



NATIONAL ACADEMY
FOR STATE HEALTH POLICY

nashp.org



National Care Coordination Standards for Children and Youth with Special Health Care Needs (CYSHCN)

IMPLEMENTATION GUIDE

By Olivia Randi, Zack Gould, Kate Honsberger

JUNE 2022

Supported by



Table of Contents

INTRODUCTION..... 3

SYSTEM-WIDE ORGANIZING ELEMENTS..... 4

STAKEHOLDERS AND PARTNERSHIPS 4
 Potential Partners, Interests, and Contributions

ASSESSING THE CURRENT SYSTEM 6
 Readiness Checklist

FINANCING CARE COORDINATION SYSTEMS 8

QUALITY MEASUREMENT 10

IMPLEMENTING THE CARE COORDINATION STANDARDS..... 11

STRATEGIES FOR IMPLEMENTING DOMAIN 1: SCREENING, IDENTIFICATION, AND ASSESSMENT..... 11
 Screening and Assessment Factors and Tools
 Quality Measures that Align with Domain 1

STRATEGIES FOR IMPLEMENTING DOMAIN 2: SHARED PLAN OF CARE..... 15
 Shared Plan of Care Template
 Quality Measures that Align with Domain 2

STRATEGIES FOR IMPLEMENTING DOMAIN 3: TEAM-BASED COMMUNICATION..... 19
 Care Team Member Checklist
 Communication Policy Assessment Tool
 Quality Measures that Align with Domain 3

STRATEGIES FOR IMPLEMENTING DOMAIN 4: CHILD AND FAMILY EMPOWERMENT AND SKILLS..... 23
 Quality Measures that Align with Domain 4

STRATEGIES FOR IMPLEMENTING DOMAIN 5: CARE COORDINATION WORKFORCE 26
 Care Coordinator Responsibilities
 Quality Measures that Align with Domain 5

STRATEGIES FOR IMPLEMENTING DOMAIN 6: CARE TRANSITIONS..... 30
 Quality Measures that Align with Domain 6

CONCLUSION..... 32

Appendix A — Implementation Checklist: Strategies to Align with the National Care Coordination Standards for CYSHCN..... 33

Appendix B — National Care Coordination Standards for Children and Youth with Special Health Care Needs..... 38

INTRODUCTION

Care coordination is a core element of efforts to strengthen systems of care and improve health outcomes for children and youth with special health care needs (CYSHCN). Family-centered care coordination is designed to facilitate the provision of services to address the multi-faceted, interrelated needs of CYSHCN and children with medical complexity. State health officials are exploring innovative approaches to improve health care delivery systems for pediatric populations. With the potential to enhance quality and reduce costs through care coordination, they have increasingly sought guidance in designing care coordination programs. This interest has established a need for a comprehensive set of standards to guide the development of robust care coordination systems for CYSHCN.

The [National Care Coordination Standards for Children and Youth with Special Health Care Needs](#), released by the National Academy for State Health Policy in October 2020, outline the core system-level components of high-quality care coordination for CYSHCN. These Standards are designed to help state health officials and other stakeholders develop and strengthen care coordination systems for CYSHCN. They are organized by the following six domains:

1. Screening, Identification, and Assessment
2. Shared Plan of Care
3. Team-Based Communication
4. Child and Family Empowerment and Skills Development
5. Care Coordination Workforce
6. Care Transitions

How to Use This Guide

This guide is intended to support state health officials (e.g., public health, Medicaid, mental health) and other stakeholders (e.g., health plans, providers, families of CYSHCN) in using, adapting, and implementing the National Care Coordination Standards for CYSHCN to develop or improve care coordination systems. This resource is designed for stakeholders that are at various stages of developing and improving their care coordination systems. As such, it includes a wide range of steps from establishing partnerships to measuring the impact of system improvements. This guide is not necessarily intended to be followed step-by-step. Instead, stakeholders can use the sections of this guide that are most supportive in advancing state goals and the status of their care coordination system improvement plans.

Throughout this guide, the term “implement” is used to describe how state health officials and other stakeholders can use the Standards to support efforts to improve care coordination systems. This term refers to a variety of uses that this guide can support, including to:

- Support and engage families of CYSHCN in care coordination
- Guide strategic planning
- Identify state-level challenges to coordinating care for CYSHCN, including duplication of and gaps in services
- Train the care coordination workforce
- Identify areas for quality measurement
- Inform contracts and service agreements
- Identify strategies for implementing the Standards within one or more domains
- Improve other aspects of existing care coordination systems

SYSTEM-WIDE ORGANIZING ELEMENTS

There are several cross-cutting organizational elements that can support implementation of the National Care Coordination Standards for CYSHCN across all domains. This section of the guide outlines considerations, examples, and resources for:

1. Identifying stakeholders and establishing partnerships across care coordination and child-serving systems
2. Assessing care coordination system capacity, gaps, and process improvements
3. Financing care coordination systems
4. Measuring and tracking the quality of care coordination services and systems

STAKEHOLDERS AND PARTNERSHIPS

Identify key stakeholders and their roles in implementing the Standards.

Effectively engaging child health stakeholders is key to the care coordination system improvement process. Throughout this guide, “stakeholders” will be used to refer to those responsible for implementing the Standards. This may include staff internal to a care coordination program or agency and/or external partners, depending on how the Standards will be used. For example, a state Title V CYSHCN program may use the Standards to guide strategic planning, which might be implemented through internal program staff. On the other hand, a health plan may use the guide to implement a high-quality screening and assessment process through primary care providers. This approach may benefit from partnerships with the state Medicaid agency to ensure alignment with other screening and assessment tools, providers and professional organizations to support buy-in and feasibility, and families of CYSHCN to advise on family-centered design and implementation.

Determining which stakeholders should be at the table to inform care coordination practices can ensure that all key stakeholder perspectives are included in implementing the Standards. Stakeholders may consider identifying systems of importance for CYSHCN and partners in the care coordination system improvement process, as well as the interests and roles of each partner. It is particularly important to ensure that partnerships with key stakeholders outside of the health system (e.g., education, social services, child welfare) are also identified as these systems are crucial to comprehensive, high-quality care coordination. Gaining support from senior leaders within these systems is essential in successfully initiating and sustaining partnerships. Stakeholders may also consider how to foster relationships between families and education, social service, and behavioral health systems to create robust systems of care for CYSHCN.

Potential Partners, Interests, and Contributions

The following table, adapted from the National Improvement Partnership Network’s [“Establishing a Child Health Improvement Partnership: A How-to Guide,”](#) can be used and built upon to identify key stakeholders, their interests, and potential roles in implementing the National Care Coordination Standards for CYSHCN. This table includes examples and is not exhaustive.

Potential Partners ¹	Primary Interest(s)	Potential Contribution(s)
State Medicaid agencies	<ul style="list-style-type: none"> • Improve health outcomes for CYSHCN while minimizing costs • Oversee and incentivize quality care 	<ul style="list-style-type: none"> • Provide policy guidance and identify opportunities • Advise on existing care coordination initiatives • Reimburse care coordination services • Incentivize improvements
Health plans/ managed care organizations	<ul style="list-style-type: none"> • Effectively coordinate care for children to reduce costs and improve quality of care and health outcomes for CYSHCN • Meet quality requirements 	<ul style="list-style-type: none"> • Identify opportunities for improvements • Provide findings from health care data
State Title V CYSHCN programs	<ul style="list-style-type: none"> • Improve health outcomes for CYSHCN • Build capacity for quality care coordination for CYSHCN 	<ul style="list-style-type: none"> • Advise on existing care coordination initiatives • Identify opportunities for improvements
Families of CYSHCN	<ul style="list-style-type: none"> • Inform family-centered care coordination systems • Partner with stakeholders to implement system improvements 	<ul style="list-style-type: none"> • Provide input on key challenges for families • Advise on family-centered system design

<p>Pediatric health care providers and care coordinators</p>	<ul style="list-style-type: none"> • Improve care coordination delivery across health and social service systems • Access training, tools, and materials for improving care coordination 	<ul style="list-style-type: none"> • Advise on existing care coordination practices • Identify training and resource needs to improve care coordination • Implement care coordination services
<p>Other state agencies/social service systems (including mental health, education, child welfare, etc.)</p>	<ul style="list-style-type: none"> • Support coordination across health and social service systems • Provide high quality care and services for CYSHCN and their families 	<ul style="list-style-type: none"> • Identify opportunities to align services • Inform improvement strategies based on existing systems
<p>Professional organizations (e.g., American Academy of Pediatrics)</p>	<ul style="list-style-type: none"> • Educate members on care coordination improvement strategies • Support members in accessing training and technical assistance 	<ul style="list-style-type: none"> • Gather and summarize input from members • Recruit providers to support system improvements
<p>Academic institutions</p>	<ul style="list-style-type: none"> • Conduct research on best practices for care coordination • Support quality improvement efforts 	<ul style="list-style-type: none"> • Guide quality measurement and evaluation • Advise on evidence-based improvement practices

ASSESSING THE CURRENT SYSTEM

Assess the care coordination system using the National Care Coordination Standards for CYSHCN as a framework.

Stakeholders can assess how closely the existing care coordination system is aligned with the National Care Coordination Standards for CYSHCN. See the Implementation Checklist in Appendix A, which can be used as a tool to identify and track progress in implementing strategies outlined in this guide to support alignment with the Standards.

Assessment includes but is not limited to:

- Analyzing population-level data on the needs of CYSHCN in the system to determine the level of unmet care coordination needs (e.g., the percent of CYSHCN with a shared plan of care)
- Crosswalking and compiling policies across the care coordination system (e.g., Medicaid managed care contracts)
- Using survey data to measure the quality of existing care coordination services
- Conducting stakeholder meetings and interviews



In **Kansas**, the Title V CYSHCN program leveraged the National Care Coordination Standards for CYSHCN to conduct an assessment of existing care coordination practices and needs. This includes:

- Reviewing core concepts from the Standards with teams of primary care providers, care coordinators, families, and other stakeholders prior to facilitating discussions on care coordination
- Focusing the agenda for each in a series of roundtable discussions with providers and other stakeholders on one or two domains from the Standards
- Using the Standards to inform questions included in a survey of providers²

The results of this process are being used to inform a [toolkit](#) and technical assistance provided by Kansas to support the delivery of high-quality care coordination services across the state. See the [input summary](#).

Equipped with this information, stakeholders can conduct system mapping activities to assess how the current system aligns with the Standards. After the assessment process, stakeholders can prioritize components of the National Care Coordination Standards for CYSHCN to implement based on the existing system's capacity and gaps, improvements with the greatest potential impact, and the feasibility of each proposed improvement.



See [Minnesota's](#) and [Wisconsin's](#) care coordination system assessment reports. These reports were developed through system mapping processes led by each state's Title V CYSHCN program. These processes included holding meetings with stakeholders across the state, identifying gaps and overlapping services, and developing recommendations for system improvements.

Stakeholders can assess their readiness to use or adapt the Standards to implement system changes, as well as the feasibility and capacity to implement care coordination system improvements.

Readiness Checklist

Below is a checklist of key readiness factors for organizations, stakeholders, and family stakeholders involved in system improvement efforts. These elements can be considered before implementation of the Standards and planning for sustainability.

Organizations/Agencies	Stakeholders	Family Stakeholders
<ul style="list-style-type: none"> <input type="checkbox"/> Have interest and the political will to improve care coordination <input type="checkbox"/> Link care coordination to organizational priorities through senior leadership <input type="checkbox"/> Identify stakeholders to engage <input type="checkbox"/> Recognize and endorse care coordination standards, and support the work of stakeholders <input type="checkbox"/> Ensure that there are no significant competing priorities 	<ul style="list-style-type: none"> <input type="checkbox"/> Possess quality improvement knowledge and skills <input type="checkbox"/> Include a range of key stakeholders and a key leader/organizer <input type="checkbox"/> Develop processes to include input from across the team and strategically plan for Standards implementation <input type="checkbox"/> Have resources and support for planning and implementation 	<ul style="list-style-type: none"> <input type="checkbox"/> Have demonstrated interest and need to improve care coordination, especially for those affiliated with organizations <input type="checkbox"/> Are engaged by organizations and stakeholders for care coordination improvement efforts <input type="checkbox"/> Are seen as equal partners in the stakeholder group

Another resource, the [Family Engagement in Systems Assessment Tools](#), can be used to further assess and identify gaps in family engagement in systems' improvement efforts.

