordinated systems of care while many families benefit from a range of more intense coordination services based on their individual needs and risks, some states have developed strategies to coordinate their care coordination services.** The Oklahoma Department of Mental Health and Substance Abuse Services triages children with behavioral health needs into two different risk categories based on results of the Client Assessment Report (CAR) and the Ohio Scales.[d,67] While

2007 - 2009

- **H.O.M.E. Pilot Program (2007-2009)**
**The pilot care coordination program in Hartford demonstrates improved outcomes for children.**

- **Adoption of Shared Principles for the Person-Centered Medical Home (2007)**
**Multiple medical associations jointly develop principles to be ascribed to a PCMH.**

2010

- **Hartford Area Care Coordination Collaborative (2010)**
**First collaborative to facilitate communication across care coordinators from different sectors.**

- **Affordable Care Act (2010)**
**Care coordination included as strategy for increasing quality and decreasing costs.**

2014

- **Children's Behavioral Health Plan (2014)**
**A legislatively-mandated plan is developed to improve the network of care.**

2015

- **Expansion of Collaborative Model (2015)**
**The Department of Public Health expands the H.O.M.E. model statewide.**

2017

- **Person-Centered Medical Home Plus (PCMH+) (2017)**
**The Department of Social Services funds enhanced care coordination to address Medicaid members' complex needs.**

2018

- **SUPPORT for Patients and Communities Act (2018)**
**Includes funding for care coordination demonstration projects.**

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[d] The Oklahoma Department of Mental Health uses both the CAR and the Ohio Scales to assess functioning. The CAR assesses the client's mood, thinking, substance use, physical condition, family and interpersonal relationships, role performance, socio-legal, and self-care. The Ohio Scales are a reliable and valid assessment tool used to track progress of children and youth receiving mental health intervention services. Ohio Scales measure both the youth's problem severity and ability to function in daily activities.

each category includes a single-plan approach to coordinating care, the activities in the plan vary, as do the frequency and types of contacts from the care coordinator and providers. Those in the higher risk category receive high-intensity Wraparound services.[68] While there are opportunities within Connecticut for regional collaboration across care coordination programs, there is not currently an infrastructure in place to support statewide communication across care coordination programs at a systems level, nor a mechanism for aligning coordination services into a single plan of care. Note that there was previously a statewide collaborative; however, this is no longer in place. The inconsistent geographic boundaries across systems make it even more challenging. States with such mechanisms in place could inform efforts to further structure, streamline, and coordinate Connecticut's organization of its care coordination programs at both the systems and family level.

Regardless of the specific model of care coordination, families are best served when systems are easily accessible. The state's behavioral health system has made progress in streamlining and increasing access to services. In the Medicaid funded behavioral health system, the state selected an administrative services organization (ASO) in 2005 to operate the Behavioral Health Partnership, and expanded its services again in 2010 (with Beacon Health Options currently serving as the ASO). There continues to be fragmentation of care, however, within the state's Behavioral Health System of Care, as evidenced by findings in the Children's Behavioral Health Plan and ongoing input from that Plan's Implementation Advisory Board (https://www.plan4children.org/). Several states have a single point of entry to coordinate care for youth with behavioral health needs, sometimes referred to as a "Care Management Entity." The entity can work across the health, juvenile justice, education, social services, and child welfare systems to ensure coordinated and comprehensive care for the child, and can provide intensive Wraparound services as needed. States implementing such approaches have found success in cost savings by reducing duplication of services, use of emergency departments, and out-of-home placements, and have also found positive clinical outcomes for children.[69]

Care must be easily available and accessible, not just within, but across systems (primary, behavioral, school-based, early childhood, juvenile justice, and social services), with "no wrong door," and systems must be able to share information and data. There are a variety of approaches to how coordination across systems can be designed. There are examples of effective coordination occurring with behavioral health on-site for prevention and low-acuity cases at primary care offices, appropriate uses of telehealth to engage families, cross-training for providers on behavioral health and social determinants of health, co-management of diagnoses, and on- or off-site care coordination. When systems are well coordinated to support

both prevention and intervention for low acuity needs, specialty and higher intensity care and coordination services can be reserved for higher acuity needs. Given the differences in approaches to care coordination between the physical and behavioral health systems, it is critical that care coordination programs identify best practices for effectively engaging one another, recognizing one another's strengths and limitations.

