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

October 2020

NASHP

NATIONAL ACADEMY
FOR STATE HEALTH POLICY

Lucile Packard Foundation
for Children's Health

Table of Contents

National Care Coordination Standards for CYSHCN Work Group Members

Richard Antonelli
Medical Director
Integrated Care
Boston Children's Hospital

Marlene Asmussen
Director,
Population Care Management
Oklahoma Health Care Authority

Kayzy Bigler
Children & Families Unit Director,
Bureau of Family Health
Kansas Department of Health and Environment

Jeffrey Brosco
Professor of Clinical Pediatrics
University of Miami
Title V CYSHCN Director, Florida Department of Health

Sandra Brown
Integrated Care Management Manager
Virginia Department of Medical Assistance Services

Treeby Brown
Chief, Integrated Services Branch Division of Services for Children with Special Health Needs
Health Resources and Services Administration,
Maternal and Child Health Bureau

Allegra Burrell
Ambulatory Case Manager,
Goldberg Center for Pediatrics
Children's National Medical Center

Cara Coleman
Program Manager
Family Voices

Meg Comeau
Senior Project Director
The Catalyst Center at Boston University

Mary Daymont
Vice President of Revenue Cycle and Care Management
Children's National Health System

Renee Fox
Medical/Health Policy Advisor
Division of Quality and Health Outcomes
Center for Medicaid and CHIP Services/The Children and Adults Health Programs Group
Centers for Medicare & Medicaid Services

Deborah Garneau
Director, Health Equity Institute
Maternal and Child Health/Special Needs Director
Rhode Island Department of Health

Holly Henry
Program Director
Lucile Packard Foundation for Children's Health

Dennis Kuo
Associate Professor and Division Chief, General Pediatrics
Department of Pediatrics
University of Buffalo, Jacobs School of Medicine and Biomedical Sciences

Jennifer Kyle
Vice President Product Strategy, Special Needs Initiative
UnitedHealthcare

Carolyn Langer
Senior Vice President and
Chief Medical Officer
Fallon Health

Eric Levey
Chief Medical Officer
Health Services for Children with Special Needs, Inc.
The HSC Health Care System, Washington, DC

Marie Mann
Senior Medical Advisor/Acting Deputy Director
Division of Services for Children with Special Health Needs
Health Resources and Services Administration,
Maternal and Child Health Bureau

Jeanne McAllister
Adjunct Associate Research Professor of Pediatrics
Indiana University School of Medicine

Margaret McManus
Co-director, Got Transition
President,
The National Alliance to Advance Adolescent Health

John Morehous
Medical Director, Community Health Services Network
Cincinnati Children's Hospital Medical Center
Assistant Professor of Pediatrics, University of Cincinnati College of Medicine

Kathleen Noonan
Chief Executive Officer
Camden Coalition of Healthcare Providers

Jennifer Oppenheim
Senior Advisor on Early Childhood
Lead, Project LAUNCH
Substance Abuse and Mental Health Services Administration

Rylin Rodgers
Director of Public Policy
Association of University Centers on Disabilities

Heather Smith
Director, Title V CSHCN and System of Supports Section
Bureau of Family Health, Kansas Department of Health and Environment

Colleen Sonosky
Associate Director, Children's Health Services
Department of Health Care Finance, Washington, DC

Kate Taft
Associate Director, Child & Adolescent Health
Association of Maternal and Child Health Programs

Wendy Tiegreen
Director, Office of Medicaid Coordination & Health System Innovation
Georgia Department of Behavioral Health and Developmental Disabilities

Renee Turchi
Chair of Pediatrics, St. Christopher's Hospital for Children
Professor, Drexel University College of Medicine and School of Public Health

Debra Waldron
Senior Vice President
Healthy and Resilient Children, Youth, and Families
American Academy of Pediatrics

About the National Care Coordination Standards for CYSHCN

Care coordination is a core component of federal and state efforts to improve health outcomes, reduce caregiver and patient burden, and decrease health care costs for children and adults with chronic and complex conditions. Historically, many policymakers and health services researchers have focused on care coordination for adult populations rather than on care coordination for children. That trend has shifted in recent years as states place priority on integrated care for children and youth with special health care needs (CYSHCN). The care coordination needs of CYSHCN deserve special attention as they may differ from those of adults due to additional service sector involvement, provider specialties required, and changes to childrens' health care conditions as they grow and mature.

In 2014 the National Standards for Systems of Care for Children and Youth with Special Health Care Needs (CYSHCN) were developed and updated in 2017, by the Association of Maternal and Child Health Programs and the National Academy for State Health Policy (NASHP), with support from the Lucile Packard Foundation for Children's Health (LPFCH). These standards describe the recommended core elements of a system of care for CYSHCN. Key elements of care coordination are included in these national standards. However, state health officials and other stakeholders who work with CYSHCN and their families expressed a need for an in-depth set of care coordination standards that could serve as a guide for the establishment of robust, high-quality care coordination programs for CYSHCN and their families.