FINANCING CARE COORDINATION SYSTEMS

Consider how various funding sources and strategies can be leveraged to support implementation of the National Care Coordination Standards for CYSHCN.

Care coordination systems can be financed by a variety of sources and strategies. One way of using the Standards is to help determine financing gaps. Stakeholders can consider if and how each current source of funding can be leveraged to support care coordination services and system improvements based on the National Care Coordination Standards for CYSHCN. Additionally, implementing the Standards may require strategic planning to maximize existing resources by effectively braiding funding streams and to identify areas where additional funding is needed.

While health plans are the primary funding stream for care coordination service reimbursement, there are other sources of funding to consider. For example, care coordination for CYSHCN often involves coordination between health care and education systems, public health programs, and behavioral health and social service agencies. Grant funding from government agencies and community foundations can serve as an important resource to support new and innovative care coordination activities, such as implementing a specific domain of the Standards.

For more information on care coordination funding sources and financing strategies (e.g., fee-for-service, per-member-per-month, etc.), see these resources:

- [“The Care Coordination Conundrum and Children and Youth with Special Health Care Needs”](#)³ describes care coordination financing considerations, including the identification of major funding sources for care coordination systems and key considerations for each. Stakeholders can use this list to assess potential sources of funding and develop a financing strategy to support implementation of the National Care Coordination Standards for CYSHCN.
- [“Care Coordination in a Statewide System of Care: Financing and Payment Strategies”](#)⁴ provides additional information on financing strategies and estimating the cost of care coordination.



Virginia’s Children’s Service Act (CSA) is one example of a statewide collaboration to support care coordination for children with complex needs. The CSA uses multiple funding sources from the departments of Social Services, Juvenile Justice, Education, and Behavioral Health and Developmental Services to coordinate care for at-risk youth and families.⁵ This funding is collectively overseen by these state agencies and other stakeholders through the State Executive Council for Children’s Services. These collaborations allow Virginia to provide social and health services and supports to children with complex needs while minimizing fragmentation and cost of care. By using funds from each department to support Medicaid eligible services such as behavioral health care and housing supports, the CSA draws down federal Medicaid funding.⁶ This funding stream increases access to essential care coordination services for families in need. Children who are eligible under the CSA are provided with a care coordinator that ensures the delivery and coordination of all services developed by the state Family Assessment and Planning team. This single point of contact helps the state and locality ensure that duplicative services are not paid for by multiple sources and helps identify any remaining gaps in the child’s plan of services.⁷

For additional examples of state approaches to financing care coordination services for CYSHCN, see [“Medicaid Financing of Care Coordination Services for Children and Youth with Special Health Care Needs”](#).

In Virginia, the CSA uses multiple funding sources from the departments of Social Services, Juvenile Justice, Education, and Behavioral Health and Developmental Services to coordinate care for at-risk youth and families.

QUALITY MEASUREMENT

Identify quality measures that can be implemented across the care coordination system and can best track progress in implementing the Standards.

Quality measurement is critical to guide care coordination systems in identifying gaps in services and quality and track progress over time in using the National Care Coordination Standards for CYSHCN to implement improvements. Building consensus among stakeholders on key care coordination metrics to track and addressing technology barriers to collecting this data can support system-wide care coordination quality measurement.

Quality measurement for care coordination may include structural measures such as having a care coordinator as part of the team, process measures such as the presence of a shared plan of care, and patient-centered outcome measures.⁸ While structure and process measures are important for analyzing trends in care coordination delivery and can serve as a proxy for patient-centered outcome measures, patient-centered outcome measures have a greater role in determining the quality and value of care coordination services.⁹ When possible, quality measures may also be assessed across sub-populations of CYSHCN to identify inequities in the delivery of care coordination services.

There are several tools that can be used to measure the quality of care coordination systems for CYSHCN. The resource “[Aligning Quality Measures with the National Care Coordination Standards for Children and Youth with Special Health Care Needs](#)” outlines measures from four surveys that assess quality from the perspective of the family and the provider and align with each of the six domains in the National Care Coordination Standards for CYSHCN. These measures are also included within the corresponding sections below. The four survey tools are:

- [National Survey of Children’s Health](#) (NSCH)
- [Family Experiences with Care Coordination](#) (FECC)
- [Consumer Assessment of Healthcare Providers and Systems](#) Survey, Item Set for Children with Chronic Conditions (CAHPS CCC)
- [Patient-Centered Medical Home Assessment](#) (PCMH-A)

Additional tools may be specific to one domain, such as the [Adolescent Assessment of Preparation for Transition \(ADAPT\) survey](#), which addresses the transition to adult care, or numerous surveys that measure teamwork in health care settings.¹⁰ In addition to these tools, two general measures can be adapted to apply across the six domains: the presence of a particular tool (e.g., a shared plan of care) and the rate of adoption of a care coordination practice (e.g., the rate of CYSHCN and families that are assessed by a validated tool).

IMPLEMENTING THE CARE COORDINATION STANDARDS

Stakeholders can identify strategies and considerations for implementation across and within the six domains of the National Care Coordination Standards for CYSHCN. A Standards [graphic](#) outlines key points from each domain and depicts how they intersect. Each domain outlined below includes a brief summary of the domain in the Standards, followed by implementation strategies, resources, and examples to consider. For a full list of the standards within each domain, see Appendix B.

STRATEGIES FOR IMPLEMENTING DOMAIN 1: SCREENING, IDENTIFICATION, AND ASSESSMENT

“Screening, identification, and assessment of a child’s needs provides the foundation for effective, high-quality care coordination. Assessment is a continuous process that reflects ongoing conversations with CYSHCN and families about their needs, preferences, and priorities.”¹¹ The standards within [Domain 1](#) support the comprehensive identification of children and families in need of care coordination by screening for a variety of factors. With the family’s consent, the results are shared with care team members to guide service delivery. Below are strategies, resources, and examples to consider for implementing the standards in this domain.

- **Determine factors to include in the care coordination screening and assessment process and identify gaps and correlating tools.** It is important to consider the range of factors that can be included in the screening process. Any gaps that stakeholders identify may be supplemented by implementing a validated screener and/or adding a module to an existing assessment tool. While some factors may be screened across all CYSHCN, others may be implemented within a particular setting or for a specific subpopulation. When applicable, consider how the screening process can leverage existing data to reduce the burden on families, who have reported that the frequency of screenings through various providers can be onerous.

Screening and Assessment Factors and Tools

The following table includes several areas of needs and strengths to consider in the screening and assessment process and examples of corresponding tools. When interested in screening for a particular need or strength for care coordination purposes and considering tools to implement, stakeholders can draw from this list and others. This list is not exhaustive. Additional tools can be found at [Bright Futures Toolkit: Links to Commonly Used Screening Instruments and Tools](#); [Mental Health Screening and Assessment Tools for Primary Care: Decision Support for Clinicians](#); and [Social Needs Screening Tools Comparison Table \(Pediatric Settings\)](#).

Needs/Strengths Area	Screening Tools
Adverse childhood experiences/trauma	<ul style="list-style-type: none"> • Center for Youth Wellness ACE-Q • Pediatric ACEs and Related Life-Events Screener (PEARLS)
Behavioral/emotional needs	<ul style="list-style-type: none"> • Ages & Stages Questionnaire: Social-Emotional (ASQ: SE) • Child and Adolescent Needs and Strengths (CANS)* • Patient Health Questionnaire-Adolescent (PHQ-A) • Protocol for Responding to and Assessing Patient Assets, Risks, and Experiences (PRAPARE)* • Pediatric Quality of Life (PedsQL) Inventory* • Short-Form 12 Survey (SF-12)* • Survey of Well-Being of Young Children (SWYC)*
Caregiver needs	<ul style="list-style-type: none"> • Child and Adolescent Needs and Strengths (CANS)* • Survey of Well-Being of Young Children (SWYC)
Developmental/life functioning	<ul style="list-style-type: none"> • Child and Adolescent Needs and Strengths (CANS)* • Pediatric Quality of Life (PedsQL) Inventory* • Short-Form 12 (SF-12) Survey* • Survey of Well-Being of Young Children (SWYC)*
Social needs	<ul style="list-style-type: none"> • Accountable Health Communities Health-Related Social Needs Screening Tool (AHC HRSN) • Healthy Opportunities Screening Tool • Children’s HealthWatch Housing Stability Vital Sign • Children’s HealthWatch Hunger Vital Sign • Protocol for Responding to and Assessing Patient Assets, Risks, and Experiences (PRAPARE)* • Survey of Well-Being of Young Children (SWYC)*
Strengths	<ul style="list-style-type: none"> • Child and Adolescent Needs and Strengths (CANS)*

**These tools screen and assess across multiple factors, which may simplify the screening process. Given the challenges for providers in adopting any tool, it is important to consider the utility and feasibility of implementation.*

- **Conduct an inventory of screening tools used across the care coordination system, streamline where possible, and adapt as needed.** The use of consistent screening and assessment tools can reduce the number of data points to track across the system and support collaboration across providers. At the same time, certain tools may be best suited for specific settings and program purposes. Developing an inventory of tools currently in use can help inform the selection of any new screeners based on what has already been implemented, when applicable. Care coordination systems may also find it useful to adapt screening and assessment tools to best fit their needs.



For example, in [Virginia](#), all children that receive Children’s Service Act (CSA) services are assessed annually using the Child and Adolescent Needs and Strengths (CANS) tool.¹² CSA serves children with behavioral issues who are in or at risk of placement in residential care, foster care services, and/or a private school education program. As such, Virginia has adapted the CANS tool by expanding a module on trauma and adding a module on child welfare.¹³

- **Tailor screening and assessment processes to meet the needs of families.** Allowing for options regarding when, where, and how screening and assessment are conducted provides flexibility for families to determine the process that best meets their needs. For example, the care coordination system may set a standard to screen families during a well-child visit and also offer the option for families to self-administer the screening at home. This approach recognizes that while there may be a benefit to providers conducting in-person screening and assessment, families may prefer a more flexible screening process due to time constraints and other barriers to completing the form in a provider’s office. See the following resources to support family-centered screening processes:
 - [“A Strengths-Based Approach to Screening Families for Health-Related Social Needs”](#)
 - [“Social Determinants of Health: Guide to Social Needs Screening”](#)
 - [“Screening for Social Determinants of Health Among Children and Families Living in Poverty: A Guide for Clinicians”](#)
- **Establish processes for sharing screening and assessment results, including consent processes.** Developing or enhancing a consent process, along with data-sharing agreements, can allow for screening and assessment information to be shared across providers when appropriate. Ideally, the consent form serves as a single document where families can select and authorize which providers their information can be shared with. Storing results electronically can enable families to promptly access them and can facilitate sharing with other providers as appropriate and in compliance with privacy regulations.
 - See the [Confidentiality Toolkit](#),¹⁴ a resource developed from the Administration for Children and Families’ Interoperability Initiative to support human services programs in sharing data across systems and navigating privacy considerations in the process.
- **Use screening and assessment results to guide the intensity of care coordination services and facilitate referrals.** Consider developing a standard process for matching the intensity of care coordination services to a child’s level of risk for adverse outcomes, as identified through the screening and assessment process. This may include the use of an algorithm (e.g., 3M Clinical Risk Groups, Pediatric Medical Complexity Algorithm, etc.) or manual scoring of screening and assessment results to stratify CYSHCN into tiers and match service intensity to need. Additionally, facilitating referrals to services and resources immediately following screening and assessment can build trust with children and their families and support their identified needs.



