Proceedings from the National Forum on Care Coordination for CYSHCN

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

Introduction

Children and youth with special health care needs (CYSHCN) often have unmet health care needs and face challenges in accessing high-quality care, as services for this population are frequently fragmented, uncoordinated, and inadequate. These inefficiencies can lead to undue financial, health, and social consequences for families of CYSHCN.[1] Given the persistence of health care inequities, CYSHCN who are Black and Latinx,[2] as well as those from low-income families,[3] rural regions,[4] and who have more complex care needs[5] face disproportionate barriers to accessing high-quality care. This substandard access to quality care can lead to poor health outcomes.[6]

NASHP | **NATIONAL ACADEMY FOR STATE HEALTH POLICY**

Nearly 20 percent of children in the U.S. have a special health care need, and an estimated 44 percent of CYSHCN are enrolled in Medicaid.[7] Given concerns around the quality and high cost of care for CYSHCN, state health officials and other stakeholders have increasingly focused their efforts on improving systems of care for this population. States are implementing strategies designed to improve access to high-quality care and health outcomes for CYSHCN, such as alternative payment models, comprehensive care coordination, and new approaches to community-based care. Care coordination is a core element of these efforts due to its potential to enhance quality and reduce costs.

DEFINITION OF CARE COORDINATION

The National Care Coordination Standards for CYSHCN defines care coordination 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."[8]

In June 2022, NASHP convened a national forum with state health officials (e.g., public health, Medicaid, mental health) and other stakeholders (e.g., health plans, providers, families of CYSHCN) to discuss innovations, strategies, and opportunities to improve high-quality, equitable care coordination for CYSHCN. This event built upon NASHP's work in developing and supporting the implementation of the "National Care Coordination Standards for Children and Youth with Special Health Care Needs"[9] (NCCS), released in 2020. These standards outline the core system-level components of high-quality care coordination for CYSHCN and are complementary to the "National Standards for Systems of Care for Children and Youth with Special Health Care Needs"[10] (NSC), released in 2017.

The "National Forum on Advancing High-Quality, Equitable Care Coordination for Children and Youth with Special Health Care Needs" centered on two key topics for improving care coordination systems for CYSHCN: integrated care coordination and the care coordination workforce. These topics were identified for their importance in improving care coordination for CYSHCN based on input from the National Work Group, a cross-system group of state and federal officials, advocates, payers, and providers with expertise in CYSHCN that informed the development and implementation of the NCCS, as well as NASHP's extensive work in this area. For additional details on the forum, see the agenda and participant list in the appendices.

Integrated Care Coordination for CYSHCN

During the forum, participants discussed key challenges, strategies, and considerations related to integrated care for CYSHCN. While there are a variety of definitions for "integrated care," a commonly used, health system-based definition is "health services that are managed and delivered so that people receive a continuum of health promotion, disease prevention, diagnosis, treatment, disease-management, rehabilitation and palliative care services, coordinated across the different levels and sites of care within and beyond the health sector, and according to their needs throughout the life course."[11]

Many states are implementing strategies to support integrated care across child- and family-serving systems as one key approach to improving access to high-quality care and health outcomes for CYSHCN. Care coordination is a core component of integrated care delivery systems because it helps connect families to appropriate care and services. This approach recognizes that families of CYSHCN often receive services from multiple systems and that these systems must collaborate in order to provide high-quality care to families. High-quality, integrated care requires strong system-level partnerships, information and data sharing, and family-centered practices. Yet, states often face barriers to integrated care including a lack of trust across agencies, privacy regulations that may hinder data sharing, and misaligned eligibility, enrollment, and referral systems.

> **Many states are implementing strategies to support integrated care across child- and family-serving systems.**

In spite of these barriers, and to help address them, states have implemented innovations to improve integrated care coordination for CYSHCN. Federal agencies have also prioritized and supported advancing integrated care. For example, the Centers for Medicare & Medicaid Services Innovation Center is currently supporting the Integrated Care for Kids (InCK) model across seven sites in six states. This model aims to improve quality of care for children, including CYSHCN, through integrated care delivery systems that include care coordination.[12]

Oregon's Approach to Advancing Integrated Care Coordination for CYSHCN

In Oregon, state health officials and other stakeholders have implemented various strategies to advance integrated care for CYSHCN and their families. These include:

- Implementing an incentive metric for the state's coordinated care organizations to collaborate with community partners
- Conducting asset mapping with system partners and care mapping with families to identify barriers and facilitators to integrated care for CYSHCN
- Defining health complexity by indicators of medical and social complexity, as defined by the Center of Excellence on Quality of Care Measures for Children with Complex Needs
- Using health complexity data to improve care coordination for CYSHCN and analyze children's access to integrated care

Care Coordination Workforce

As described in the NCCS, a high-quality 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."[13] Yet, one key challenge facing state health officials and other child health stakeholders in implementing high-quality, integrated care coordination systems for CYSHCN is recruiting, retaining, and supporting the care coordination workforce. Additionally, states have struggled with developing a diverse, culturally competent workforce that can best serve all families. Often, these workforce challenges create barriers for families in accessing high-quality care coordination services, both due to workforce shortages and poor alignment across care coordinators from siloed child-serving systems.

State health officials and other stakeholders have implemented a variety of strategies to support the care coordination workforce. In the face of recruitment and retention challenges, states have modified licensure requirements and created new pathways for families of CYSHCN and people with lived experience to meet employment qualifications. Aligning care coordinators across child-serving systems, designating a lead care coordinator, and providing comprehensive training for care coordinators can support families in receiving high-quality care coordination.

Rhode Island's Approach to Supporting the Care Coordination Workforce

In Rhode Island, state health officials have supported people with lived experience, including those who may be unlicensed, in becoming care coordinators and other health professionals. This includes:

- Developing a state definition of Community Health Worker (CHW) that allows for flexibility in the role and includes family members of CYSHCN who provide care coordination as parent consultants through the Rhode Island Parent Information Network

- Supporting parent consultants in obtaining CHW certification

- Reimbursing parent consultants as CHWs through Medicaid, including through Medicaid managed care and fee-for-service approaches

- Training CHWs in core components of care coordination

The state defines CHWs as "frontline public health workers who are trusted members of the community they serve. This trusting relationship enables them to serve as a liaison/link/intermediary between health/social services and the community to facilitate access to services and improve the quality and cultural responsiveness of service delivery." While these services have been largely grant-funded,[14] the state Medicaid agency can provide Medicaid reimbursement to CHWs through a state plan amendment effective July 1, 2021.[15]

Strategies and Approaches to Support Integrated Care and the Care Coordination Workforce for CYSHCN

Forum participants identified a variety of strategies to advance integrated care across child-serving systems and strengthen the care coordination workforce. These strategies focused on four overall approaches: 1) strengthening partnerships; 2) leveraging data and technology; 3) placing families at the center of care; and 4) supporting a family-centered workforce. The following strategies and examples are not exhaustive, but they highlight key points discussed during the forum. State examples of each strategy are included, several of which highlight Oregon, Rhode Island, and other states featured during the forum.

Strengthening Partnerships

System-level partnerships and strong communication are key to reducing fragmentation across care coordination programs and child-serving systems. Through these partnerships, stakeholders can identify and alleviate gaps and reduce duplicative services that can lead to families "coordinating the coordinators." Partnerships are strongest when they are based on a collective impact model, focusing on a common vision and developing shared accountability. Related strategies and approaches discussed during the forum include:

- **Engaging stakeholders across agencies and disciplines.** Participants described engaging with a variety of stakeholders to support efforts to improve care coordination systems for CYSHCN, ranging from early childhood and education systems to adult provider organizations. For example, **Kansas** identified a gap in transition support for children aging out of the Program for Infants and Toddlers with Disabilities through Part C of the Individuals with Disabilities Act, which supports children up to age 3. To alleviate this gap, Kansas's public health agency partnered with the state's early childhood system to develop the Bridges program, which is a care coordination program designed to support CYSHCN through this transition up to age 8.[16]

- **Developing clear care coordination roles across agencies.** Collaboration can be most effective when there are clear responsibilities for each participating agency, and when agency mission, capacity, staff expertise, and other factors are considered. Participants identified this as a key strategy to increase alignment and reduce duplication of efforts. For example, after **New Mexico** shifted its Medicaid program to a managed care approach, the state required its contracted Medicaid managed care organizations (MCOs) to provide care coordination services to their enrollees. To avoid duplication of its existing care coordination services, New Mexico's Title V CYSHCN program conducted outreach, trainings, and meetings with the MCOs. As a result, services were better aligned and the MCOs referred CYSHCN to the Title V CYSHCN program for care coordination given the program staff's expertise in serving this population.