In order to achieve an integrated system of care, there are multiple systemic barriers to address. These include challenges with information sharing across systems of care, which are driven by differences in privacy policies and electronic health record (EHR) systems. Additionally, there are gaps in insurance coverage for families and gaps in payments for providers. In the behavioral health area, for example, many behavioral health services are reimbursed by Medicaid, whereas behavioral health care coordination is primarily grant-funded. These barriers, combined with the sector variability across practice culture, training, financing, and values, present challenges in implementing an integrated system and supporting care coordination success statewide and across child-serving sectors.

## Families’ and Caregivers’ Perspectives

The literature on parents and caregivers’ experiences with care coordination demonstrates parent satisfaction with care coordination services, but frustrations with gaps in coordination, including incorporation of social services, and even communication challenges across multiple care coordination programs.[70] Oftentimes, a care coordination program is operated within a specialty provider network and they do not coordinate with the primary care provider or other specialties, leaving families again having to coordinate care, but now among the care coordinators.[71] Challenges with communication across EHR systems result in families needing to provide the same information over and over with concerns that they will forget to mention a critical part of their child’s health history.[72]

In Connecticut, meetings with families and youth were held throughout the state (originally in 2014, and repeated in 2017, 2018, and 2019) regarding their experience with the existing network of behavioral health care. Only comments that were shared by multiple participants were included in the reports. These conversations, while not specific to care coordination, demonstrate what is important to families being served in a system of care, and largely mirror the broader literature on care coordination, regardless of system (i.e., behavioral health, medical, other). Following are some of the themes of family perspectives that have informed the recommendations in this IMPACT and can shape the design, implementation, and quality improvement of the state’s care coordination efforts.[73]

- **Families and youth should be included in developing care plans.**
- **Families and youth want opportunities for peer-to-peer relationship-building to expand their natural support network.**
- **Families need more support in accessing services for basic needs (housing, food, and other services).**
- **Families feel overwhelmed in sorting through information and accessing services.**
- **Families need more support in transitioning from one level of care to the next and from child to adult services.**
- **Staff should reflect the community in regard to race/ethnicity and language, and staff need to be trained on cultural competency.**
- **Staff across systems should be trained in working with families’ trauma history as well as in behavioral health needs.**
- **Providers should be able to easily access information from other providers, and not have families repeat the same information over and over.**

## Recommendations

### *Guidance to Strengthen Care Coordination in Connecticut*

### Policy and System Development Recommendations

1. **Promote policies that directly address conditions that lead to health disparities, particularly racial and ethnic disparities**

   Care coordination exists within a broader context of health policy and systems. Connecticut would benefit from a reconsideration and reframing of health policy to better align and focus the state's efforts to address inequities according to race/ethnicity, gender identity, language, culture or immigration status, geographic location, or insurance type, and to better address social determinants of health. Relevant policies may include those that directly fund service delivery, as well as policies that impact economic conditions, housing, transportation, and other barriers to improving health equity.

2. **Expand reimbursement for care coordination activities through a braided funding model**

   Given the literature and trends in practice supporting expansion of care coordination, there are multiple efforts underway that reimburse or otherwise provide payment for care coordination activities (many of them

noted earlier in this report, including the PCMH Plus program for Husky members). In many cases, however, funding covers only a portion of the coordination activities and time. Fully funding care coordination efforts through a braided funding model is critical. While increased reimbursement rates and incentives through value-based care payments are desirable, it is also important to allow for flexibility to leverage existing and potential funding opportunities to promote innovation and sustainability. As outcomes continue to be realized and documented, additional funding sources will likely become available, and, when braided with other sources, will support a robust and diverse investment in coordinated systems of care. As an example, the 211 Child Development Infoline, a phone-based care coordination service connecting families to developmental promotion and assessment services, blends funding from the state's Office of Early Childhood, the State Department of Education, the Department of Public Health, and United Way of Connecticut.

3. **Streamline access to behavioral health through a care management entity that includes access to care coordination services**

   Access, quality, and outcomes of behavioral health services will be drastically improved by further streamlining and integration at the systems level. The state should continue efforts to integrate the multiple child-serving systems involved in delivering behavioral health care by identifying a single point of access for children and youth with behavioral health needs in the form of a single statewide care management entity, or its equivalent. All systems and stakeholders (e.g., education, child welfare, juvenile justice, pediatric primary care) that refer children and families for behavioral health services would refer to this entity. The entity could be staffed with care coordinators to screen children, develop a single plan of care, and identify appropriate services. This entity would be responsible for managing care coordination efforts across various child-serving systems, utilizing data to inform ongoing quality improvement, and providing high-fidelity Wraparound services to families that need it.