For example, [Texas](#) uses the STAR Kids Screening and Assessment Instrument (SK-SAI) for children enrolled in the STAR Kids specialized managed care program for CYSHCN.¹⁵ The results of this assessment help to stratify CYSHCN enrolled in the program into one of three tiers, based on the child’s level of need and the intensity of care coordination services.¹⁶



For example, [California’s](#) ACEs Aware initiative provides Medicaid reimbursement for providers that screen children for adverse childhood experiences (ACEs) using the PEARLS tool. The state requires participating providers to complete a training on trauma and requirements for conducting the screening.¹⁷ This training outlines the screening [workflow](#), including the algorithm that informs a child’s risk level and that the clinical response includes linking to appropriate services.

Quality Measures that Align with Domain 1

The table below includes examples of quality measures, drawn from the four tools as described in the [Quality Measurement](#) section, that could be considered for measuring progress in implementing the standards within this domain. This list is not exhaustive. See more information in [Aligning Quality Measures with the National Care Coordination Standards for Children and Youth with Special Health Care Needs](#).

Tool	Measure
CAHPS CCC	<ul style="list-style-type: none"> • Does your child’s personal doctor understand how your child’s medical, behavioral, or other health conditions affect your child’s day-to-day life? • Does your child’s personal doctor understand how your child’s medical, behavioral, or other health conditions affect your <i>family’s</i> day-to-day life?
NSCH	<ul style="list-style-type: none"> • Does this child have special health care needs based on the CSHCN screener? • Is this young child flourishing, age 6 months–5 years; 6 years–17 years?¹⁸ • Does this child have a mental, emotional, developmental, or behavioral problem? • Indicators 6.1–6.27 (focus on family health and activities, covering multiple topics relating to SDOH, family relational health, and parental mental and physical health)
FECC	<ul style="list-style-type: none"> • Care coordinator has asked about concerns and health changes.
PCMH-A	<ul style="list-style-type: none"> • Assessing patient and family values and preferences is systematically done and incorporated in planning and organizing care. (Score 1–12)

STRATEGIES FOR IMPLEMENTING DOMAIN 2: SHARED PLAN OF CARE

“The shared plan of care provides a roadmap and an accountability system for integrating care based on family needs and priorities identified in the assessment and is used in coordinating a child’s care.”¹⁹ The standards within [Domain 2](#) identify the recommended core elements of a shared plan of care and support a family-centered approach to its development and use. Policies, procedures, training, and technology are key to facilitating the effective use of a shared plan of care while complying with privacy regulations. Below are strategies, resources, and examples to consider for implementing the standards in this domain.

- Design and implement a system-wide shared plan of care template, with input from key stakeholders, especially families.** Providing a system-wide shared plan of care template can help to ensure that care coordinators and providers recognize a variety of child- and family-serving systems and needs. Incorporating the perspectives of a range of stakeholders and partnering with families and family-led organizations can support the design of a template that recognizes the diverse needs of CYSHCN. These partners are also critical in testing the utility and quality of the shared plan of care template and engaging families in its use.
 - See “[Achieving a Shared Plan of Care for Children and Youth with Special Health Care Needs](#),”²⁰ a report from the Lucile Packard Foundation for Children’s Health, as a resource on creating and operationalizing a shared plan of care with families. A model for designing a shared plan of care in partnership with families is included on page 5 of the [report](#). In the report’s [implementation guide](#),²¹ step 5 of the “Ten Steps to the Shared Plan of Care,” provides approaches for identifying needed partners, especially families, and collaborating with them to develop a shared plan of care.

Shared Plan of Care Template

This template, excerpted from “[Achieving a Shared Plan of Care for Children and Youth with Special Health Care Needs](#),” outlines key components of a shared plan of care.

Major Components of a Shared Plan of Care ²²	
Part I Medical Summary	
Describe the Child/Youth/Family	
Names/Likes to Be Called:	
Sex	Diagnosis
Date of Birth	Problem list
Race	Short summary
First Language	Mental status
Emergency plan on record? (___ Yes/Link) (___ Not Needed)	

Medical Home Neighborhood Mapping (Contacts: e.g., family support, health, school, and community partners)	Responsibilities/Roles	Best Way to Contact
1.		
2.		
3.		

Family Structure — Succinct Social/Educational Summary; Includes Strengths	
<ul style="list-style-type: none"> Siblings (ages, health/wellness concerns, functional ability, etc.) Cultural considerations/preferences 	<ul style="list-style-type: none"> Primary concern of the family (in their words) Family response to “What I/we want you to know about me/us”

Part II Medical Summary — Describe/list	
<ul style="list-style-type: none"> The diagnoses Problem list Short narrative summary Mental status/level of consciousness 	<ul style="list-style-type: none"> Current interventions, treatments, and therapies Other approaches tried and not tried Developmental concerns Environmental concerns Other_____

Part III “Negotiated Actions” (Strategies and Plans to Address Each Goal)	
What are the family/child/youth’s identified goals (i.e., what matters to them?)	
<ul style="list-style-type: none"> Patient goal(s) (dated) 	<ul style="list-style-type: none"> Family goal(s) (dated)
Clinical treatment goals (best available evidence)	
<ul style="list-style-type: none"> Primary care clinical goal (dated) Sub-specialist(s) goal (dated) 	<ul style="list-style-type: none"> Community provider(s) goal (dated)

For each prioritized goal, identify actions/strategies, accountable persons (including subspecialists and community partners), and the timeline for completing the actions:			
Goals	Actions/Strategies	Accountable Person	Timeframe
Patient			
Family			
Clinical			
Evaluate the shared care process			
<ul style="list-style-type: none"> • Are there methods in place for effective communication? • Has the use of the SPOC been widely adopted? • Is the plan practical and feasible? • Are resources obtainable? • Are there any additional barriers? 		<ul style="list-style-type: none"> • Are the activities adequate to facilitate use of the plan? • Is there adequate documentation of actions? • Is progress assessed for each goal? • Are there cultural issues that call for tailoring of the SPOC to different groups? 	
Signatures and dates (lead clinician, family, coordinator, other)			

• **Assess the technological capacity for documenting shared plans of care across providers.**

Ideally, shared plans of care are documented in an electronic health record (EHR) that is shared across a care team. After establishing the design of the shared plan of care, stakeholders can assess technology across the care coordination system to determine the existing technological capacity, any technology modifications necessary, and processes for providers that cannot access the EHR to access the most up-to-date shared plan of care. In developing these processes, stakeholders can ensure compliance with privacy regulations across child-serving systems and determine how consent processes can be implemented to meet these requirements.



For example, [Iowa's](#) Medicaid managed care program implemented a shared plan of care that can be electronically accessed by providers, families, the state, and other care team members through its Pediatric Integrated Health Home Program.²³

- **Implement training to support use of the shared plan of care.** Comprehensive training for providers and families can ensure that they are consistently using the shared plan of care to support the needs of CYSHCN. This may include training on how to use, maintain, and update the shared plan of care; how to effectively partner with families and providers; and how to adhere to new or modified workflows.²⁴ Training around privacy regulations may also help providers address potential misconceptions and support appropriate data sharing.²⁵



For example, [Oregon’s](#) Title V CYSHCN program provides resources for care coordination staff to support the development of shared plans of care, including a [website](#) with a variety of tools.^{26,27}

- See “[Care Notebook: Documents & Resources to Support Your Child’s Shared Plan of Care](#),” developed by Family Voices of Wisconsin, a resource designed to support families in working with their care team.
- **Identify opportunities to promote and incentivize the use of shared plans of care across the care coordination system.** There are a variety of opportunities to promote the implementation of shared plans of care, which may differ across initiatives and programs that support sub-populations of CYSHCN. One opportunity is for Medicaid agencies to require managed care organizations (MCO) to use shared plans of care within their managed care contracts. Medicaid agencies and other payers may also provide financial incentives for providers to use a shared plan of care. Another opportunity is through State Title V CYSHCN programs, which can provide recommendations, oversight, training, and other support to promote the use of a shared plan of care across a variety of providers who serve CYSHCN.²⁸



For example, [West Virginia’s](#) Title V CYSHCN program has established memoranda of understanding (MOUs) with the state’s Medicaid MCOs. These MOUs outline expectations for serving CYSHCN, including that MCOs must use a shared plan of care for any member with a chronic condition.²⁹

Quality Measures that Align with Domain 2

The table below includes examples of quality measures, drawn from the four tools as described in the [Quality Measurement](#) section, that could be considered for measuring progress in implementing the standards within this domain. This list is not exhaustive. See more information in [Aligning Quality Measures with the National Care Coordination Standards for Children and Youth with Special Health Care Needs](#).

Tool	Measure
CAHPS CCC	<ul style="list-style-type: none"> • In the last 6 months, when there was more than one choice for your child’s treatment or health care, did your child’s doctor or other health provider ask you which choice was best for your child? (yes/no) • When decisions were made in the last 6 months, how often did your child’s doctors or other health providers discuss with you the good and bad things about each of the different choices for your child’s health care? (never, sometimes, usually, always)³⁰
NSCH	<ul style="list-style-type: none"> • Has this child’s doctors or other health care providers worked with you and this child to create a plan of care to meet his or her health goals and needs?

FECC	<ul style="list-style-type: none"> • Caretaker has access to electronic health record. • Caregivers report that main provider created a shared care plan. • Child has a shared care plan. • Care coordinator asked about progress towards goals.
PCMH-A	<ul style="list-style-type: none"> • Care plans are developed collaboratively, include self-management and clinical management goals, are routinely recorded, and guide care at every subsequent point of service. (Score 1–12)

STRATEGIES FOR IMPLEMENTING DOMAIN 3: TEAM-BASED COMMUNICATION

“Communication between members of the care team is timely, efficient, respectful, and culturally sensitive.”³¹ The standards within [Domain 3](#) emphasize that the family is the center of the multidisciplinary care team. While all care team members are able to support a family in accessing services, there is a designated single point of contact for care coordination for each family. Below are strategies, resources, and examples to consider for implementing the standards in this domain.

- **Develop a process for identifying and aligning efforts across all care coordinators serving a family.** Families of CYSHCN have reported that one of their primary challenges is having to coordinate across numerous care coordinators. To alleviate this challenge, stakeholders can develop standard processes to identify all care coordinators that serve a family and facilitate their alignment. These processes may involve information sharing across the care coordination system to identify partners and initiatives serving each family and developing guidelines for communication across care coordinators. Ideally, this process would include steps for identifying a single care coordinator (or another individual) to lead efforts across care coordinators. The shared plan of care can also be used as a tool to align efforts across care coordinators.



The Louisiana Office of Public Health’s Children’s Special Health Services, the state’s Title V CYSHCN program, has developed a [Care Coordination Toolkit](#) that includes information to support primary care providers in delivering comprehensive care coordination services.³² This includes guidance on designing roles and workflows across the care team, processes for reporting on care coordination activities, and a Care Coordination/Communication Assessment Tool that providers can use to identify gaps in internal and external communication processes.³³

- **Develop processes for structuring the care team.** Care team members and roles will differ depending on the strengths, needs, and preferences of a child and their family. Comprehensive screening and assessment and the shared plan of care can help to identify care team members across medical, behavioral health, social service, and education systems. The family and care

coordinator can partner to identify care team members and outline appropriate roles and responsibilities, including determining whether the child is involved in care planning. These roles may include who updates the shared plan of care and which members attend care planning meetings, if any. Standardizing these processes throughout the care coordination system can help to ensure that each family has a full care team with clear roles and that care coordination is family-driven.