- **Assessing existing strategies, capacity, and gaps.** Cross-system quality improvement efforts rely on strong partnerships to identify existing resources, gaps, and priorities for care coordination systems for CYSHCN. In **Oregon**, state health officials conducted asset mapping[17] with system partners as well as care mapping with families to identify barriers and facilitators to high-quality integrated care for CYSHCN. States also conduct assessments to develop a shared understanding of care coordination efforts across agencies and build alignment. In **Rhode Island**, the public health agency conducted a study to better understand the capacity of the CHW workforce, which includes parent

consultants who provide care coordination for CYSHCN through the Rhode Island Parent Information Network.[18] This study involved collaboration with accountable care organizations, MCOs, the state Medicaid agency, community-based organizations, and other stakeholders.

Leveraging Data and Technology

Data are central to both direct care coordination service provision, as well as care coordination system monitoring and quality improvement efforts. An integrated care delivery system with high-quality care coordination requires data- and information-sharing across child-serving systems, yet state health officials and other child health stakeholders face barriers to effectively doing so. Participants identified common challenges, including distrust, privacy regulations and data-sharing agreements, accountability, and technological capacity. Related strategies and approaches discussed during the forum include:

- **Building and leveraging information-sharing systems.** Shared databases, electronic health records, health information exchanges (HIE), and other health information systems can be effective in supporting high-quality care coordination systems for CYSHCN. While challenges remain in building up these systems, including connecting data between health and other child-serving systems, many states have made significant progress. For example, in **Maryland** and the **District of Columbia**, the state HIE, CRISP, enables disparate health information systems to electronically share clinical information.[19] This includes systems used by various types of providers, including long-term care, ambulatory services, hospitals, federally qualified health centers, and others.[20]

- **Using data to support a family-centered and trauma-informed approach to engage with families.** Many families report that they are frequently asked the same questions about their child's care and that they are often screened and assessed by tools that cover similar domains and questions. Some of these questions and tools, particularly those related to health-related social needs, may be traumatizing for families to repeatedly discuss. Participants noted that one way to support a family-centered and trauma-informed approach is by using existing data to inform care coordination, thereby reducing families' need to repeat this information. For example, **Oregon** uses data from a range of sources to score children's health complexity based on multiple indicators of medical and social complexity. This health complexity data are used for multiple purposes, including to prioritize children for intensive care coordination.

- **Empowering families to own and use their data.** Before data can be shared between entities, families must provide consent for them to do so. Families' preferences range widely in terms of what data they are willing to share, if any.

One approach to facilitate data sharing while adhering to families' preferences is to allow families greater control over their data and information. For example, to reduce unwanted barriers to information-sharing that supports care coordination for CYSHCN, **Wisconsin's** Complex Care program provides each family with a copy of their shared plan of care, which they can directly share with anyone they choose, including providers.[21]

Placing Families at the Center of Care

A high-quality care coordination system is co-created by families of CYSHCN, who are also core partners on their child's care team. Families may vary in their level of interest in participating in system-level planning and advocacy. Additionally, while families often lead their child's care team, they may not always be comfortable in taking on this role. State health officials and other child health stakeholders can ensure that there are a variety of opportunities and supports available to families to meet their preferences. Related strategies and approaches discussed during the forum include:

- **Involving families in program design.** Families of CYSHCN can provide critical insight on the quality of the care coordination system, as well as gaps and key priorities. In **Kansas**, the Title V CYSHCN program engages a family advisory council (FAC) on an ongoing basis. This FAC was a core partner in the development of the state's care coordination program. Family networks and associations can also serve as an important partner and leader in designing care coordination systems for CYSHCN. For example, in **Wisconsin**, the state's Family Voices chapter initiated the adaptation and implementation of the training curriculum for care coordinators in the state, "Pediatric Care Coordination Curriculum: An Interprofessional Resource to Effectively Engage Patients and Families in Achieving Optimal Child Health Outcomes,"[22] in partnership with the state Medicaid agency.