4. **Remove barriers to integrating primary and behavioral health care**

   A variety of barriers exist that present challenges to successful integration of primary and behavioral health care. At the policy level, there are regulations or common practices that hinder communication across providers. Regulations regarding information sharing are critical for ensuring privacy, especially for children; however, conflicting privacy policies across types of providers can present a barrier to collaborative care. Policies can be designed that both protect children and families' privacy and decision-making powers, and allow for effective and efficient sharing of information across systems. The use of tools such as "The Green Form" (developed by the Connecticut Chapter of the American Academy of Pediatrics) can support a standardized approach to communication between primary and behavioral health providers.

5. **Enhance statewide collaboration: One Family, One Plan**

   Develop a statewide collaborative to coordinate efforts across care coordination programs. It is important that programs be designed specific to the needs being addressed and the intended outcomes, and, in turn, at a statewide level, a collaborative body can identify the ways in which care coordination programs overlap with respect to target population, geography, and services, and reduce duplication whenever possible. For families who are involved in multiple care coordination programs, a collaborative body can develop tools and mechanisms for those programs to communicate with one another, support the family in developing a single plan of care, and prevent that coordination burden from falling on families.

6. **Invest in a collaborative-ready workforce across systems of care**

   The workforce that supports the overall wellness of children and their families (pediatric primary and specialty care, social services, school-based services, early childhood, juvenile justice, and behavioral health care) values collaboration and one another's expertise and contribution to the wellness of the children and families they serve; however, the professionals delivering services in these systems often lack the readiness to work on-site (or even off-site) together. The practices of pediatrics and behavioral health providers, alone, are different in their service models and practice cultures. Efforts in Connecticut to maintain behavioral health staff on-site in primary care settings have been mostly unsuccessful, and while school-based clinics, behavioral health, and social services have increased, they are often not integrated with the medical home or other outside services. In recognition of the increase in the number of children who experience a behavioral health need and the desire to treat the "whole child" in an integrated approach, it would be beneficial to establish shared competencies, or even institute tracts in higher education across the varied sectors of the workforce supporting children's well-being. This will result in a workforce with the knowledge and skills to work with one another and in one another's practices.

7. **Support research to fill gaps in understanding of care coordination best practices**

   As referenced in the above report, in spite of a considerable body of research on care coordination, it is challenging to distinguish which care coordination strategies are attributable to which outcomes, especially in the context of care coordination for children. Research to support identification of best practices in implementation would be beneficial to child-serving systems. Likewise, the now widespread use of telehealth for care coordination services due to the COVID-19 pandemic presents an opportunity to assess the benefits and challenges to using telehealth platforms for coordinating care for children and families, and to identify in what circumstances its use is most appropriate, valuable, and cost effective. Investing in a systematic evaluation of care coordination practices will support planning efforts for an effective care coordination system in Connecticut as well as other states.

## Practice Recommendations

**1. Use Wraparound principles to implement a family-driven approach to care coordination across all child-serving systems**

While care coordination models based on the Wraparound values and principles are designed for children who meet specific criteria (e.g., serious emotional disturbance in the case of Wraparound), the values and principles that guide a strengths-based, family-driven approach can be used within any care coordination program or other service setting. Statewide efforts to collaborate across care coordination programs should include adoption of this common set of values and principles that will also support the role of care coordination in addressing SDOH and linking to social services. Developing and supporting the role of natural or informal supports can be a centerpiece of the plan of care, and a sustainable benefit for families that supports their long-term in-home management of needs, within their culture and community. A trusting relationship with families helps to facilitate better understanding of families' strengths, goals, and needs, and engages them in supporting the children and families' wellness.

**2. Cross-train between and across sectors**

To complement the systems approach to preparing a collaborative-ready workforce recommended above, there must be opportunities for training across sectors (physical and behavioral health, school-based, early childhood, juvenile justice, and social services). For example, since many low acuity behavioral health diagnoses can and often are cared for within schools and primary care settings, it is important for pediatric primary care providers and relevant school personnel to be trained in screening, assessment, and appropriate treatment options for common pediatric behavioral health needs, such as anxiety and depression. It would also be beneficial to invest in training on how to link families across systems of care and employ effective prevention strategies to support the family's overall wellness, including how to recognize and address the impacts of trauma, racism, and social determinants of health. Child-serving sectors should further receive training on and oversight of culturally appropriate services, driven by a framework such as the National Standards for Culturally and Linguistically Appropriate Services (CLAS Standards).[e]

3. **Address social determinants of health through care coordination efforts**

Given that 50% of health outcomes are driven by social determinants, wellness outcomes for families will be greatly impacted by the degree to which providers across sectors understand not only families' physical and behavioral health concerns, but the social and economic conditions that may cause those concerns or present barriers to addressing them. While some care coordination programs, such as Wraparound and the Center for Care Coordination, already embed addressing these in their practice, others do not. In addition to screening for social determinants of health, programs need to be prepared to support the family in connecting to various social services to address needs, such as housing, food insecurity, employment, and other critical supports.