For example, [Virginia's](#) Medicaid managed care plan for children and adults with complex care needs requires that each enrollee be assigned an interdisciplinary care team (ICT).³⁴ The managed care contract specifies that certain staff, including the care coordinator, primary care provider, and behavioral health clinician, must have the opportunity to join the ICT.³⁵ The enrollee can decide whether family members, peer support professionals, advocates, and other support staff are also included on these teams.³⁶ The contract also requires that the MCO design and submit policies and procedures for ICT communication, including processes for facilitating participation in the ICT and related meetings, aligning with other care coordination teams, connecting to services, and conducting follow-up.³⁷

Care Team Member Checklist

This checklist includes potential members of the care team to consider.

Potential Care Team Members	Required	Optional
Family members	<input type="checkbox"/>	<input type="checkbox"/>
Care coordinators	<input type="checkbox"/>	<input type="checkbox"/>
Primary care providers	<input type="checkbox"/>	<input type="checkbox"/>
Medical specialists	<input type="checkbox"/>	<input type="checkbox"/>
Behavioral health specialists	<input type="checkbox"/>	<input type="checkbox"/>
Social service providers	<input type="checkbox"/>	<input type="checkbox"/>
Education/school health providers	<input type="checkbox"/>	<input type="checkbox"/>
Child welfare/juvenile justice staff	<input type="checkbox"/>	<input type="checkbox"/>
Peer support professionals	<input type="checkbox"/>	<input type="checkbox"/>
Advocates	<input type="checkbox"/>	<input type="checkbox"/>

- Establish guidelines for communication across the care team.** In addition to defining roles and responsibilities for each care team member, clear communication guidelines can support the care team in delivering comprehensive care. This may include identifying a main point of contact for the family while also adhering to a “no wrong door” approach. Communication protocols may outline when the family should contact the care coordinator/care team members, when the care coordinator should contact the family/care team members, and when other care team members should contact the family/care coordinator. Communication guidelines may also include resources to support collaborative care planning, care team meeting facilitation, and strategies to engage providers and families.
 - See these resources: [“Guiding Principles for Team-Based Pediatric Care,”](#)³⁸ [“Enhancing Provider Engagement in Practice Improvement: A Conceptual Framework,”](#)³⁹ and [“Engaging Families in Improving the Health Care System for Children with Special Health Care Needs.”](#)⁴⁰

Communication Policy Assessment Tool

This resource, adapted from the [Care Coordination Toolkit](#) from the Louisiana Office of Public Health’s Children’s Special Health Services, is an example of a tool that state health policymakers can use to support care coordination providers in assessing and developing comprehensive care coordination communication policies. The rate of policy adoption across providers and programs can also be used as a quality indicator.

Policy/process topic ⁴¹	Is a policy in place?		Tracking mechanism	Responsible staff	Current effectiveness (rank 1–5)
	Yes	No			
Care team communication					
Identifying CYSHCN and connecting to care team					
Updating and tracking shared plan of care					
Scheduling care team meetings					
Facilitating care team meetings					
Ongoing provider communication					

Policy/process topic ⁴¹	Is a policy in place?		Tracking mechanism	Responsible staff	Current effectiveness (rank 1–5)
	Yes	No			
Family-centered care					
Patient/family communication					
Health literacy and education					
Family understanding and access to care plan					
Referrals and services					
Community-based resource referrals					
Follow-up to referrals and appointments					
Engagement in new services or care transitions					
Events (e.g., emergency department visits)					

- Determine technology and data-sharing needs.** A shared platform across the care team can support care management for CYSHCN, closed-loop referrals to community-based services, and notification of change(s) in health status (e.g., hospital admission). The development and use of these platforms may require information-sharing agreements and processes to request a family’s consent to share protected information across providers. Information-sharing agreements may also be implemented to facilitate regular and appropriate communication across the care team while adhering to relevant privacy regulations.
 - See “[Community Resource Referral Platforms: A Guide for Health Care Organizations](#),”⁴² which includes considerations for implementing a shared referral platform across health and social service systems.



For example, [Colorado](#) leveraged a grant from the Administration for Children and Families to improve interoperability of information technology systems across child welfare and behavioral health systems, as well as other health and human services. This project, the Colorado Client Information Sharing System, facilitated data sharing to support direct services, as well as to inform program management and county- and state-level decision-making.⁴³

Quality Measures that Align with Domain 3

The table below includes examples of quality measures, drawn from the four tools as described in the [Quality Measurement](#) section, that could be considered for measuring progress in implementing the standards within this domain. This list is not exhaustive. See more information in [Aligning Quality Measures with the National Care Coordination Standards for Children and Youth with Special Health Care Needs](#).

Tool	Measure
CAHPS CCC	<ul style="list-style-type: none"> In the last 6 months, did you need your child’s doctors or other health providers to contact a school or day care center about your child’s health or health care? Doctor explained care in a way that is easy to understand; doctors listened carefully.
NSCH	<ul style="list-style-type: none"> During the past 12 months, did this child’s health care provider communicate with the child’s school, child care provider, or special education program? During the past 12 months, have you felt that you could have used extra help arranging or coordinating this child’s care among the different health care providers or services? During the past 12 months, did this child need a referral to see any doctors or receive any services? If yes, how difficult was it to get referrals?
PCMH-A	<ul style="list-style-type: none"> Visits are organized to address both acute and planned care needs. Tailored guideline-based information is used in team huddles to ensure all outstanding patient needs are met at each encounter. (Score 1–12)

STRATEGIES FOR IMPLEMENTING DOMAIN 4: CHILD AND FAMILY EMPOWERMENT AND SKILLS

“Care coordination includes education, coaching, and training for CYSHCN, families, and care teams. These activities empower children and families and advance their well-being, while at the same time enabling other members of the care team to gain the understanding and insights needed to serve families effectively.”⁴⁴ The standards within [Domain 4](#) encourage care coordination systems to provide strengths-based services and supports for families. Below are strategies, resources, and examples to consider for implementing the standards in this domain.

- Train care coordinators and care team members.** The care coordination system can provide training for care coordinators and care team members in how to effectively interact with other members of the care team and support families in building skills and self-management. This may include education in strengths-based approaches, methods to clearly communicate complex concepts, and effective strategies to support family engagement. Training can also include the identification of services that support the development of families’ strengths and skills, including peer supports, youth programs, and caregiver support services. Systems may also provide resources, such as facilitation tips and worksheets, to support care coordination staff in these efforts. See the following training tools and resources to support care coordination team members:

- [“Pediatric Care Coordination Curriculum: An Interprofessional Resource to Effectively Engage Patients and Families in Achieving Optimal Child Health Outcomes”](#)⁴⁵: This curriculum from Boston Children’s Hospital is organized into five modules and can be used to train a variety of audiences in the core concepts of pediatric care coordination.
- [Family Centered Case Management Training for Service Coordinators](#): This training module from the Texas Department of Health and Human Services is used to support service coordinators in providing family-centered care coordination for Early Childhood Intervention, an initiative to support families of children with developmental and medical needs.
- **Establish policies to support education and empowerment for families.** A family’s comprehensive understanding of the child’s conditions, needs, and strengths is key to improving self-management and developing related skills. The care coordination system can set policies that guide the care team in providing clear information that considers families’ culture, language, and health literacy levels.
 - See the following resources on family education and empowerment: [“Guide to Leveraging Opportunities Between Title V and Medicaid for Promoting Social-Emotional Development”](#)⁴⁶ and [Strengthening Families and the Protective Factors Framework](#),⁴⁷ which includes [action sheets](#) and [“Using Protective Factors to Help Identify Relevant Strengths”](#) to support implementation of a strengths-based approach.



For example, the [Rhode Island](#) Department of Health and Human Services partners with the Rhode Island Parent Information Network, Family Voices, the Neighborhood Health Plan of Rhode Island, and the Rhode Island American Academy of Pediatrics to operate the state’s Pediatric Practice Enhancement Project (PPEP).⁴⁸ Through PPEP, family members of CYSHCN are hired as consultants and work directly with pediatric providers to support comprehensive family-centered care coordination.⁴⁹ These consultants support families in improving their understanding of the health care system and increasing their sense of empowerment as key decision-makers.⁵⁰

- **Support people with lived experience as key members of the care team.** Including peer support professionals in care teams can increase cultural sensitivity and improve family engagement. Stakeholders can implement policies that support employment for peer support professionals and family caregivers and equitable compensation for the care coordination they provide. This may include requiring or recommending peer support professionals as part of the care team, reviewing and modifying provider eligibility and rates through Medicaid and other payers as needed, and providing stipends. Increasing access to education, training, and respite services can also support family empowerment.

- For resources to support the empowerment of family caregivers as members of the care team, see the [website](#) for Family Voices, a national organization advocating for family participation in health care; [Find Your Parent Center](#), a parent training and information network directory from the Center for Parent Information and Resources; and “[Medicaid Funding for Family and Youth Peer Support Programs in the United States](#).”⁵¹



For example, the [Arkansas](#) Department of Human Services provides Medicaid reimbursement for family peer support professionals through the [Children’s Services Targeted Case Management state plan amendment](#).⁵² “Parent aides,” parents of CYSHCN, are employed by the state Title V CYSHCN program to provide care coordination services for families.⁵³ Services include conducting a comprehensive assessment of a child’s needs, developing and monitoring a service plan, and providing service connection and follow-up.⁵⁴ To be eligible for the services under this policy, the child must be enrolled with the state’s Title V CYSHCN program, the Supplemental Security Income/Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA) Disabled Children Program, or meet certain medical criteria.⁵⁵

Quality Measures that Align with Domain 4

The table below includes examples of quality measures, drawn from the four tools as described in the [Quality Measurement](#) section, that could be considered for measuring progress in implementing the standards within this domain. This list is not exhaustive. See more information in [Aligning Quality Measures with the National Care Coordination Standards for Children and Youth with Special Health Care Needs](#).

Tool	Measure
NSCH	<ul style="list-style-type: none"> • Has this child’s doctor or other health care provider actively worked with this child to: make positive choices about his or her health; gain skills to manage his or her health and health care?
FECC	<ul style="list-style-type: none"> • Care coordinator was knowledgeable, supportive, and advocated for child’s needs.
PCMH-A	<ul style="list-style-type: none"> • Test results and care plans are systematically communicated to patients in a variety of ways that are convenient to patients. (Score 1–12)

STRATEGIES FOR IMPLEMENTING DOMAIN 5: CARE COORDINATION WORKFORCE

“The care coordination workforce is well-trained and prepared to serve CYSHCN and their families. All care team members have opportunities to gain the knowledge and understanding needed to perform their roles effectively.”⁵⁶ The standards within [Domain 5](#) focus on supporting a diverse care coordination workforce that can provide high-quality care coordination services for CYSHCN. Below are strategies, resources, and examples to consider for implementing the standards in this domain.

- **Provide training and clear expectations for care coordination staff.** Care coordination systems can serve a crucial role in providing ongoing training, resources, and support for care coordination staff. Stakeholders can develop guidance for recommended criteria for care coordinators to meet or work toward. This guidance can help establish consistent expectations for care coordinators, while also allowing flexibility for care coordination programs to hire staff that meet the specific needs of the families they serve. These competencies may be leveraged in job descriptions and throughout the hiring process and may help guide orientation and ongoing training topics.



For example, the Kansas Title V CYSHCN program developed the [Holistic Care Coordination Implementation Toolkit](#), which outlines guidance for providers in implementing high-quality care coordination programs that are organized by and align with the National Care Coordination Standards for CYSHCN. Kansas is also providing technical assistance through a [Project ECHO Series](#) and a Community of Practice to support implementation.⁵⁷

- See the [OPIP Quality Improvement Tools & Strategies](#), a webpage developed by the Oregon Pediatric Improvement Partnership at Oregon Health & Science University, for a variety of resources to support pediatric care coordination providers.