Children and youth with special health care needs are commonly defined as children who "have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally."[1] Increased attention has focused on a subset of CYSHCN that have been termed children with medical complexity (CMC).[2] This population of children is typically defined as having medical fragility, substantial functional limitations, increased need for health care services and increased health care costs.[3] Nearly one in five (18 percent) of all children in the United States have special health care needs, while CMC account for less than 1 percent of all children in the United States.[4],[5]

Care Coordination Standards Development Process

NASHP conducted a comprehensive literature review on care coordination for children and adults to provide an evidence base for the development of the National Care Coordination Standards for CYSHCN. The literature review examined and compiled evidence from studies of care coordination models (both pediatric and adult), examples of care coordination initiatives in states and health systems, and model frameworks, key elements, and definitions of care coordination. NASHP identified over 80 pieces of care coordination literature through internet and database searches, citations in journal articles, and information from subject-matter experts. NASHP's literature review found that many studies have investigated the impact of care coordination on CYSHCN for a broad range of outcomes. Interpretation of the research is confounded by variability in the populations studied and heterogeneity in the different types of models used.[6] There are, however, essential characteristics of care coordination that were present across most evaluated care coordination programs that serve children. These elements include an identified care coordinator,[7] shared care plan,[8] child and family needs assessment[9] and goal setting,[10] provision of resources and education, and family support and advocacy.[11], [12] Similar elements can be found in adult care coordination programs and include a comprehensive needs assessment, individualized care plans, connection to services and supports, and regular monitoring and communication.[13]

Furthermore, the literature review identified more than a dozen definitions of care coordination. NASHP identified and synthesized key elements of multiple existing definitions of care coordination to develop a working definition for the purposes of the project. For the purpose of the National Care Coordination Standards for CYSHCN, care coordination is defined as: "patient- and family-centered, assessment-driven, team-based activities designed to meet the needs of children and youth. Care coordination addresses interrelated medical, social, developmental, behavioral, educational and financial needs to achieve optimal health and wellness outcomes, and efficient delivery of health-related services and resources within and across systems."[14],[15],[16]

To further inform the development of the Care Coordination Standards, NASHP conducted more than a dozen key informant interviews with representatives from state Medicaid and Children's Health Insurance Program (CHIP) programs, public health agencies, health plans, families of CYSHCN, health services researchers, adult care coordination programs, federal agencies (e.g., the Centers for Medicare & Medicaid Services (CMS) and the Health Resources and Services Administration (HRSA)), and others. Interviews were designed to seek early input from stakeholders to guide the project, gain insights on innovative and promising health care delivery models, identify policy considerations for development of the standards, and pinpoint priority areas for standards to address. A list of key informants is listed in Appendix B.

NASHP also convened a national work group of over 30 members representing state and federal agencies, child and family advocates, health plans and health insurers, and health care providers with expertise in CYSHCN who provided guidance and feedback throughout the project. The national work group was convened over an 18-month period, through two virtual and one in-person meeting in the fall of 2019 to guide and reach consensus on essential elements of care coordination, the specific domains of the standards, and priority areas for additional development. Themes from the key informant interviews and work group discussions are described in the next section.

Major Themes from Key Informants on the Focus of National Care Coordination Standards

Major themes from the key informant interviews and work group meetings are described below. These themes are reflected in the language of individual standards.

- **An age-agnostic approach with a focus on the unique needs of CYSHCN:** Care coordination programs should include a common set of elements, activities, and tools that can be applied to both pediatric and adult populations. However, specific models and strategies for care coordination for different populations can vary. Care coordination for the pediatric population should consider their unique needs and reflect the types of providers, community-based programs and supports, and delivery systems (e.g., education, early care and education, and social services) that serve children and youth.

- **Family-centeredness:** Building a trusting relationship with the family is a critical, and an oftentimes under-emphasized, element of care coordination programs and the responsibility of a care coordinator. The standards should reflect families as central to the care team. Care teams should operate in accordance with family beliefs, values, strengths, and aspirations. Family needs and preferences should guide all decision-making, including decisions about modes of communication among care team members.

- **Relational care coordination:** Care coordination should not be limited to "checking the box" when specified benchmarks are met. Rather, it should be a relational process. Care coordinators should aim to build trust and longitudinal relationships that enable effective engagement with CYSHCN and families to achieve shared goals. Families have the ultimate responsibility for coordinating their child's services – often at considerable financial, physical, and psychological cost – and families have different preferences for how much assistance they would like in coordinating their child's care. At the same time, care coordination programs should be structured so that care coordinators are not overburdened and can consistently follow through on tasks they are responsible for, to build trust with families and ensure that the needs of families are met including during times of crisis. Finally, families should be involved in advising and guiding the development and implementation of care coordination programs.

- **High-quality, effective care coordination:** Many CYSHCN are assigned numerous care coordinators, both within and outside of the health care system. Communication between care coordinators is often lacking. Siloed care coordination services can lead to duplication of services, weaken accountability systems, and burden families with the task of coordinating the coordinators. To avoid these outcomes, it is important to establish clear roles for care coordinators and to design effective, efficient systems for information-sharing.

- **Health equity:** Care coordination should be based on the premise of health equity, which is the concept that all children and families should have an equal opportunity to attain their full health potential, and no barriers should prevent children and their families from achieving this potential. The goal of advancing health equity should be foundational to all care coordination standards and guides care coordination activities. Care coordination systems should aim to reduce access barriers and increase the range of services that are available through care coordination to meet the diversity of families' needs.

- **Scope of care coordination:** Care coordination is not limited to the management of health care services alone. Care coordinators should address the full range of social, behavioral, environmental, and health care needs of CYSHCN and their families. The role of a care coordinator should include connecting families to community resources to address health-related social needs.

- **A dynamic process:** Care coordination should be a dynamic process that adapts to meet the changing needs, circumstances, and preferences of the child and family. Core elements of the process, including the assessment and shared plan of care, should be updated regularly.