## Conclusion

Within and across the systems of care, care coordination has become a widely used strategy for improving a range of outcomes for children, families, providers, and systems. While there is widespread agreement that care coordination is critical for children and families with emerging concerns or complex needs, consensus is lacking on the particular elements of care coordination design that will maximize outcomes.

Connecticut's care coordination efforts are widespread and varied, offering opportunities to learn from experience and expertise of the state's providers and families. This report has examined these as well as practice models in other states and the care coordination literature more broadly.

As leaders in the state seek to expand or improve care coordination services for children and families, this report outlines opportunities at the policy, systems, and practice levels to strengthen and streamline coordination of care, improving efficiency, cost-effectiveness, quality of care, and wellness outcomes for children and families.

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[e] Support for implementing the CLAS Standards is available through the CLAS Toolkit (accessible through the CHDI website) and technical assistance is offered thorough CONNECTing Children and Families to Care.

# Appendix A: Connecticut Care Coordination Program Descriptions

## Autism Care Management Services

The Connecticut Behavioral Health Partnership serves children statewide who are covered by Husky (Connecticut's Medicaid program). Children must be under 21 with a diagnosis of autism spectrum disorder (ASD) or in need of an autism diagnostic evaluation. More than 2,000 children were served in 2019. Beacon Health Options, the Administrative Service Organization of the Connecticut Behavioral Health Partnership, can authorize behavioral health services for HUSKY A, C, or D members under the age of 21 and provide support for families through care coordination or peer support services regardless of HUSKY benefit package or age. The program coordinates care for families in person as appropriate; the peer specialist and/or care coordinator assesses the family's strengths and needs, then assists the family to navigate systems, understand benefits, and access services, both traditional and non-traditional. Staff connect families to qualified providers for diagnostic evaluations, in-home or community-based services, and social groups. ASD staff may meet with the family in the home as needed to accommodate child care needs and/or to observe the youth in his or her home environment. The program has resulted in expansion of the ASD provider network, provider quality monitoring, skillset improvement, and reductions of maladaptive behaviors.

## Birth to Three System/IDEA Part C Service Coordination

The Connecticut Office of Early Childhood is the lead agency administering the Birth to Three System that is funded by state funds, commercial insurance, Medicaid, family cost participation fees, and funding from the U.S. Department of Education. Birth to Three provides statewide supports for families with concerns about the development of their children, from birth to 3 years old. Approximately 11,000 children are served annually. Twenty community-based Birth to Three programs work with families to evaluate each child's development and, if eligible, create an Individualized Family Service Plan (IFSP) that describes the family's priorities for their child and family, and the supports needed to help them reach their goals. Service coordinators help connect families to resources in their community as part of family outcomes. Part C supports are coordinated with health care providers and any other family support programs available. IFSPs are reviewed at least every six months and, with parent consent, as the child approaches age 3, a transition conference is held with their school district. Service Coordinators coach families about communicating with others about their child's abilities and challenges and families are offered a connection with CPAC, Inc. for ongoing support with advocacy. Early Intervention Service (EIS) practitioners include speech pathologists, physical and occupational therapists, social workers, licensed behavioral analysts and certified teachers many of whom have advanced degrees. In addition, all EIS staff complete an initial Birth to Three certificate required by the OEC. Service Coordinators then complete additional training. All 20 Birth to Three programs have staff trained to fidelity in the evidence-based practices of using coaching from a primary services provider with activities in natural learning environments. The OEC completes an annual performance report for the US Dept of Education that includes progress towards targets for child and family outcomes, IDEA compliance and other results indicators. This data is then publicly reported by program at Birth23.org.