Care Coordinator Responsibilities

The following table includes potential responsibilities that state health policymakers and providers could draw from to develop job descriptions, guidance, requirements, and other resources for care coordination programs. This list is organized by the six domains in the National Care Coordination Standards for CYSHCN. This list is not exhaustive. See these sample job descriptions for additional examples of care coordinator responsibilities and competencies: [Practice Based Care Coordination Job Description](#)⁵⁸, [Pediatric Nurse Case Manager, Special Needs Program](#)⁵⁹, and [Care Coordinator Sample Job Description](#).⁶⁰

Domain 1: Screening, Identification, and Assessment

- Prompt families and/or providers when screening and/or assessment is needed, both initial and reassessments.
- Conduct screening and/or assessment.
- Track screening and assessment results in appropriate platforms.
- Gather data and information prior to meeting with families to inform screening and assessment.

Domain 2: Shared Plan of Care

- Engage families and service providers to develop a shared plan of care that includes a health summary, long- and short-term goals, upcoming care transitions, and an emergency plan.
- Track adherence to the shared plan of care, and make updates as needed.
- Support care team members, including the family, in accessing and updating the shared plan of care.

Domain 3: Team-Based Communication

- Serve as the main point of contact for the child and their family and care team members.
- Support communication between the family and care team.
- Conduct pre-visit planning calls with the family.
- Provide referrals to services and supports as needed.
- Conduct follow-up and track engagement in services.
- Schedule appointments and ensure records are accessible as needed.
- Facilitate care team meetings.

Domain 4: Child and Family Empowerment and Skills Development

- Educate families about available community resources, including peer support services.
- Support families in understanding health diagnoses and care needs.

Domain 5: Care Coordination Workforce

Attend care coordination trainings, which may include:

- | | |
|--|--|
| <ul style="list-style-type: none"> • Learning from and building partnerships with families • Motivational interviewing • Identification of family strengths, priorities, and goal setting • Shared plan of care development • Cultural and linguistic competency • Implicit bias | <ul style="list-style-type: none"> • Health insurance policies and procedures • Confidentiality • Health Insurance Portability and Accountability Act (HIPAA) and Family Educational Rights and Privacy Act (FERPA) compliance training • Health literacy • Community-based resources • Transition and referral processes • Education systems for CYSHCN⁶¹ |
|--|--|

Domain 6: Care Transitions

Proactively identify upcoming care transitions.

Assess care transition readiness.

Support families in identifying and connecting with adult providers.

Ensure records are transferred, and conduct follow-up post-transition.

- Prioritize the hiring of care coordinators with lived experience and those that expand the cultural, racial, ethnic, and linguistic diversity of care coordination staff.** Stakeholders can support a diverse workforce by increasing care coordination-related training and educational opportunities for people with lived experience and those with diverse cultural, racial, ethnic, and linguistic backgrounds. Additionally, stakeholders can consider identifying and modifying licensing regulations that may serve as barriers to employment as a care coordinator. These strategies can be coupled with enhanced plans to recruit diverse staff across the care coordination system and cultural competency and implicit bias training for existing staff, management, and leadership to improve hiring practices.⁶²

 - See [Think Cultural Health](#) and [The EveryONE Project Implicit Bias Resources](#) for resources to support care coordinators in providing culturally appropriate services and reducing biases.
- Develop caseload ratios that allow care coordinators to maintain high-quality service delivery.** The care coordination system can establish a method of standardizing caseload ratios across care coordinators while also allowing flexibility for providers to adjust the method to best fit their needs. One approach is to use an acuity scoring tool that accounts for the required intensity of care coordination services, the complexity of the case, and other capacity considerations to inform caseload assignment.



For example, [Georgia’s](#) Department of Behavioral Health and Developmental Disabilities, in partnership with the Georgia Department of Community Health and its MCOs, contract with behavioral health provider organizations to provide intensive care coordination for children and youth with complex behavioral health needs.⁶³ Georgia sets a caseload ratio of one care coordinator for every 10 families. The state requires care coordinators to have a bachelor’s degree but allows experience to substitute for this.⁶⁴ Training for care coordinators includes cultural competency, trauma-informed care, and partnering with families.⁶⁵

- Establish policies for reviewing data to assess the care coordinator and care team performance.** System-level guidelines that outline key data points to track and recommend data review processes can support care coordination program management. Guidelines may also include recommendations regarding the frequency of data review and report-out, when and how to make appropriate adjustments, and technology capacity and needs. Potential data points may include:
 - The number of cases for each care coordinator
 - The complexity of each care coordinator’s caseload
 - The intensity of care coordination services required from each care coordinator’s caseload
 - The time required for care coordinators to provide services, including travel time
 - Care coordination activities and services
 - Outcomes from care coordination activities and services
 - Care coordinator staff turnover
 - Child and family feedback on care coordination services

Quality Measures that Align with Domain 5

The table below includes examples of quality measures, drawn from the four tools as described in the [Quality Measurement](#) section, that could be considered for measuring progress in implementing the standards within this domain. This list is not exhaustive. See more information in [Aligning Quality Measures with the National Care Coordination Standards for Children and Youth with Special Health Care Needs](#).

Tool	Measure
NSCH	<ul style="list-style-type: none"> How often did you get as much help as you wanted with arranging or coordinating care? During the past 12 months, did anyone help you arrange or coordinate this child’s care among the different doctors or services that this child uses?
PCMH-A	<ul style="list-style-type: none"> The practice routinely assesses training needs, ensures that staff are appropriately trained for their roles and responsibilities, and provides cross-training to ensure that patient needs are consistently met. (Score 1–12) Non-physician practice team members perform key clinical service roles that match their abilities and credentials. (Score 1–12) Linking patients to supportive community-based resources is accomplished through active coordination between the health system, community service agencies, and patients, and accomplished by a designated staff person. (Score 1–12) Patient comprehension of verbal and written materials is supported at an organizational level by translation services, hiring multi-lingual staff, and training staff in health literacy and communication techniques (such as closing the loop), ensuring that patients know what to do to manage conditions at home. (Score 1–12)

STRATEGIES FOR IMPLEMENTING DOMAIN 6: CARE TRANSITIONS

“Care transitions refer to the transfer of care between and within medical, behavioral health, social service, education, and justice systems. Emphasis is placed on preparing youth for transitions from pediatric to adult care and promoting independence in the transition to adulthood. Advance preparation and careful integration of services following transitions are essential to a successful transition process.”⁶⁶ Below are strategies, resources, and examples to consider for implementing the standards in [Domain 6](#).

- **Develop policies to proactively identify and plan for upcoming transitions.** Care coordination systems can identify key data points to monitor that may indicate an upcoming transition. Transition policies may outline how these data points are tracked, monitored, and flagged, as well as steps in the transition planning and care transfer process. For example, for the transition from pediatric to adult care, a transition policy may identify the age at which planning for the transition begins, processes for tracking age, how it is flagged that a child has reached the age to begin transition planning, steps for transition planning, and how care is transferred to adult providers. These policies may also include special considerations for transfer of care between providers or to other care settings, such as a child entering or exiting school, inpatient care, or a congregate care setting. See the following resources:
 - [Got Transition](#): This website from The National Alliance to Advance Adolescent Health serves as a resource center on health care transition.
 - [Assessment of Health Care Transition Activities in Care Coordination Programs](#):⁶⁷ This worksheet from Got Transition supports care coordination programs in assessing their care transition policies and activities.
 - [Transition Planning](#): This page from the Got Transition website provides resources specific to transition planning, which is Element Four of Got Transition’s Six Core Elements of Health Care Transition.
 - [Implementation Guide for Transition Planning](#):⁶⁸ This guide from Got Transition can support the implementation of policies and programs to identify of and plan for upcoming youth transitions.
 - [“Health Care Transition in State Title V Programs: A Review of 2018 Block Grant Applications and Recommendations for 2020”](#):⁶⁹ This resource reviews care transition strategies that state Title V agencies reported in their 2018 applications/2016 annual reports and highlights key state examples.

Advance preparation and careful integration of services following transitions are essential to a successful transition process.



As an example, [Texas](#) Health and Human Services sets contractual requirements for Medicaid MCOs to support care transitions for CYSHCN enrolled in the STAR Kids health plan, which serves children with disabilities up to age 20.⁷⁰ The contract requires that the MCO employ transition specialists who work with care coordinators to plan for adolescents' transition to adult-serving health plans and providers beginning at age 15.⁷¹ The specialized plan's handbook lists recommended activities to support this transition, organized by age.⁷²

- **Provide training and resources to care coordination staff to support effective transitions.**

The care coordination system can provide training for care coordination staff and the care team to ensure clarity of roles and responsibilities related to transition planning. Transition readiness assessments, transition planning tools, and transfer packets can support CYSHCN and their families in effectively transitioning between providers.⁷³ Providing standardized tools and training across the care coordination system can help to ensure that care coordination providers are equipped with resources to support CYSHCN and their families.

- See [Education & Training for Health Care Professionals, Health Care Transition Curricula](#), a resource developed by Florida Health and Transition Services to support the education of care coordination team members on health care transitions.

- **Develop processes for tracking care transition activities.** Tracking care transition activities and outcomes supports accountability, as well as providing clear communication and information sharing to facilitate a warm hand-off to the new provider(s). These activities and/or the result of the care transfer can be documented in the shared plan of care to ensure that the care team is aware of new provider contacts.



For example, the [Kentucky](#) Department for Public Health administers the state's Title V CYSHCN program through the Office for Children with Special Health Care Needs (OCSHCN). OCSHCN has developed a series of five checklists, organized by age, with key questions for families of CYSHCN to track and identify care transition considerations, including potential new services and supports.⁷⁴ OCSHCN has also developed a transition policy statement for transition-age youth, administers a transition readiness assessment, and employs a transition administrator who conducts regular follow-up for young adults who have recently aged out of youth services.⁷⁵

Quality Measures that Align with Domain 6

The table below includes examples of quality measures, drawn from the four tools as described in the [Quality Measurement](#) section, that could be considered for measuring progress in implementing the standards within this domain. This list is not exhaustive. See more information in [Aligning Quality Measures with the National Care Coordination Standards for Children and Youth with Special Health Care Needs](#).

Tool	Measure
NSCH	<ul style="list-style-type: none"> • Do any of this child’s doctors or other health care providers treat only children? If yes, have they talked with you about having this child eventually see doctors or other health care providers who treat adults? • Have this child’s doctors or other health care providers worked with you and this child to create a plan of care to meet his or her goals and needs? Does this plan of care address transition to doctors and other health care providers who treat adults? • Have this child’s doctor or other health care providers actively worked with this child to understand changes in health care that happen at age 18?

CONCLUSION

State health officials, health plans, providers, families, and other stakeholders can use the National Care Coordination Standards for CYSHCN to guide improvements to best support CYSHCN and their families. This implementation guide provides information and guidance for using or adapting these standards in care coordination systems. This includes key considerations, state examples, and supplemental resources to support planning, implementing, and sustaining care coordination system improvements.

Appendix A – Implementation Checklist: Strategies to Align with the National Care Coordination Standards for CYSHCN

Stakeholders can use this checklist to identify and track their progress in adopting strategies outlined in this implementation guide. This list of strategies is not exhaustive, and this tool is not intended to indicate the extent to which a system meets the Standards. However, strategies that are not being addressed may indicate an area to prioritize for further focus.

STRATEGIES FOR IMPLEMENTING DOMAIN 1: SCREENING, IDENTIFICATION, AND ASSESSMENT

a. Determine factors to include in the care coordination screening and assessment process.

- Implemented
- Partially implemented
- Not implemented

Notes:

b. Identify factors that are not currently included in existing screening and assessment processes and correlating tools that could be implemented.

- Implemented
- Partially implemented
- Not implemented

Notes:

c. Inventory screening tools used across the care coordination system, streamline where possible, and adapt as needed.

- Implemented
- Partially implemented
- Not implemented

Notes:

d. Tailor screening and assessment processes to meet the needs of families.

- Implemented
- Partially implemented
- Not implemented

Notes:

e. Establish processes for sharing screening and assessment results, including consent processes.

- Implemented
- Partially implemented
- Not implemented

Notes:

f. Establish guidelines for leveraging screening and assessment results to guide the intensity of care coordination services.