- **Workforce and training:** Care coordination workforce capacity and training is extremely important and should be considered in development of the Care Coordination Standards. The standards should not be overly prescriptive or limit care coordination to specific professional qualifications. Care coordinators should have the training and experience best aligned to meet the needs of CYSHCN. Lived experience of having or caring for a child with special health care needs should be an important consideration in hiring. Care coordinator training should address a broad range of issues beyond the realm of health care, such as cultural and linguistic competency and implicit bias.

- **Quality measurement:** To create systems of accountability for care coordination, appropriate outcome measures need to be identified or developed. These measures should focus on integration of services across systems, quality of life, reduction in duplicative and/or preventive health care utilization, as well as care coordination processes. Current emphasis on reduced utilization as an outcome of care coordination, especially prominent in the adult literature, is insufficient for pediatric care coordination. Instead, measures that capture the extent to which patients' and families' goals and needs are met and burdens reduced should be considered. Consequently, the impact of care coordination on CYSHCN may be measured best through family surveys and quality-of-life measures. Because care coordination should bridge between the health care system and other community-based services and systems (e.g., education, child welfare), the impact on those other services should be included in quality measurement.

- **Insurance coverage and care coordinator payment:** Payment systems should be adequate to support care coordination. Insurance coverage of care coordination should be available so that services are accessible, affordable and comprehensive. Payment or reimbursement for care coordination – and the compensation provided to care coordinators – should reflect the qualifications and workload of care coordinators, as well as the intensity of services they provide.

Guiding Principles for Development of the National Care Coordination Standards for CYSHCN
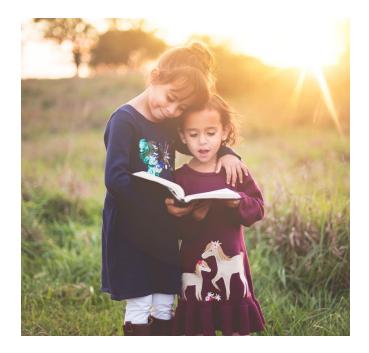
The following principles guided development of the National Care Coordination Standards for CYSHCN. These principles were informed by the work group and previous work in developing the National Standards for Systems of Care for CYSHCN.

1 The experiences of families of CYSHCN are central to the creation of system and process standards to address major barriers and challenges. Family engagement in the development and implementation of care coordination standards is a priority.

2 The standards are based on and grounded in evidence-based and evidence-informed practices in pediatric and adult-serving care coordination models.

3 The care coordination standards are aligned with and designed to be a companion resource that can be implemented in conjunction with the National Standards for Systems of Care for CYSHCN.

4 The standards focus on process- and system-level approaches to guide development and implementation of policies and/or practices that result in high-quality care coordination. They are not intended to guide clinical practice.

5 The standards focus on the care coordination needs of CYSHCN and their families, and elements of the standards may help inform or improve care coordination for other populations across the age continuum.

6 The primary audiences for the standards are state health officials (e.g., staff of state Medicaid agencies, public health, and Title V CYSHCN programs), health plans, providers, and community-based organizations and systems that serve CYSHCN and their families.

7 The standards do not specify *who* should be responsible for adoption or implementation of the standards so that they can be tailored to the unique policy context and operational landscape within each state and health care delivery system.

8 The standards consider related national care coordination guidelines, such as accreditation standards developed by the National Committee for Quality Assurance, as well as relevant federal requirements and guidance.

9 The standards are designed to be applicable in a variety of care coordination models, health care delivery systems, and among both public and private payers.

10 The standards reflect the fact that care coordination requires interaction among multiple child-serving systems and includes consideration of systems outside the health care sector that serve CYSHCN (e.g., education, long-term services and supports, behavioral health, community-based services, social services, and child welfare). Given that there are care coordination models within each of these systems, a goal of the care coordination standards is to streamline and promote efficiencies across all relevant systems.

11 The standards consider the impact of social determinants of health – including housing, food security, involvement with the juvenile justice system, employment status, family resources, and cultural factors – and also address the impact of disparities on service delivery.

12 The need for sufficient funding to ensure high-quality care coordination and mechanisms to keep it affordable are important considerations for state policymakers and other health leaders. However, standards are not included based on their potential costs or financial benefits.

13 The inclusion of care coordination standards is not limited by the availability of related quality measures.

14 The standards are informed by expert input from the National Care Coordination Standards for CYSHCN Work Group and are the result of consensus, not endorsement, by the work group members.

National Care Coordination Standards for CYSHCN

Foundational Standards
for Care Coordination

The National Care Coordination Standards for CYSHCN are guided by the following foundational standards. These seven standards are the foundation for all standards in each domain, and are critical to ensure comprehensive, high-quality care coordination for CYSHCN.

1. Care coordination for CYSHCN is based on the premise of health equity, that all children and families should have an equal opportunity to attain their full health potential, and no barriers should exist to prevent children and their families from achieving this potential.
2. Care coordination addresses the full range of social, behavioral, environmental, and health care needs of CYSHCN.
3. Families are co-creators of care coordination processes and are active, core partners in decision making as members of the care team. CYSHCN, families, and care coordinators work together to build trusting relationships.
4. Care coordination is evidence based where possible, and evidence informed and/or based on promising practices where evidence-based approaches do not exist.
5. Care coordination is implemented and delivered in a culturally competent, linguistically appropriate, and accessible manner to best serve CYSHCN and their families.
6. Insurance coverage of care coordination for CYSHCN allows for it to be accessible, affordable, and comprehensive.
7. Performance of care coordination activities is assessed with outcome measures that evaluate areas including:
   a. the process of care coordination (e.g., number of families with a shared plan of care);
   b. Family experience with integration of care across medical, behavioral, social and other sectors and systems;
   c. Quality of life for CYSHCN and families; and
   d. Reduction in duplicative and/or preventable health care utilization.