## Community Support for Families

The Connecticut Department of Children and Families (DCF) funds agencies throughout the state to implement the Community Support for Families program. The program is a voluntary, strengths-based, and family-driven program for families referred by DCF who have needs, but do not meet statutory definitions of abuse or neglect. More than 2,000 children are served annually. Agencies work with families to identify strengths and needs to help sustain a healthy safe home environment for their children. The program uses care coordination services to provide families with linkages to appropriate social services, behavioral health referrals, parenting or child development education, and other community supports. Staff also work closely with families to identify natural supports in their own familial or social network and build relationships with their child's school.

## Connecticut Children's Center for Care Coordination

The Connecticut Children's Center for Care Coordination works on a family, collaborative, and system level to improve coordination of care for children in the state. It provides direct care coordination services to children birth to 21 years and their families, inclusive of medical, behavioral health, social services, and basic needs, and utilizes the Strengthening Families Protective Factors Framework to build knowledge, skills, and resilience among parents. Additionally, the center provides training to providers in the community to build their capacity for care coordination and education on addressing the social determinants of health. Finally, the center developed the state's model for regional collaboratives to support an organized approach to care coordination within regions. The center serves as the lead for the North Central region of the state.

## Connecticut Home Visiting System

Multiple home visiting programs operate in Connecticut. Funded by a combination of state and federal sources, the Connecticut Office of Early Childhood operates the following six evidence-based home visitation programs to expecting families and families with young children across the state: Child First, Parents as Teachers, Nurse-Family Partnership, Family Check-Up, Early Head Start, and Minding the Baby. Families are served regardless of insurance status. Programs work with families to emphasize their strengths and support challenges. In addition to in-home education and interventions to support the parent-child relationship, programs provide care coordination services to connect families to medical, behavioral health, early intervention, early education, and social services. They work to reduce stress for the family and increase stability. Qualifications for home visitors vary from training and work experience requirements to bachelor's level degree and/or clinical licensing. Each of the programs is evidence-based, with published evaluations finding positive outcomes for children and families served.

## Enhanced Care Clinic (ECC) Initiative

The Connecticut Behavioral Health Partnership serves as the lead agency for this initiative, with funding from the state (DCF and DSS). The ECCs are regional clinics for children and adults with behavioral health needs and serve more than 7,000 children annually. While ECCs are regional clinics, the six regions provide statewide coverage. The ECCs provide timely outpatient services and coordinate behavioral health and addiction services with primary care. Care coordination services include developing formal agreements with primary care providers regarding communication protocols, transition of medication management, clinical consultation, and co-management. Evaluations found positive feedback from pediatric primary care providers who had partnered with an ECC.[74]

## Federally Qualified Health Centers (FQHCs)[f]

Connecticut has 16 Federally Qualified Health Centers (FQHCs or health centers) and one FQHC look-alike, with more than 100 locations across the state. Health centers are located in medically underserved

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[f] All Federally Qualified Health Centers must meet the National Committee for Quality Assurance's (NCQA) Patient-Centered Medical Home Recognition program requirements which include coordination to reduce fragmentation.

areas and operate standing clinics as well as more than eighty school-based health centers. The health centers collectively serve roughly 400,000 patients every year, and roughly 28%, or more than 120,000 of these patients, are children. Patients can receive primary care, dental care, and behavioral health services at health centers regardless of their insurance type or ability to pay. Connecticut's health centers also provide care coordination and case management, and help people sign up for health insurance. Research has found that health centers are effective at coordinating care for children, especially when addressing chronic conditions like asthma. Care coordinators obtain information from patients, identify gaps in care, refer patients to specialty care, make appointments, and follow up with patients.

## Help Me Grow

The Connecticut Office of Early Childhood funds and serves as the lead agency for Help Me Grow. Help Me Grow serves children statewide, prenatal to age 8, who are at risk of developmental delay but may not qualify for Part C services—more than 2,000 children annually. Help Me Grow takes a systems approach to linking services and works with communities to identify available resources and then finds opportunities to strengthen collaboration among early childhood services to support healthy development. It also works directly with parents through the Child Development Info Line, and links parents, expecting parents, and providers to community resources to support children's developmental and behavioral health needs and concerns, including home visitation programs. The program continues to provide ongoing support while the referral is established. Additionally, it organizes in-person networking opportunities for providers. Family referrals have an 80% success rate for connections to services, and families overall report positive family outcomes.[75]