- **Providing training for families on a range of roles and topics.** Families should have the opportunity to receive training related to their family's care, as well as system-level advocacy and engagement. Virtual and self-paced resources can support families whose schedules may not allow for in-person training. For example, **Wisconsin's** Complex Care program offers free online training for families of CYSHCN titled "Bridge to Independence." Training modules include advocacy, emergency planning, and personal health records, among others.[23] Similarly, in **California**, Stanford Children's Health's Complex Primary Care Clinic offers roughly 50 online training modules, facilitated by parent mentors, for families of CYSHCN on topics such as preparing for vacation with a child with special health care needs.

- **Prioritizing care mapping, shared plans of care, and care team meetings.**
  Forum participants agreed that care mapping, shared plans of care, and
  care team meetings with families are key components of high-quality care
  coordination for CYSHCN. Care mapping is not only useful in providing care
  coordination services but can also support a family-centered approach to
  system-level discussions, as used in Oregon. Shared plans of care are also a
  useful tool to support a family-centered approach to care coordination. In **Ohio**,
  Cincinnati Children's Hospital Medical Center requires that each shared plan
  of care include at least one patient-directed goal to support a family-centered
  approach. While care team meetings are critical, coordinating schedules and
  locations across team members remains a challenge. Increasing the use of
  telecommunication and leveraging the shared plan of care can alleviate these
  barriers. For example, **Virginia's** state Medicaid agency revised its model
  of care for its managed care program to allow for flexibility and electronic
  communication across the team. Additionally, a revised care plan is distributed
  following each meeting, which provides essential updates to any care team
  members unable to attend.

Supporting a Family-Centered Workforce

Titles, training, licensure requirements, and the scope of services that care coordinators
provide for CYSHCN vary widely both across and within states. These factors may
impact the quality of services that CYSHCN and their families receive. State health
officials and child health stakeholders can increase access to high-quality care
coordination by supporting the care coordination workforce. Related strategies and
approaches discussed during the forum include:

- **Assessing and revising licensure requirements for care coordinators.**
  Forum participants noted that licensure requirements are not always necessary
  for care coordinators to provide high-quality services for CYSHCN but may
  create barriers to entry into the care coordination workforce. People with lived
  experience in particular may be apt for the care coordinator role whether or
  not they have an advanced degree. To reduce these barriers, state health
  officials and other stakeholders can consider creating opportunities for those
  without licenses to be reimbursed for care coordination services. For example,
  Wisconsin's Complex Care Program is staffed by teams of care coordination
  assistants, who are not required to have a license, as well as registered nurses
  and physicians. The state Medicaid agency reimburses these providers through
  the state plan's targeted case management benefit.[24]

- **Recognizing families for the care coordination they provide.** Family caregivers of CYSHCN often provide care, including care coordination, that is uncompensated. Reimbursing family caregivers for the services they provide is one strategy available to states that can support families of CYSHCN in delivering high-quality, comprehensive care coordination while alleviating workforce shortages.[25] For example, in **Rhode Island**, parent consultants are paid as care coordinators for CYSHCN through Medicaid, governmental grants, and other sources, regardless of whether they have a license. Parent consultants are considered one type of community health worker in the state, which also includes peer recovery coaches, diabetes prevention coaches, and other types of professionals.

- **Supporting a diverse care coordination workforce. Ideally, the care coordination workforce reflects the diversity of CYSHCN.** State health officials and child health stakeholders can support efforts to recruit and retain care coordinators that have a variety of skills and experience. This may include medical expertise, language skills, community networking knowledge, and lived experience, among other types of qualifications. In **Rhode Island**, the Rhode Island Parent Information Network serves as an important resource for identifying family leaders and care coordinators who reflect the diversity of the CYSHCN population in the state.

Key Themes, Considerations, and Opportunities

In addition to the specific strategies described above, forum participants discussed several key considerations and opportunities to advance high-quality care coordination for CYSHCN. These include:

- **Expanding and sustaining innovations to support care coordination for CYSHCN.** One objective of the forum was to identify new strategies and innovations that state health officials and other child health stakeholders have implemented to advance the field of care coordination for CYSHCN. However, participants noted that, rather than additional innovative approaches, expanding and sustaining the use of established best practices such as those outlined in the NCCS would likely be more impactful to improving care coordination systems for CYSHCN. Federal, state, and local policymakers can consider how to facilitate the spread of existing approaches to improve care coordination systems for CYSHCN.