- Implemented
- Partially implemented
- Not implemented

Notes:

STRATEGIES FOR IMPLEMENTING DOMAIN 2: SHARED PLAN OF CARE

a. Design and implement a system-wide shared plan of care template, with input from key stakeholders, especially families.

- Implemented
- Partially implemented
- Not implemented

Notes:

b. Assess the technological capacity for documenting shared plans of care across providers.

- Implemented
- Partially implemented
- Not implemented

Notes:

c. Implement training to support use of the shared plan of care.

- Implemented
- Partially implemented
- Not implemented

Notes:

d. Identify opportunities to promote and incentivize the use of shared plans of care across the care coordination system.

- Implemented
- Partially implemented
- Not implemented

Notes:

STRATEGIES FOR IMPLEMENTING DOMAIN 3: TEAM-BASED COMMUNICATION

a. Develop a process for identifying and aligning care coordination efforts across all care coordinators serving a family.

- Implemented
- Partially implemented
- Not implemented

Notes:

b. Develop processes for structuring the care team and identifying members.

- Implemented
- Partially implemented
- Not implemented

Notes:

c. Establish guidelines for communication across the care team.

- Implemented
- Partially implemented
- Not implemented

Notes:

d. Determine technology and data-sharing needs for communication between members of the care team, including the family.

- Implemented
- Partially implemented
- Not implemented

Notes:

STRATEGIES FOR IMPLEMENTING DOMAIN 4: CHILD AND FAMILY EMPOWERMENT AND SKILLS

a. Train care coordinators and care team members to support the building of family skills and strengths.

- Implemented
- Partially implemented
- Not implemented

Notes:

b. Establish policies to support education and empowerment for families.

- Implemented
- Partially implemented
- Not implemented

Notes:

c. Identify ways to support people with lived experience as key members of the care team.

- Implemented
- Partially implemented
- Not implemented

Notes:

STRATEGIES FOR IMPLEMENTING DOMAIN 5: CARE COORDINATION WORKFORCE

a. Provide training and clear expectations for care coordination staff on core components of their roles.

- Implemented
- Partially implemented
- Not implemented

Notes:

b. Prioritize the hiring of care coordinators with lived experience and those that expand the cultural, racial, ethnic, and linguistic diversity of care coordination staff.

- Implemented
- Partially implemented
- Not implemented

Notes:

c. Establish policies for caseload ratios that allow care coordinators to maintain high-quality service delivery.

- Implemented
- Partially implemented
- Not implemented

Notes:

d. Establish policies for collecting and reviewing data to assess the care coordinator and care team performance.

- Implemented
- Partially implemented
- Not implemented

Notes:

STRATEGIES FOR IMPLEMENTING DOMAIN 6: CARE TRANSITIONS

a. Develop policies to proactively identify and plan for upcoming care transitions.

- Implemented
- Partially implemented
- Not implemented

Notes:

b. Provide training and resources to care coordination staff to support effective transitions.

- Implemented
- Partially implemented
- Not implemented

Notes:

c. Develop processes for tracking care transition activities.

- Implemented
- Partially implemented
- Not implemented

Notes:

Appendix B — National Care Coordination Standards for Children and Youth with Special Health Care Needs

The list of standards from the National Care Coordination Standards for CYSHCN is included here for easy reference. For more information, please access the full document [here](#).

Domain 1: Screening, Identification, and Assessment

Screening, identification, and assessment of a child's needs provides the foundation for effective, high-quality care coordination. Assessment is a continuous process that reflects ongoing conversations with CYSHCN and families about their needs, preferences, and priorities.

1. A systematic, timely, and clearly documented screening process is in place to identify all children and families who are in need of care coordination.
2. The process of screening a child to identify need for care coordination uses information and data from multiple sources, including providers, medical records, claims, hospital admission, discharge, and transfer (ADT) records, families and youth, education records, and records from other child-serving systems.
3. The screening process for identifying a child's care coordination needs considers multiple factors, including:
 - Child and family strengths and resiliency;
 - Complexity of the child's health status, based on physical and behavioral health conditions, functional limitations (e.g., need for assistance with activities of daily living (ADLs)), and technology dependence;
 - Health and social inequities that may create barriers to accessing and receiving needed care, services, or supports;
 - Whether the child has had multiple preventable and/or planned hospital admissions and/or emergency department (ED) visits, receives treatment from multiple health care providers, or has unmet needs for evidence-based primary, preventive, and specialty care services;
 - Social and environmental factors affecting health, such as housing instability, food insecurity, income, access to transportation, systemic racism and identity-based bias, and family risk factors, such as trauma and addiction; and
 - Family beliefs, preferences, expressed needs, and goals for care coordination, based on past experiences and current priorities.
4. If identified through screening as needing additional assessment for care coordination services, children and families have the option of engaging in a care coordination assessment and ultimately, whether to participate in or opt out of receiving care coordination services.
5. Care coordination assessments should be the result of a collaborative conversation with families to identify needs and strengths.

6. A care coordination assessment should be conducted in addition to, or in alignment with, other initial assessments upon enrollment in a health plan or other service delivery system.
7. The care coordination assessment incorporates key information from the child's physical and behavioral health status and history, as well as information about:
 - Insurance status;
 - Eligibility for and involvement in public programs such as Medicaid, the Children's Health Insurance Program (CHIP), Supplemental Security Income (SSI), the Supplemental Nutrition Assistance Program (SNAP), the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC), public housing assistance, the Title V CYSHCN program, early childhood education programs (e.g., Head Start), and other community services;
 - Whether the child is involved in the justice system;
 - Involvement in the child welfare system;
 - Education needs;
 - Language needs and preferences;
 - Health literacy and health education needs;
 - Social determinants of health;
 - Preferred method of communication (e.g., phone, e-mail, in person);
 - Demographics (including race and ethnicity);
 - Availability of support systems, including a family support network;
 - Unmet needs for services and support;
 - The family's self-management skills and capacity to navigate care systems;
 - Health status of the caregiver and sibling(s), if applicable;
 - Guardianship; and
 - Foster care involvement.
8. Action items documented in the care coordination assessment include child and family goal-setting that is based on family needs, priorities, and next steps, and whether the family consents to move forward with receiving care coordination services and supports.
9. The care coordination assessment includes documentation of connection to services both in the community and within the health care system to address identified needs.
10. Care coordination assessment results are documented in a centralized electronic health record and shared with the family as soon as possible. With family consent and pursuant to all applicable laws and regulations, these results are shared with all members of the care team in a timely manner.
11. The information collected during the care coordination assessment process can help identify the child's risk for experiencing adverse outcomes. This risk is a factor in decision-making about the intensity of care coordination services.

12. Care coordination reassessments are conducted at least every six months, or as determined by the family in collaboration with the care coordinator and/or provider. They are conducted regardless of whether the initial assessment resulted in the provision of care coordination services, as some assessments may not lead to the delivery of these services because a family may not need or choose to receive them. Reassessments also occur when there are significant changes in the child's health and functional status, life circumstances, and/or social service needs.
13. The reassessment process includes a re-review of the child and family's need for care coordination services. Reassessment documentation should include a mechanism to track whether and when the child receives recommended services.

Domain 2: Shared Plan of Care

The shared plan of care provides a roadmap and an accountability system for integrating care based on family needs and priorities identified in the assessment and is used in coordinating a child's care.

1. The shared plan of care is a dynamic document that addresses the clinical, functional, and social service needs identified in the assessment. The shared plan of care considers and builds on the child's and family's strengths, and it describes delivery and coordination of all needed services.
2. The process for developing a shared plan of care:
 - a. Engages the family as an active and equal partner;
 - b. Reflects the family's unique knowledge, lived experiences, values, and beliefs; and
 - c. Is both strength-based and trauma-informed.
3. The shared plan of care includes the child's:
 - a. Health summary (e.g., medical and behavioral health history, family preferences and strengths, treating providers, medications, immunizations), as well as personal, educational, behavioral, and social circumstances.
 - b. Long- and short-term clinical, functional (e.g., need for assistance with activities of daily living (ADLs)), developmental, and social (e.g., ability to interact with peers), goals – which are specific, achievable, and time-specific – as well as aspirational (e.g., long-term hopes). Aspirational goals include those that bring joy to the child and family (e.g., a special vacation).
 - c. Upcoming medical and social service transitions, as well as strategies to support continuity of care during times of transition.
 - d. Emergency plan, to be accessed by emergency medical technicians (EMTs) and emergency department (ED) providers as needed. The emergency plan includes a list of medications, needed accommodations (e.g., local anesthesia for intravenous access), allergies, a list of providers most involved in the child's care, and their contact information.
 - e. Disaster plan, which provides guidance for responding to situations such as loss of power, natural disaster, act of terrorism, and public health emergencies.
4. The shared plan of care goals specify measurable steps and benchmarks, as well as assigned time frames and persons responsible for completion of the plan.
5. The shared plan of care identifies all members of the care team, including the care coordinator.

6. The shared plan of care clearly delineates all care team member roles, responsibilities, and accountability, as agreed upon by the care team.
7. The shared plan of care indicates family and provider preferences for communication (e.g., phone, email, text) and includes information for families on how best to contact other members of the care team during work hours and after hours for routine and emergent matters.
8. The shared plan of care references policies and procedures that the care coordinator will use to coordinate with any other care coordinators serving the child, to avoid communication gaps and duplication of services.
9. The shared plan of care is reviewed and updated at least every six months or more frequently as needed, depending on the intensity of care coordination and/or in response to a triggering event (e.g., a medical emergency or significant change in health status). Care coordinators and members of the care team track progress toward goals and make updates to the shared plan of care to align with changes in the child's functional, clinical, self-management, education, and social service needs.
10. The shared plan of care is accessible within a centralized electronic health record (EHR) to all members of the care team, including the family. When access to the EHR is not feasible for a care team member, the care team will find alternate means for access to the most updated version of the plan at all times, such as securely emailing an electronic copy of the plan to the member.
11. With the family's consent and pursuant to applicable laws and regulations, the shared plan of care is shared with other providers and child-serving systems (e.g., education, child welfare, juvenile justice) to facilitate optimal coordination and integration of services for the child and family.

Domain 3: Team-Based Communication

Communication between members of the care team is timely, efficient, respectful, and culturally sensitive.

1. Care teams are multidisciplinary and function within the context of a medical home that includes, but is not limited to, the family, primary care provider, medical and behavioral health specialists, care coordinator, and professionals from rehabilitation, social services, and education systems. Care coordinators are key members of the care team and lead care coordination efforts.
2. The family is the center of the care team and informs all decision-making. The care team operates in accordance with the family's values, beliefs, strengths, and aspirations.
3. The care team has a clearly identified single point of contact for communication with the family, likely the care coordinator, who proactively addresses any barriers to communication as they arise.
4. The family's language, cultural, technological, and communication preferences are documented and shared with all other members of the care team. Care team communication with family members is in accordance with the family's preferences.
5. All written materials provided to CYSHCN and their families are culturally appropriate and provided in their primary language whenever possible. Written materials should be formatted and delivered in a manner that is appropriate for children and their parents or caregivers who have limited English proficiency, lower levels of literacy, or sensory impairments.

6. When communicating with the family, the care team, including the care coordinator, makes optimal use of electronic notification systems, smartphone technology, electronic care management systems (i.e., IT systems to track care coordination), and other electronic tools in accordance with applicable laws and regulations, as well as family preferences and abilities.
7. Care coordinators aim to build trust and longstanding relationships with the child and family. These relationships should promote shared goals, knowledge, and mutual respect.
8. Families have the option of changing care coordinators at any time. Care teams have established procedures to communicate changes in care team members and roles, and to transfer responsibilities from one care coordinator to another as needed.
9. All members of the care team can support families in accessing care coordination services.
10. Care team members remain in regular communication with each other and with any other providers serving the child using electronic tools, to the extent possible, to address challenges, and discuss solutions in a timely and efficient manner.
11. The care team receives regular reports from an electronic care management system and/or the care coordinator. These reports include but are not limited to:
 - a. Changes in the child's clinical or functional status;
 - b. Changes in family status;
 - c. Hospital admissions and discharges;
 - d. Emergency department visits;
 - e. Transfers to subacute care facilities (e.g., rehabilitation centers);
 - f. Completed reassessments;
 - g. Updates to the shared plan of care;
 - h. Planned and unplanned transitions in care; and
 - i. Changes in insurance status.
12. Care coordinators have policies and procedures in place to identify any other care coordinators who are serving the child, and to facilitate communication and coordination between them.
13. The care coordinator communicates and has referral arrangements with community-based organizations and agencies to address the child's medical, financial, educational, and social needs.