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.[17],[18]

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: [19],[20]

  a. Child and family strengths and resiliency;
  b. 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;
  c. Health and social inequities that may create barriers to accessing and receiving needed care, services, or supports;
  d. 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;
  e. 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
  f. 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.[21],[22]

7 The care coordination assessment incorporates key information from the child's physical and behavioral health status and history, as well as information about:[23],[24],[25],[26],[27],[28],[29]

a. Insurance status;

b. 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;

c. Whether the child is involved in the justice system;

d. Involvement in the child welfare system;

e. Education needs;

f. Language needs and preferences;

g. Health literacy and health education needs;

h. Social determinants of health;

i. Preferred method of communication (e.g., phone, e-mail, in person);

j. Demographics (including race and ethnicity);

k. Availability of support systems, including a family support network;

l. Unmet needs for services and support;

m. The family's self-management skills and capacity to navigate care systems;

n. Health status of the caregiver and sibling(s), if applicable;

o. Guardianship; and

p. 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.[30]

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. [31],[32]
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.[33],[34],[35]
13	The reassessment process includes a re-review of the child and family's need for care coordination services.[36] Reassessment documentation should include a mechanism to track whether and when the child receives recommended services.[37],[38]

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;[39],[40],[41]

b. Reflects the family's unique knowledge, lived experiences, values, and beliefs;[42] and

c. Is both strength-based and trauma-informed.

3 The shared plan of care includes the child's:[43]

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.[44]

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.[45],[46],[47]

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.[48]

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.[49] 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.[50]

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: [51],[52]

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.[53]

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.[54]

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.[55]

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:[56],[57]

a. Learning from and building partnerships with families;
b. Motivational interviewing;
c. Identification of family strengths, priorities, and goal setting;
d. Shared plan of care development;
e. Cultural and linguistic competency;
f. Implicit bias;
g. Health insurance policies and procedures;
h. Confidentiality;
i. Health Insurance Portability and Accountability Act (HIPAA) and Family Educational Rights and Privacy Act (FERPA) compliance training;
j. Health literacy;
k. Community-based resources;
l. Transition and referral processes; and
m. 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.[58],[59]

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.[60],[61]

7

Payment or reimbursement for care coordination reflects the qualifications, workload, and intensity of services provided by care coordinators.[62]

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:[63],[64],[65]
a. Be driven by youth and families, based on their goals, needs, and preferences;
b. Clearly identify roles and responsibilities of the family, care team members, providers, and other entities involved in transitions; and
c. 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.[66],[67],[68]

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.[69],[70]

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,[71] and advance CYSHCN independence, self-efficacy, and self-advocacy in the transition to adulthood.

National Care Coordination Standards for CYSHCN Graphic

Multidisciplinary Care Team

Primary Care Provider

Rehabilitation Professionals

Education Partners

Behavioral Health Specialists

Child & Family
- Informs all decisions
- Is an equal partner
- Receives training

Care Coordinators (single point of contact)

Resources, Supports, and Services

Medical Specialists

- Based on the premise of equity, that all children and families should have an equal opportunity and no barriers to attaining their full health potential
- Functions as part of expanded medical home
- Relies on the family as an equal team member/partner
- Determined in partnership with family
- Everyone has a designated role, responsibility, and is accountable

Screening, Identification, and Assessment
- Identifies family's strengths, needs, beliefs, culture, and preferences
- Evaluates complexity of the child's health condition
- Evaluates impact on social determinants of health
- Identifies risk as a factor for intensity of care coordination

Care Coordination Workforce
- Aligns credentials and/or experience to meet needs
- Is culturally, linguistically, racially and ethnically diverse
- Takes into account case complexity and intensity of services when determining case load ratios
- Develops long term caring relationships with families

Care Transitions
- Includes policies to facilitate effective transition between various entities
- Actively engages youth and families in care transition plan development
- Identifies and collaborates with adult providers for youth transitioning to adult health care systems

Team-based Communication
- Clearly defines team member roles
- Is informed by family, who are at the center of the care team
- Have a single point of contact for communication with the family
- Addresses family's language, cultural, and communication preferences

Child and Family Empowerment and Skills Development
- Increases understanding of the child's condition and builds self-management and efficacy skills
- Appropriately reimburses individuals with lived experience who serve in care coordination roles
- Connects family with peer supports

Shared Plan of Care
- Is used to develop shared goals and emergency plan
- Addresses clinical, functional, social, and aspirational issues
- Identifies contacts for emergent and routine issues