## Medical Home Initiative for Children and Youth With Special Health Care Needs (CYSHCN)

The initiative includes five regional care coordination centers funded by the Department of Public Health, through the Title V Block Grant. It serves children and youth from birth to 21 years who have, or are at increased risk for, a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally. More than 1,200 children and youth were served in 2019. Care coordinators are required to have a bachelor's degree, with some being licensed medical staff. Care coordinators partner with families to develop and implement a plan of care that identifies needs, and how and when services will be accessed. There is medical home coordination of medical, behavioral health, education, social services, respite care, medical financing, and transition to adulthood. The initiative also offers regional care coordination collaboratives to work across care coordination programs. Providers review challenging cases and identify how to meet the care coordination needs of the families. To create sustainable coordination across systems, the initiative also develops policy recommendations. National survey data is collected regarding families' access to a medical home, plan of care, linkages to care, and satisfaction. Evaluations of a comprehensive medical home approach for CYSHCN found positive child and family outcomes.[76]

## PCMH Plus (PCMH+)

PCMH+ builds on the Department of Social Services existing PCMH model by incorporating enhanced care coordination activities related to the integration of primary care and behavioral health care; by building provider competencies to support Members who have complex medical conditions and disability needs; and by promoting linkages to community supports that can assist beneficiaries in accessing and utilizing covered Medicaid services and addressing social determinants of health that may present barriers to improved health. Typical barriers that inhibit the use of services covered by Medicaid include housing instability, food insecurity, lack of personal safety, limited office hours at medical practices, chronic conditions, poverty, homelessness, exposure to neighborhood violence, trauma, and low literacy. Under PCMH+, participating entities (PE) provide enhanced care coordination activities to improve the quality, efficiency, and effectiveness of the provision of care. FQHCs that participate in the program provide care coordination add-on payment activities that are in addition to the enhanced care coordination activities and the care coordination activities that are already required for their participation in the DSS PCMH program. All PCMH+ participating entities (both FQHCs and advanced networks) that meet identified benchmarks on quality performance standards and comply with under-service prevention requirements are eligible to receive shared savings payments at the end of the program year. DSS also makes care coordination add-on payments to PCMH+ participating entities that are FQHCs to support the care coordination add-on payment activities. Significant improvements from 2017 to 2018 were seen in behavioral health screening, developmental screening, and decreased emergency department usage. It resulted in $2.3 million in savings in 2017.[77]

## School-Based Health Centers

In 2018–2019, the state's Department of Public Health supported 91 school health service sites in 28 communities. Of these, 80 were school- based health centers (SBHC) and 11 were expanded school health (ESH) sites. SBHCs serve students, Pre K to grade 12, and are located in elementary, middle, and high schools. SBHCs provide access to physical, mental health, and dental (in some locations) services to students enrolled in the school regardless of their ability to pay. In 2018–2019, a total of 20,216 students made 62,159 clinic visits. They serve all students, regardless of insurance. Centers provide comprehensive health services on-site at schools inclusive of medical, mental, and oral health, as well as coordination with social services. SBHCs are staffed by an interdisciplinary team of professionals with expertise in child and adolescent health. Centers demonstrate high utilization across sites, with a proportion of students returning to class following a visit to the center. Many sites integrate a mental health screening and a body mass index (BMI) screening, and check in on chronic conditions into each visit.[78]

## 211 Child Development Infoline

United Way of Connecticut serves as the lead agency for the 211 Child Development Infoline, with funding blended from the state's Office of Early Childhood, the Department of Education, the Department of Public Health, and United Way of Connecticut. It is a phone-based care coordination service connecting families to developmental promotion and assessment services. Families who are expecting or have young children can call 211 to obtain information or discuss concerns about development or behavior. Care coordinators provide support to families and, if appropriate, refer to one or more child development programs and services.

## WrapCT Care Coordination/Intensive Care Coordination

The Connecticut Department of Children and Families and Beacon Health Options serve as the lead agencies, with funding from the Connecticut Department of Children and Families. It is a statewide program for children meeting the criteria for serious emotional disturbance and at risk for out-of-home placement. Utilizing the Wraparound model, through Child and Family Team meetings (usually held in the family's home), a care coordinator works with the family to develop a plan of care and, over time, strengthens the roles of "natural supports" in implementing the plan of care. It includes coordination with behavioral health, medical, school, and social services. The program serves as the direct care component of the CONNECTing Children and Families to Care initiative and works with six regional network of care collaboratives and 26 local community collaboratives. More than 1,300 children received WrapCT Care Coordination services in fiscal year 2019. Care coordinators have at least a bachelor's level degree in social services and complete multiple trainings to achieve certification. Evaluations have found improvements in children's functioning and problem severity following services.[79]

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