Domain 4: Child and Family Empowerment and Skills Development

Care coordination includes education, coaching, and training for CYSHCN, families, and care teams. These activities empower children and families and advance their well-being, while at the same time enabling other members of the care team to gain the understanding and insights needed to serve families effectively.

1. Based on findings from the assessment and reassessments, the care coordinator and other members of the care team provide training and/or coaching to help children and families to:
 - a. Leverage their strengths;
 - b. Increase understanding of the child's condition(s);
 - c. Build self-management and self-efficacy skills (e.g., medical and durable medical equipment management,

navigation of the health care system, optimal use of electronic tools to facilitate coordination, transition from pediatric to adult systems, and communication with providers); and

d. Develop the knowledge and skills needed to achieve their identified goals.

2. The care coordinator and other members of the care team connect the child and family to peer supports (e.g., parent and youth mentors, support groups, family advocacy groups, internet-based patient communities, and condition-specific organizations) as appropriate. Peer supports leverage the value of lived experience in obtaining access to needed services, provide guidance for navigating systems of care, and help the child and family build confidence and competence in articulating goals and expectations.
3. Individuals with lived experience, including family members serving as officially designated care coordinators, either for their children or for other children, receive appropriate compensation for providing care coordination services.

Domain 5: Care Coordination Workforce

The care coordination workforce is well trained and prepared to serve CYSHCN and their families. All care team members have opportunities to gain the knowledge and understanding needed to perform their roles effectively.

1. A child's care coordinator has the credentials and experience that is best aligned to meet the needs of the child. Licensed as well as nonlicensed providers, including but not limited to nurses, social workers, patient advocates, community health workers, and family members may serve as care coordinators.
2. The care coordination workforce is culturally, linguistically, racially, and ethnically diverse.
3. Care coordinators have the competencies needed for successful navigation across health, behavioral health, social service, and other child-serving systems. An individual's lived experience or practical knowledge and understanding of navigating the health system is an important consideration in care coordination hiring.
4. Care coordinators engage in training to achieve the knowledge, skills, and abilities needed for effective care coordination. Family caregivers have the opportunity to obtain care coordinator training and credentialing. Training is an ongoing process with continuing education opportunities. Training topics may include but are not limited to:
 1. Learning from and building partnerships with families;
 2. Motivational interviewing;
 3. Identification of family strengths, priorities, and goal setting;
 4. Shared plan of care development;
 5. Cultural and linguistic competency;
 6. Implicit bias;
 7. Health insurance policies and procedures;
 8. Confidentiality;

9. Health Insurance Portability and Accountability Act (HIPAA) and Family Educational Rights and Privacy Act (FERPA) compliance training;
 10. Health literacy;
 11. Community-based resources;
 12. Transition and referral processes; and
 13. Education systems for CYSHCN.
5. Care coordination caseload ratios account for factors affecting capacity, such as variations in case complexity, travel times for in-person visits, and intensity of care coordination services.
 6. Policies, procedures, and mechanisms are in place, including child and family feedback, to review care coordinator and care team activities on a regular basis to assess the quality of care coordination and related outcomes.
 7. Payment or reimbursement for care coordination reflects the qualifications, workload, and intensity of services provided by care coordinators.

Domain 6: Care Transitions

Care transitions refer to the transfer of care between and within medical, behavioral health, social service, education, and justice systems. Particular emphasis is placed on preparing youth for transitions from pediatric to adult care and promoting independence in the transition to adulthood. Advance preparation and careful integration of services following transitions are essential to a successful transition process.

1. Care coordination policies and procedures are developed to facilitate effective transitions between and among providers, care settings, health insurance entities (e.g., private insurers or Medicaid), education, justice, behavioral health, and social service systems, and other entities. These policies and procedures should:
 - Be driven by youth and families, based on their goals, needs, and preferences;
 - Clearly identify roles and responsibilities of the family, care team members, providers, and other entities involved in transitions; and
 - Identify and track engagement with transition support services.
2. Care coordinators and/or other members of the care team work proactively with families to formulate a plan that identifies upcoming transitions and determines transition-related needs, and to conduct a readiness assessment using a standardized tool to inform transition procedures.
3. Updated records from the health care, social service, education, behavioral health, and justice systems, including the most recently updated shared plan of care, are made available to youth and families to support successful transitions and enable continuity of services.
4. The child's care team works to identify appropriate providers for youth transitioning from pediatric to adult health care systems, facilitate warm hand-offs between providers, and advance CYSHCN independence, self-efficacy, and self-advocacy in the transition to adulthood.

Endnotes

- ¹ National Improvement Partnership Network. (2015). *Establishing a Child Health Improvement Partnership: A How-to Guide*. Vermont Child Health Improvement Program (VCHIP), University of Vermont College of Medicine, Commonwealth Fund, and Vermont Department of Health. http://contentmanager.med.uvm.edu/docs/default-source/nipn-documents/establishingachildhealthip-ahow-toguide_000.pdf?sfvrsn=2
- ² Kansas Department of Health and Environment, Division of Public Health. (2021). *Holistic Care Coordination Provider Input Summary*. www.kdhe.ks.gov/DocumentCenter/View/21580/Holistic-Care-Coordination-Provider-Input-Summary-PDF?bidId=
- ³ Bachman S, Comeau M, Jankovosky K. (2015). *The Care Coordination Conundrum and Children and Youth with Special Health Care Needs*. The Catalyst Center. <https://ciswh.org/wp-content/uploads/2016/03/Care-Coordination-Conundrum.pdf>
- ⁴ Comeau M. (2010). *Care Coordination in a Statewide System of Care: Financing Models and Payment Strategies*. The Catalyst Center. <https://ciswh.org/wp-content/uploads/2015/04/carecoordination2010-09.pdf>
- ⁵ Clary A, Riley T. (2016). *Pooling and Braiding Funds for Health-Related Social Needs: Lessons from Virginia's Children's Services Act*. The National Academy for State Health Policy. www.nashp.org/wp-content/uploads/2016/06/CSA-Virginia-Brief-1.pdf
- ⁶ Ibid
- ⁷ Ibid
- ⁸ Frank L, Basch E, Selby J. The PCORI perspective on patient-centered outcomes research. *JAMA*. 2014; 515 (12): 1513-1514. <https://pubmed.ncbi.nlm.nih.gov/25167382/>
- ⁹ Ibid
- ¹⁰ Agency for Health Services Research and Quality. *Adolescent preparation for transition to adult focused health care*. Accessed June 2nd 2021, www.ahrq.gov/sites/default/files/wysiwyg/policymakers/chipra/factsheets/chipra_1415-p012-ef.pdf; Valentine MA NI, Edmonson AC. *Measuring teamwork in health care settings: A review of survey instruments*. Harvard Business Review: Working Paper 2012.
- ¹¹ The National Academy for State Health Policy. (2020). *National Care Coordination Standards for Children and Youth with Special Health Care Needs, Domain 1: Screening, Identification, and Assessment*. www.nashp.org/national-care-coordination-standards-for-children-and-youth-with-special-health-care-needs/#toggle-id-3
- ¹² Clary A, Riley T. (2016). *Pooling and Braiding Funds for Health-Related Social Needs: Lessons from Virginia's Children's Services Act*. The National Academy for State Health Policy. www.nashp.org/wp-content/uploads/2016/06/CSA-Virginia-Brief-1.pdf
- ¹³ Ibid; Virginia Office of Children's Services.(2016). *Virginia Child and Adolescent Needs and Strengths (CANS) Assessment: Item and Rating Definitions Manual*. [www.csa.virginia.gov/Content/doc/CANS_DSS-Enhanced_Item_and_Rating_Definitions_Manual_Ages_\(5-21\).pdf](http://www.csa.virginia.gov/Content/doc/CANS_DSS-Enhanced_Item_and_Rating_Definitions_Manual_Ages_(5-21).pdf)

¹⁴ Administration for Children and Families, U.S. Department of Health and Human Services. (2014). *Confidentiality Toolkit: A resource tool from the ACF Interoperability Initiative* <https://www.acf.hhs.gov/opre/report/confidentiality-toolkit>

¹⁵ Texas Health and Human Services. (2020). *STAR Kids Handbook, Section 3000, STAR Kids Screening and Assessment and Service Planning, Revision 20-2*. www.hhs.texas.gov/laws-regulations/handbooks/skh/section-3000-star-kids-screening-assessment-service-planning

¹⁶ Honsberger K, Normile B, Schwalberg R, and VanLandeghem K. (2018). *Structuring Care Coordination Services for Children and Youth with Special Health Care Needs in Medicaid Managed Care: Lessons from Six States*. The National Academy for State Health Policy. www.nashp.org/wp-content/uploads/2018/04/Structuring-Care-Coordination-Services-for-Children-and-Youth-with-Special-Health-Care-Needs-in-Medicaid-Managed-Care.pdf

¹⁷ DelFavero, M., Chhean, E., Tewarson, H., Haldar, S., Hockenberry, S. (2021, October). *A Case Study of California's ACEs Aware Program: Screen. Treat. Heal.* Washington, DC: Duke-Margolis Center for Health Policy, National Academy for State Health Policy, National Governors Association Center for Best Practices. <https://www.nga.org/center/publications/case-study-californias-aces-aware-initiative/>

¹⁸ See this resource for additional information on measuring “flourishing”: www.childhealthdata.org/docs/drc/resilience-and-positive-factors-poster-final.pdf

¹⁹ The National Academy for State Health Policy. (2020). *National Care Coordination Standards for Children and Youth with Special Health Care Needs, Domain 2: Shared Plan of Care*, www.nashp.org/national-care-coordination-standards-for-children-and-youth-with-special-health-care-needs/#toggle-id-4

²⁰ McAllister, J. (2014). *Achieving a Shared Plan of Care with Children and Youth with Special Health Care Needs*. Lucile Packard Foundation for Children's Health, 5. <https://www.lpfch.org/publication/achieving-shared-plan-care-children-and-youth-special-health-care-needs>

²¹ Ibid

²² Ibid, 31

²³ The National Academy for State Health Policy. (2018). *Iowa Case Study: Shared Plans of Care to Improve Care Coordination for CYSHCN*. www.nashp.org/wp-content/uploads/2018/10/SPoC-Iowa-Case-Study.pdf

²⁴ Wirth B, VanLandeghem K, Normile B, Kim E, and Handler M. (2018). *State Strategies for Shared Plans of Care to Improve Care Coordination for Children and Youth with Special Health Care Needs*. The National Academy for State Health Policy. www.nashp.org/wp-content/uploads/2018/10/SPoC-Issue-Brief-Final.pdf

²⁵ Ibid

²⁶ The National Academy for State Health Policy. (2018). *Oregon Case Study: Shared Plans of Care to Improve Care Coordination for CYSHCN*. www.nashp.org/wp-content/uploads/2018/10/SPoC-Oregon-Case-Study.pdf

²⁷ Ibid

²⁸ Wirth B, VanLandeghem K, Normile B, Kim E, and Handler M. (2018). *State Strategies for Shared Plans of Care to Improve Care Coordination for Children and Youth with Special Health Care Needs*. The National Academy for State Health Policy. www.nashp.org/wp-content/uploads/2018/10/SPoC-Issue-Brief-Final.pdf

²⁹ The National Academy for State Health Policy. (2018). West Virginia Case Study: Shared Plans of Care to Improve Care Coordination for CYSHCN. www.nashp.org/wp-content/uploads/2018/10/SPoC-WVa-Case-Study.pdf

³⁰ These measures are related to shared decision-making, which supports partnerships between providers and families in development of the shared plan of care.