Appendix A: Glossary of Terms

1. **Assessment:** a health assessment that identifies the specific needs, beliefs and goals of the family and child and how they can be best addressed by the health care system.
2. **Care Coordination:** patient and family-centered, assessment-driven, team-based activities designed to meet the needs of children and youth that address interrelated medical, social, developmental, behavioral, educational and financial needs to achieve optimal health and wellness outcomes and efficient delivery of health-related services and resources both within and across systems.[72],[73],[74]
3. **Care Coordinator:** an identified individual who can assist patients, families and caregivers with referrals to specialists and other care providers, communication between the child's primary care physician, service providers and subspecialty physicians, support for family concerns, and problem solving to promote the patients' well-being.[75]
4. **Care Teams:** a multidisciplinary team, including care coordinators, primary, specialty, and social service providers, functioning as part of an expanded medical home in which the family is an equal team member and partner.
5. **Centralized Electronic Health Record:** a digital version of a patient's paper chart that instantly allows authorized users to securely access real-time, patient-centered records information.[76]
6. **Children and Youth with Special Health Care Needs (CYSHCN):** Children who have or are at increased risk for chronic physical, developmental, behavioral or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.[77]
7. **Health Literacy:** the degree to which an individual has the capacity to obtain, communicate, process, and understand basic health information and services to make appropriate health decisions.[78]
8. **Persons with Lived Experience:** individuals who have first-hand experience of the medical and/or behavioral health condition(s) under consideration. This may be someone who has been diagnosed with the condition themselves or a caregiver of someone diagnosed with the condition.[79]
9. **Medical Home:** Also known as Patient or Family-Centered Medical Home, a Medical Home is an approach to providing comprehensive primary care that facilitates partnerships between patients, clinicians, medical staff, behavioral health specialists, care coordinators, families, and professionals from rehabilitation, social services, and education systems.[80]
10. **Outcome Measures:** measures that reflect the impact of a health care service or intervention on the health status of patients.[81]
11. **Shared Plan of Care:** a concise yet comprehensive, integrated, and user-friendly compilation of child and family specific information and goals that guides care and facilitates its coordination among the family and their lead clinical team in concert with the appropriate "constellation" of subspecialists and community resource providers.[82]
12. **Trauma-informed Care:** an approach in the human service field that assumes that an individual is more likely than not to have a history of trauma, recognizes the presence of trauma symptoms, and acknowledges the role trauma may play in an individual's life.[83]

Appendix B: Key Informants

Family Leaders

o Cara Coleman, Program Manager, Family Voices
o Teresa Jurado, Parent Mentor, Stanford Children's Hospital
o Rylin Rodgers, Director of Public Policy, Association of University Centers on Disabilities
o Nora Wells, Executive Director, Family Voices
o Family Voices State Affiliate Organization Representatives

Children's Hospitals

o Tracy Huentelman, Senior Project Specialist, Cincinnati Children's Hospital Medical Center
o Dr. John Morehous, Medical Director, Fairfield Primary Care, Cincinnati Children's Hospital Medical Center

Health Plans

o Jennifer Kyle, Vice President Product Strategy, Special Needs Initiative, UnitedHealthcare

Centers for Medicare & Medicaid Services (CMS)

o Renee Fox, Division of Quality and Health Outcomes, Center for Medicaid and CHIP Services
o Melissa Harris, Disabled and Elderly Health Programs Group, Center for Medicaid and CHIP Services
o Susan Ruiz, Oral Health and EPSDT lead, CMS San Francisco Regional Office, Division of Medicaid & Children's Health Operations
o Ellen Marie Whelan, Chief Population Health Officer, Center for Medicaid and CHIP Services

Health Resources and Services Administration (HRSA)

o Treeby Brown, Chief, Integrated Services Branch, Maternal and Child Health Bureau, HRSA
o Marie Mann, Senior Medical Advisor, Maternal and Child Health Bureau, HRSA
o Leticia Manning, Public Health Analyst, Maternal and Child Health Bureau, HRSA

Providers/Provider Groups

o Rich Antonelli, Medical Director, Integrated Care, Boston Children's Hospital
o Dennis Kuo, Chief, Division of General Pediatrics, University of Buffalo
o Kathleen Noonan, Camden Coalition of Healthcare Providers

State Medicaid Programs

o Sandra Brown, Integrated Care Management Manager, Virginia Department of Medical Assistance Services (DMAS)
o Emily Creveling, Maternal and Child Health Manager, Virginia DMAS
o Katie Hill, Integrated Care Senior Advisor, Virginia DMAS
o Estelle Kendall, Nurse Case Manager, Virginia DMAS

State Title V CYSHCN Programs

o Jeff Brosco, Florida Title V CYSHCN Director

Endnotes

[1] McPherson M, Arango P, Fox H, et al. A new definition of children with special health care needs. Pediatrics. 1998;102(1 Pt 1):137-140.

[2] Cohen E, Berry JG, Sanders L, Schor EL, Wise PH. Status Complexicus? The Emergence of Pediatric Complex Care. Pediatrics. 2018;141(Supplement 3):S202-S211.

[3] Cohen E, Kuo DZ, Agrawal R, et al. Children with medical complexity: an emerging population for clinical and research initiatives. Pediatrics. 2011;127(3):529-538.

[4] Child and Adolescent Health Measurement Initiative. 2017 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by Cooperative Agreement U59MC27866 from the U.S. Department of Health and Human Services, Health Resources and Services Administration's Maternal and Child Health Bureau (HRSA MCHB). Retrieved from https://www.childhealthdata.org/browse/survey/results?q=6546&r=1.

[5] Cohen E, Berry JG, Camacho X, Anderson G, Wodchis W, Guttmann A. Patterns and costs of health care use of children with medical complexity. Pediatrics. 2012;130(6):e1463-1470.

[6] J P. A Review of the Literature for Outcomes Associated with Aspects of Care Coordination and the Presence of a Care Coordinator for Children with Complex Needs. Center of Excellence on Quality of Care Measures for Children with Complex Needs. 2012.

[7] Peter S, Chaney G, Zappia T, Van Veldhuisen C, Pereira S, Santamaria N. Care coordination for children with complex care needs significantly reduces hospital utilization. J Spec Pediatr Nurs. 2011;16(4):305-312.