- **Increasing support for families of CYSHCN and people with lived experience.** The vast majority of discussion during the forum focused on, or included key consideration of, families of CYSHCN. While family-centered strategies and approaches have been implemented within many care

coordination systems, participants identified additional opportunities to support families at both the system and individual care levels. One key opportunity is to implement funding requirements and/or incentives that support family engagement in program design and monitoring. Care mapping was noted as a particularly underutilized resource to engage families and to inform system quality improvements. A second key opportunity is creating streamlined pathways for people with lived experience to become compensated as care coordinators, including modifying licensure and/or certification requirements as needed. Relatedly, the recruitment and hiring process for care coordinators can reflect the value of lived experience through job descriptions and competency requirements.

- **Aligning measurement, funding, and accountability with care coordination system quality improvement efforts.** Measurement and financing were raised as key mechanisms to improve care coordination systems for CYSHCN. One important opportunity is to implement value-based payments that require quality measurement focusing on integrated care and incentivize high-quality care coordination. This may be implemented through contract requirements, including managed care contracts and contracts between health plans and providers. Child health stakeholders can also consider braiding funding to incentivize cross-agency coordination and create joint accountability.

- **Strengthening cross-system communication and partnerships in tandem with advancing new technologies.** Participants noted that partnerships, communication, and trust are foundational to advancing high-quality, integrated care coordination systems for CYSHCN. While technology can be helpful to facilitate communication and information-sharing, barriers remain to maximizing its use. There are several opportunities to advance technology to support integrated care. Guidance and resources from the federal level could support improved information-sharing that aligns with privacy regulations across child-serving systems. Additionally, streamlining platforms at the federal, state, and/or local level for families to provide consent for sharing their protected health information would improve information-sharing capacity.

- **Improving equitable access to care coordination for CYSHCN.** As described in the NCCS, "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."[26] While states have made advances toward implementing high-quality care coordination systems for CYSHCN, sub-populations of CYSHCN face disproportionate access barriers. These sub-populations include CYSHCN of color, those who have more complex care needs, and those from low-income families, non-English-speaking families,

and rural regions. Participants noted the need for improvements in tracking demographic data, which would allow for a better understanding of disparities across sub-populations of CYSHCN and a stronger focus on health equity.

- **Leveraging opportunities arising from the COVID-19 pandemic.** The COVID-19 pandemic has led to various challenges in providing care coordination for CYSHCN, as well as new opportunities to improve care coordination systems. The increased use of telehealth and telecommunication has allowed for greater flexibility for families and providers to connect, though barriers remain for families that lack technology and internet access. Additionally, many states implemented flexibilities during the public health emergency (PHE) to allow family caregivers to be reimbursed through Medicaid for the services they provide, which may include care coordination.[27] With the impending unwinding of the PHE, some states are considering whether and how to extend this flexibility beyond the PHE.

Conclusion

State health officials and other child health stakeholders have made advancements in designing, implementing, and improving care coordination systems for CYSHCN. Integrated care delivery systems with high-quality care coordination and the care coordination workforce are two essential topic areas for moving the field forward. Participants in the forum identified various strategies and innovations to support high-quality care coordination systems for CYSHCN but noted that disseminating and scaling up existing best practices may be even more important to these efforts. Partnering with families and other child health stakeholders, as well as aligning approaches with funding and quality measurement, were also identified as critical to this work. For additional guidance, see the NCCS[28], as well as the companion resources, the NCCS "Implementation Guide"[29], "Medicaid Financing of Care Coordination Services for CYSHCN"[30], and "Aligning Quality Measures with the National Care Coordination Standards for CYSHCN"[31].