³¹ The National Academy for State Health Policy. (2020). National Care Coordination Standards for Children and Youth with Special Health Care Needs, Domain 3: Team-Based Communication. www.nashp.org/national-care-coordination-standards-for-children-and-youth-with-special-health-care-needs/#toggle-id-5

³² Children's Special Health Services, Louisiana Office of Public Health. (2015). CSHS Care Coordination Toolkit. www.ldh.la.gov/assets/oph/Center-PHCH/Center-PH/cshs/LACSHSCCToolkit.pdf

³³ Children's Special Health Services, Louisiana Office of Public Health. (2015). CSHS Care Coordination Toolkit. www.ldh.la.gov/assets/oph/Center-PHCH/Center-PH/cshs/LACSHSCCToolkit.pdf

³⁴ Commonwealth of Virginia, Department of Medical Assistance Services. (2021). Commonwealth Coordinated Care Plus MCO Contract for Managed Long Term Services and Supports, July 1, 2020 – June 30, 2021. www.dmas.virginia.gov/media/2964/final-ccc-plus-mid-year-amendment-effective-jan-1-2021.pdf, 140

³⁵ Ibid, 141

³⁶ Ibid, 141

³⁷ Ibid, 162

³⁸ Katkin JP, Kressly SJ, Edwards AR, et al. Guiding Principles for Team-Based Pediatric Care. *Pediatrics*. 2017; 140(2): e20171489. <https://pediatrics.aappublications.org/content/140/2/e20171489>

³⁹ Hess DW, Reed VA, Turco MG, et al. Enhancing Provider Engagement in Practice Improvement: A Conceptual Framework. *Foundations*. 2015; 35(1): 71-79. <https://sacme.org/Resources/Documents/Virtual%20Journal%20Club/Hess-2015-Enhancing-engagement.pdf>

⁴⁰ Marbell, P. (2017). *Engaging Families in Improving the Health Care System for Children with Special Health Care Needs*. The Lucile Packard Foundation for Children's Health. www.lpfch.org/publication/engaging-families-improving-health-care-system-children-special-health-care-needs

⁴¹ Barovechio, P, Berry, S, Duplantier, M, Pierce, D. (2015). *CSHS Care Coordination Toolkit*. Children's Special Health Services (CSHS), Louisiana Office of Public Health. www.ldh.la.gov/assets/oph/Center-PHCH/Center-PH/cshs/LACSHSCCToolkit.pdf

- ⁴² Cartier Y, Fichtenberg C, Gottlieb L. (2019). *Community Resource Referral Platforms: A Guide for Health Care Organizations*. Social Interventions Research & Evaluation Network. <https://sirenetwork.ucsf.edu/sites/default/files/wysiwyg/Community-Resource-Referral-Platforms-Guide.pdf>
- ⁴³ Administration for Children & Families. *State of Colorado Interoperability and Integration Project, HHS-2012-ACF-OCSE-FQ-0551*. Accessed April 25, 2022. www.acf.hhs.gov/state-colorado-interoperability-and-integration-project
- ⁴⁴ The National Academy for State Health Policy. (2020). National Care Coordination Standards for Children and Youth with Special Health Care Needs, Domain 4: Child and Family Empowerment and Skills Development. www.nashp.org/national-care-coordination-standards-for-children-and-youth-with-special-health-care-needs/#toggle-id-6
- ⁴⁵ Antonelli, RC, Huth, Rosenberg, H, Bach, A, Eds. (2019). *Pediatric Care Coordination Curriculum: An Interprofessional Resource to Effectively Engage Patients and Families in Achieving Optimal Child Health Outcomes, 2nd Edition*. Boston Children’s Hospital. <https://medicalhomeinfo.aap.org/tools-resources/Documents/PCCC%202nd%20Edition/Full%20Pediatric%20Care%20Coordination%20Curriculum.pdf>
- ⁴⁶ Johnson K, Willis D, Doyle S. (2020). *Guide to Leveraging Opportunities Between Title V and Medicaid for Promoting Social-Emotional Development*. Center for the Study of Social Policy. <https://cssp.org/wp-content/uploads/2020/12/CSSP-Leveraging-TitleV-FULL-REPORT.pdf>
- ⁴⁷ Center for the Study of Social Policy. (n.d.) About Strengthening Families and the Protective Factors Framework. <https://cssp.org/wp-content/uploads/2018/11/About-Strengthening-Families.pdf>; Center for the Study of Social Policy. (n.d.) Using the Protective Factors to Help Identify Relevant Strengths. <https://cssp.org/wp-content/uploads/2018/08/Using-PFs-to-identify-relevant-strengths.pdf>; Center for the Study of Social Policy. (n.d.) Protective and Promotive Factors Action Sheets. <https://cssp.org/wp-content/uploads/2018/08/ProtectiveFactorsActionSheets.pdf>
- ⁴⁸ Silow-Carroll S. (2010). *Rhode Island’s Pediatric Practice Enhancement Project: Parents Helping Parents and Practitioners*. The Commonwealth Fund. www.commonwealthfund.org/publications/case-study/2010/jan/rhode-islands-pediatric-practice-enhancement-project-parents
- ⁴⁹ Ibid
- ⁵⁰ Ibid
- ⁵¹ Schober M, Baxter K. (2020). *Medicaid Funding for Family and Youth Peer Support Programs in the United States*. The National Technical Assistance Network for Children’s Behavioral Health. <https://theinstitute.umaryland.edu/media/ssw/institute/national-center-documents/PSM10.2020.pdf>
- ⁵² Arkansas Department of Human Services. *Children’s Services Targeted Case Management*. Accessed August 27, 2021. <https://humanservices.arkansas.gov/divisions-shared-services/medical-services/helpful-information-for-providers/manuals/cstcm-prov>
- ⁵³ Arkansas Department of Human Services. *Children’s Services Targeted Case Management, Section 200.100 — Qualifications of Children’s Services TCM Provider*. Accessed August 27, 2021. <https://humanservices.arkansas.gov/divisions-shared-services/medical-services/helpful-information-for-providers/manuals/cstcm-prov/>

- ⁵⁴ Arkansas Department of Human Services. *Children’s Services Targeted Case Management, Section 213.000 — Description of Service Activities*. Accessed August 27, 2021. <https://humanservices.arkansas.gov/divisions-shared-services/medical-services/helpful-information-for-providers/manuals/cstcm-prov/>
- ⁵⁵ Arkansas Department of Human Services. *Children’s Services Targeted Case Management, 212.000 — Target Population Covered by Children’s Services*. Accessed August 27, 2021. <https://humanservices.arkansas.gov/divisions-shared-services/medical-services/helpful-information-for-providers/manuals/cstcm-prov/>
- ⁵⁶ The National Academy for State Health Policy. (2020). National Care Coordination Standards for Children and Youth with Special Health Care Needs, Domain 5: Care Coordination Workforce. www.nashp.org/national-care-coordination-standards-for-children-and-youth-with-special-health-care-needs/#toggle-id-7
- ⁵⁷ Kansas Department of Health and Environment, Division of Public Health. *Holistic Care Coordination*. Accessed May 26, 2022. <https://www.kdheks.gov/hcc/>
- ⁵⁸ National Resource Center for Patient/Family-Centered Medical Home, American Academy of Pediatrics. *For Practices: Care Coordination*. Accessed May 26, 2022. medicalhomeinfo.aap.org/tools-resources/Pages/For%20Practices.aspx
- ⁵⁹ National Resource Center for Patient/Family-Centered Medical Home, American Academy of Pediatrics. *For Practices: Care Coordination*. Accessed May 26, 2022. medicalhomeinfo.aap.org/tools-resources/Pages/For%20Practices.aspx
- ⁶⁰ Stratis Health. (2014). Care Coordinator Sample Job Description. <http://stratishealth.org/wp-content/uploads/2020/07/3-Care-Coordinator-Sample-Job-Description.pdf>
- ⁶¹ The National Academy for State Health Policy. (2020). The National Care Coordination Standards for CYSHCN: Care Coordination Workforce. www.nashp.org/national-care-coordination-standards-for-children-and-youth-with-special-health-care-needs/#toggle-id-7
- ⁶² Coronado F, Beck AJ, Shah G, et al. Understanding the Dynamics of Diversity in the Public Health Workforce. *Journal of Public Health Management and Practice*. 2020; 26(4): 389-392. https://journals.lww.com/jphmp/Citation/2020/07000/Understanding_the_Dynamics_of_Diversity_in_the.19.aspx
- ⁶³ Substance Abuse and Mental Health Services Administration. (2019). Intensive Care Coordination for Children and Youth with Complex Mental and Substance Use Disorder. <https://store.samhsa.gov/sites/default/files/d7/priv/samhsa-state-community-profiles-05222019-redact.pdf>
- ⁶⁴ Ibid
- ⁶⁵ Ibid
- ⁶⁶ The National Academy for State Health Policy. (2020). National Care Coordination Standards for Children and Youth with Special Health Care Needs, Domain 6: Care Transitions. www.nashp.org/national-care-coordination-standards-for-children-and-youth-with-special-health-care-needs/#toggle-id-8

⁶⁷ Got Transition. (n.d.). Assessment of Health Care Transition Activities in Care Coordination Programs. <https://gottransition.org/resource/?assessment-of-hct-in-cc-programs>

⁶⁸ Got Transition, Center for Health Care Transition Improvement. (2020). Six Core Elements of Health Care Transition 3.0: An Implementation Guide. <https://gottransition.org/6ce/?!leaving-ImplGuide-full>

⁶⁹ Ilango S, McManus M, Beck D. (2018). Health Care Transition in State Title V Programs: A Review of 2018 Block Grant Applications and Recommendations for 2020. Got Transition, Center for Health Care Transition Improvement. www.gottransition.org/resource/?2018-review-hct-titlev

⁷⁰ Texas Health and Human Services Commission. (2021). STAR Kids Contract Terms. www.hhs.texas.gov/sites/default/files/documents/services/health/medicaid-chip/programs/contracts/star-kids-contract.pdf

⁷¹ Ibid

⁷² Texas Health and Human Services. (2020). *STAR Kids Handbook, Appendix VI, STAR Kids Transition Activities*. www.hhs.texas.gov/laws-regulations/handbooks/skh/appendices/appendix-vi-star-kids-transition-activities

⁷³ Got Transition, Center for Health Care Transition Improvement. Accessed August 27, 2021. <https://gottransition.org>

⁷⁴ Kentucky Cabinet for Health and Family Services. Pediatric to Adult Transition Resources. Accessed August 27, 2021. <https://chfs.ky.gov/agencies/ccshcn/Pages/transitionresources.aspx>

⁷⁵ Kentucky Cabinet for Health and Family Services. (2020). Maternal and Child Health Services Title V Block Grant FY 2021 Application/FY 2019 Annual Report. <https://chfs.ky.gov/agencies/dph/dmch/Documents/KYTitleVPrintV.pdf>

Acknowledgements

The National Academy for State Health Policy (NASHP) extends its thanks and appreciation to the Lucile Packard Foundation for Children's Health, and program director Holly Henry in particular, for their support of this work. NASHP also sincerely thanks the many individuals at the national and state level who contributed their insight and expertise to the development of this implementation guide and the accompanying National Care Coordination Standards for Children and Youth with Special Health Care Needs.

This work was authored by NASHP Policy Associate Olivia Randi, NASHP Project Director Kate Honsberger, and NASHP Research Analyst Zack Gould. Many thanks to NASHP Senior Program Director Karen VanLandeghem for leading and contributing to this guide and to project consultant David Bergman of Stanford Children's Hospital for supporting the work.



Visit nashp.org
for more information.



@NASHPhealth



NASHP