[8] McAllister JW, Presler E, Cooley WC. Practice-based care coordination: a medical home essential. Pediatrics. 2007;120(3):e723-733.

[9] Peter S et al., Care coordination for children with complex care needs.

[10] Farmer JE, Clark MJ, Drewel EH, Swenson TM, Ge B. Consultative care coordination through the medical home for CSHCN: a randomized controlled trial. Matern Child Health J. 2011;15(7):1110-1118.

[11] Peter S et al., Care coordination for children with complex care needs.

[12] Farmer JE, Clark MJ, Sherman A, Marien WE, Selva TJ. Comprehensive primary care for children with special health care needs in rural areas. Pediatrics. 2005;116(3):649-656.

[13] Stewart K, Bradley K et al. Care Coordination for Children with Special Health Care Needs in Medicaid: Lessons from Medicare. Am. Journal of Managed Care; 24(4); April 2018.

[14] Antonelli RC, McAllister JW, Popp J. Making Care Coordination a Critical Component of the Pediatric Health System: A Multidisciplinary Framework. New York, NY: The Commonwealth Fund; 2009.

[15] Council on Children With Disabilities and Medical Home Implementation Project Advisory Committee. Patient- and family-centered care coordination: a framework for integrating care for children and youth across multiple systems. Pediatrics. 2014;133(5).

[16] "Care Coordination Measures Atlas Update", Agency for Healthcare Research and Quality, June 2014, https://www.ahrq.gov/professionals/prevention-chronic-care/improve/coordination/atlas2014/chapter2.html.

Endnotes

[17] Bachman S, Comeau M, Jankovosky K. The Care Coordination Conundrum and Children and Youth with Special Health Care Needs. Boston, MA: The Catalyst Center; 2015.

[18] National Committee for Quality Assurance. Standards and Guidelines for NCQA's Patient-Centered Medical Home (PCMH) 2017, Version 4. Care Management and Support, Competency A.

[19] National Committee for Quality Assurance. Standards and Guidelines for NCQA's Patient-Centered Medical Home (PCMH) 2017, Version 4. Standard CM-01.

[20] Silow-Carroll S, Rodin D, Pham A. Interagency, Cross-Sector Collaboration to Improve Care for Vulnerable Children: Lessons from Six State Initiatives. Albany, NY: Health Management Associates; 2018.

[21] Antonelli RC, McAllister JW, Popp J. Making Care Coordination a Critical Component of the Pediatric Health System: A Multidisciplinary Framework. New York, NY: The Commonwealth Fund; 2009.

[22] Bachman S, Comeau M, Jankovosky K. The Care Coordination Conundrum and Children and Youth with Special Health Care Needs. Boston, MA: The Catalyst Center; 2015.

[23] Antonelli RC, McAllister JW, Popp J. Making Care Coordination a Critical Component of the Pediatric Health System: A Multidisciplinary Framework. New York, NY: The Commonwealth Fund; 2009.

[24] Barth S et al., Care Coordination in Integrated Care Programs Serving Dually Eligible Beneficiaries – Health Plan Standards, Challenges and Evolving Approaches. Health Management Associates: March 2019.

[25] Kuo D et al., Care Coordination for Children With Medical Complexity: Whose Care Is It, Anyway?. Pediatrics: March 2018.

[26] Massachusetts Child Health Quality Coalition. Care Coordination Strengths and Needs Assessment: Recommendations for a Structured Tool. February 2015. http://www.masschildhealthquality.org/wp-content/uploads/2015/02/1.-CHQC-CC-Needs-Assessment-Tool-Recommendations-HIGH-LEVEL.pdf

[27] Care Coordination Measures Atlas Update. Content last reviewed June 2014. Agency for Healthcare Research and Quality, Rockville, MD. http://www.ahrq.gov/professionals/prevention-chronic-care/improve/coordination/atlas2014/index.html

[28] National Committee for Quality Assurance. Standards and Guidelines for NCQA's Patient-Centered Medical Home (PCMH) 2017, Version 4. Standard KM-02.

[29] National Committee for Quality Assurance. Standards and Guidelines for NCQA's Case Management Accreditation 2017. Standards CM-2 Element D, LTSS-1 Element F, LTSS-1 Element G.

[30] Stille C et al., Aligning Services with Needs: Characterizing the Pyramid of Complexity Tiering for Children with Chronic and Complex Conditions. 2018. Lucille Packard Foundation for Children's Health.

[31] Stille C et al., Aligning Services with Needs: Characterizing the Pyramid of Complexity Tiering for Children with Chronic and Complex Conditions. 2018. Lucille Packard Foundation for Children's Health.

[32] National Committee for Quality Assurance. Standards and Guidelines for NCQA's Patient-Centered Medical Home (PCMH) 2017, Version 4. Standard CM-02, Element C.

[33] Stille C et al., Aligning Services with Needs: Characterizing the Pyramid of Complexity Tiering for Children with Chronic and Complex Conditions. 2018. Lucille Packard Foundation for Children's Health.

[34] National Committee for Quality Assurance. Standards and Guidelines for NCQA's Patient-Centered Medical Home (PCMH) 2017, Version 4. Standard CM-02, Element C.

[35] National Committee for Quality Assurance. Standards and Guidelines for NCQA's Population Health Program Accreditation 2019. Standard PHP 4, Element A.

[36] Antonelli RC, McAllister JW, Popp J. Making Care Coordination a Critical Component of the Pediatric Health System: A Multidisciplinary Framework. New York, NY: The Commonwealth Fund; 2009.

[37] Care Coordination Measures Atlas Update. Content last reviewed June 2014. Agency for Healthcare Research and Quality, Rockville, MD.

[38] National Committee for Quality Assurance. Standards and Guidelines for NCQA's Population Health Program Accreditation 2019. Population Segmentation, element A.

Endnotes

[39] National Quality Forum (NQF), Preferred Practices and Performance Measures for Measuring and Reporting Care Coordination: A Consensus Report, Washington, DC: NQF; 2010.

[40] McAllister, J. (2014). Achieving a Shared Plan of Care with Children and Youth with Special Health Care Needs: A White Paper and Implementation Guide, Lucille Packard Foundation for Children's Healthcare.

[41] National Committee for Quality Assurance. Standards and Guidelines for NCQA's Case Management Accreditation 2017

[42] McAllister, J. (2014). Achieving a Shared Plan of Care with Children and Youth with Special Health Care Needs: A White Paper and Implementation Guide, Lucille Packard Foundation for Children's Healthcare.

[43] Ibid.

[44] American Academy of Pediatrics. Council on Children with Disabilities and Medical Home Implementation Project Advisory Committee. Patient- and Family-Centered Care Coordination: A Framework for Integrating Care for Children and Youth Across Multiple Systems. Pediatrics May 2014, 133 (5) e1451-e1460. https://pediatrics.aappublications.org/content/133/5/e1451.full

[45] National Quality Forum (NQF), Preferred Practices and Performance Measures for Measuring and Reporting Care Coordination: A Consensus Report, Washington, DC: NQF; 2010.

[46] McAllister, J. (2014). Achieving a Shared Plan of Care with Children and Youth with Special Health Care Needs: A White Paper and Implementation Guide, Lucille Packard Foundation for Children's Healthcare.

[47] National Committee for Quality Assurance. Standards and Guidelines for NCQA's Case Management Accreditation 2017.

[48] Patience H. White, W. Carl Cooley. Transitions Clinical Report Authoring Group, American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians. Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home Pediatrics November 2018, 142 (5) e20182587. https://pediatrics.aappublications.org/content/142/5/e20182587.

[49] Berry JG, Goldmann DA, Mandl KD, et al. Health information management and perceptions of the quality of care for children with tracheotomy: a qualitative study. BMC Health Serv Res. 2011;11:117

[50] Ziniel SI, Rosenberg HN, Bach AM, Singer SJ, Antonelli RC. Validation of a Parent-Reported Experience: Measure of Integrated Care. Pediatrics. 2016;138(6):e20160676

[51] AHRQ Care Coordination Measures Atlas, Antonelli RC, McAllister JW, Popp J. Making Care Coordination a Critical Component of the Pediatric Health System: A Multidisciplinary Framework. New York, NY: The Commonwealth Fund; 2009.

[52] Antonelli RC, McAllister JW, Popp J. Making Care Coordination a Critical Component of the Pediatric Health System: A Multidisciplinary Framework. New York, NY: The Commonwealth Fund; 2009.

[53] "Joint Principles of the Patient-Centered Medical Home," American Academy of Family Physicians, American Academy of Pediatrics, American College of Physicians, and American Osteopathic Association, March 2007, https://www.aafp.org/dam/AAFP/documents/practice_management/pcmh/initiatives/PCMHJoint.pdf

[54] Antonelli, RC, Huth, Rosenberg, H, Bach, A, Eds. 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. 2019. https://medicalhomeinfo.aap.org/tools-resources/Documents/PCCC%202nd%20Edition/Full%20Pediatric%20Care%20Coordination%20Curriculum.pdf

[55] Thorpe JH, Hayes K. Selected Provisions from Integrated Care RFPs and Contracts: Care Coordination. Integrated Care Resource Center. 2013. http://www.chcs.org/media/ICRC_Care_Coordination_FINAL_7_29_13.pdf

[56] Boston Children's Hospital. Care coordination curriculum. 2013. Available at: www.childrenshospital.org/care-coordination-curriculum.

[57] National Committee for Quality Assurance. Standards and Guidelines for NCQA's Case Management Accreditation 2017.16/03/Care-Coordination-Conundrum.pdf

Endnotes

[58] Thorpe JH, Hayes K. Selected Provisions from Integrated Care RFPs and Contracts: Care Coordination. Integrated Care Resource Center. 2013. http://www.chcs.org/media/ICRC_Care_Coordination_FINAL_7_29_13.pdf

[59] National Committee for Quality Assurance. Standards and Guidelines for NCQA's Case Management Accreditation 2017

[60] Ziniel SI, Rosenberg HN, Bach AM, Singer SJ, Antonelli RC. Validation of a Parent-Reported Experience: Measure of Integrated Care. Pediatrics. 2016;138(6):e20160676

[61] National Committee for Quality Assurance. Standards and Guidelines for NCQA's Case Management Accreditation 2017

[62] Sara S. Bachman, Meg Comeau, and Katharyn M. Jankov, "The Care Coordination Conundrum and Children and Youth with Special Health Care Needs," The Catalyst Center, November 2015, http://cahpp.org/wp-content/uploads/2016/03/Care-Coordination-Conundrum.pdf

[63] Got Transition, Center for Health Care Transition Improvement. Six Core Elements of Health Care Transition 2.0. Available at: http://www.gottransition.org/resourceGet.cfm?id=206.

[64] National Committee for Quality Assurance. Standards and Guidelines for NCQA's Patient-Centered Medical Home (PCMH) 2017, Version 4.

[65] American Academy of Pediatrics. American Academy of Family Physicians, and American College of Physicians. Transitions Clinical Report Authoring Group. Supporting the health care transition from adolescence to adulthood in the medical home. Pediatrics. 2011; 128-182.

[66] Antonelli RC, McAllister JW, Popp J. Making Care Coordination a Critical Component of the Pediatric Health System: A Multidisciplinary Framework. New York, NY: The Commonwealth Fund; 2009.

[67] National Committee for Quality Assurance. Standards and Guidelines for NCQA's Patient-Centered Medical Home (PCMH) 2017, Version 4.

[68] White, Patience H, and Carl Cooley. "White PH, Cooley WC; Transitions Clinical Report Authoring Group; American Academy of Pediatrics; American Academy of Family Physicians; American College of Physicians. Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home. Pediatrics. 2018;142(5):e20182587." Pediatrics 143, no. 2 (2019). https://doi.org/10.1542/peds.2018-3610.

[69] Care Coordination Measures Atlas Update. Content last reviewed June 2014. Agency for Healthcare Research and Quality, Rockville, MD. http://www.ahrq.gov/professionals/prevention-chronic care/improve/coordination/atlas2014/index.html

[70] National Committee for Quality Assurance. Standards and Guidelines for NCQA's Patient-Centered Medical Home (PCMH) 2017, Version 4.

[71] Agency for Healthcare Research and Quality. Implementation Quick Start Guide Warm Handoff: The Guide to Improving Patient Safety in Primary Care Settings by Engaging Patients and Families. https://www.ahrq.gov/sites/default/files/wysiwyg/professionals/quality-patient-safety/patient-family-engagement/pfeprimarycare/warm-handoff-qsg-brochure.pdf

Endnotes

[72] Antonelli RC, McAllister JW, Popp J. Making Care Coordination a Critical Component of the Pediatric Health System: A Multidisciplinary Framework. New York, NY: The Commonwealth Fund; 2009

[73] Council on Children With Disabilities and Medical Home Implementation Project Advisory Committee. Patient- and family-centered care coordination: a framework for integrating care for children and youth across multiple systems. Pediatrics. 2014;133(5).

[74] "Care Coordination Measures Atlas Update", Agency for Healthcare Research and Quality, June 2014, https://www.ahrq.gov/professionals/prevention-chronic-care/improve/coordination/atlas2014/chapter2.html.

[75] "Managing the Practice: Patient Care Coordinator." American Academy of Pediatrics, n.d. https://www.aap.org/en-us/professional-resources/practice-transformation/managing-practice/Pages/Patient-Care-Coordinator.aspx.

[76] "What Is an Electronic Health Record (EHR)?" Health IT.gov, September 10, 2019. https://www.healthit.gov/faq/what-electronic-health-record-ehr.

[77] "Children with Special Health Care Needs." HRSA Maternal and Child Health. Health Resources and Services Administration, August 2019. https://mchb.hrsa.gov/maternal-child-health-topics/children-and-youth-special-health-needs.

[78] The Patient Protection and Affordable Care Act of 2010, Title V. https://www.congress.gov/111/plaws/publ148/PLAW-111publ148.pdf

[79] Rittenbach, Katherine, Candice G. Horne, Terence O'Riordan, Allison Bichel, Nicholas Mitchell, Adriana M. Fernandez Parra, and Frank P. Macmaster. "Engaging People with Lived Experience in the Grant Review Process." BMC Medical Ethics 20, no. 1 (December 16, 2019). https://doi.org/10.1186/s12910-019-0436-0.

[80] "What Is Medical Home?" Engaging Patients and Families. American Academy of Pediatrics, n.d. https://www.aap.org/en-us/professional-resources/practice-transformation/managing-patients/Pages/what-is-medical-home.aspx.

[81] "Types of Health Care Quality Measures." Agency for Healthcare Research and Quality, July 2015. https://www.ahrq.gov/talkingquality/measures/types.html.

[82]McAllister, Jeanne W. "Achieving a Shared Plan of Care with Children and Youth with Special Health Care Needs: An Implementation Guide." Lucile Packard Foundation for Children's Health, May 2014. https://www.lpfch.org/sites/default/files/field/publications/achieving_a_shared_plan_of_care_implementation.pdf.

[83] "What Is Trauma-Informed Care?" The Institute on Trauma and Trauma-Informed Care (ITTIC). University of Buffalo Center for Social Research, n.d. http://socialwork.buffalo.edu/social-research/institutes-centers/institute-on-trauma-and-trauma-informed-care/what-is-trauma-informed-care.html.

Acknowledgements

About NASHP

The National Academy for State Health Policy is a nonpartisan forum of policymakers throughout state governments, learning, leading, and implementing innovative solutions to health policy challenges. To accomplish our mission NASHP:

- Convenes state leaders to solve problems and share solutions;
- Conducts policy analyses and research;
- Disseminates information on state policies and programs; and
- Provides technical assistance to states.

The responsibility for health care and health care policy does not reside within a single state agency or department. NASHP provides a unique forum for productive interchange across all lines of authority, including the executive and legislative branches.

About the Lucile Packard Foundation for Children's Health

The Lucile Packard Foundation for Children's Health works in alignment with the Lucile Packard Children's Hospital Stanford and the child health programs of Stanford University. The mission of the foundation is to elevate the priority of children's health and increase the quality and accessibility of children's health care through leadership and direct investment. The vision of the Lucile Packard Foundation for Children's Health is that all children in the communities it serves are able to reach their maximum health potential.