Appendix A – National Forum Agenda

National Academy for State Health Policy (NASHP)

**National Forum on Advancing High-Quality, Equitable Care Coordination
for Children and Youth with Special Health Care Needs**

Tuesday June 7, 2022 | 1–5 p.m. ET

Meeting Objectives

- Discuss innovations, strategies, and models to advance and improve high-quality, equitable care coordination for children and youth with special health care needs (CYSHCN) through advancements in integrated care and workforce development

- Develop recommendations for advancing high-quality, equitable care coordination for CYSHCN at the federal, state, and community level

- Review and reflect on progress in advancing and sustaining the "National Standards for CYSHCN (NSC)" and the "National Care Coordination Standards for CYSHCN"

Time	Event
1–1:30 p.m.	**Welcome, Introductions, and Review of the Agenda** *Karen VanLandeghem, Senior Program Director, NASHP* *Holly Henry, Program Director, Lucile Packard Foundation for Children's Health*

1:30–1:50 p.m.	**Ensuring and Sustaining a Workforce for High-Quality, Equitable Care Coordination**
	Presenter (10 minutes)
	  • *Deb Garneau, Director, Health Equity Institute, Maternal and Child Health/ Special Needs Director, Rhode Island Department of Health*
	Reactants (3–4 minutes each)
	  • *Adenike Chon, Waiver Manager, Partners in Community Supports, Connected Volunteer Support Parent, Family Voices of Minnesota*
	  • *Mary Daymont, Vice President of Revenue Cycle and Care Management, Children's National Health System*
	  • *Amy Zapata, Director, Bureau of Family Health, Louisiana Department of Health*
	
	This session will focus on innovations, strategies, and new models and approaches to ensure and sustain a workforce that advances high-quality, equitable care coordination for CYSCHN. A brief presentation will be followed by comments from two to three National Work Group reactants. This includes:
	• Training to support a range of roles/responsibilities, including for families
	• Expanding the care coordination workforce to meet the needs of CYSHCN
	• Strategies and approaches to avoid duplicative care coordination for CYSHCN
	• Consolidation of care coordination across child-serving agencies

Time	Event
1:50–2:35 p.m.	**Care Coordination Workforce Group Discussion Breakouts** During this session, participants will be divided into three groups to discuss key components and strategies to advance integrated care coordination for CYSHCN. Each group will include a facilitator and identify a reporter who will share key takeaways from the discussion. Each group will focus on one of the following topics and discussion questions: **1. Training** a. What innovative strategies are being used to design and implement training… i. For care coordinators for CYSHCN? ii. For providers who work with care coordination staff? iii. For families of CYSHCN? b. What are key considerations and opportunities to incorporate health equity into training for care coordinators and families? c. What additional policies, guidance, and/or resources are needed to improve training for care coordinators and families? **2. Expanding the care coordination workforce** a. What innovative strategies are being implemented to expand the care coordination workforce through … i. Recruitment and retainment efforts? ii. Modifying provider qualifications and credentials? iii. Telehealth? iv. Financing approaches? b. What are key considerations and opportunities to support a diverse care coordination workforce and equity in access and service quality for CYSHCN? c. What additional policies, guidance, and/or resources are needed to improve efforts to expand the care coordination workforce? **3. Avoiding duplication** a. What innovative strategies are being implemented to avoid duplicative care coordination services and providers for families (i.e., "coordinating the coordinators")? i. Within programs? ii. Within the medical system? iii. Across child-serving systems? b. What are key considerations and opportunities to incorporate health equity into strategies that avoid duplicative care coordination? c. What additional policies, guidance, and/or resources are needed to avoid duplicative care coordination services?
2:35–2:50 p.m.	**Review of Key Takeaways from Care Coordination Workforce Breakout Discussions** *Karen VanLandeghem* Each group's designated reporter will highlight key takeaways from the discussion.

Time	Event
2:50– 3 p.m.	**(Break)**
3–3:20 p.m.	**Advancements in Integrated Care and Implications for High-Quality, Equitable Care Coordination** *Presenter (10 minutes)* • *Colleen Reuland, Director, Oregon Pediatric Improvement Partnership* *Reactants (3–4 minutes each)* • *Cara Coleman, Director of Public Policy and Advocacy, Family Voices* • *Jennifer Kyle, Vice President Product Strategy, Special Needs Initiative, UnitedHealthcare* This interactive session will focus on innovations, strategies, and new models and approaches for improving how care is integrated across primary care, behavioral health, and other child-serving systems and the role of high-quality, equitable care coordination. A brief presentation will be followed by comments from three National Work Group reactants. This includes: • Interdisciplinary, cross-team communication practices • Family-centered approaches and considerations • Strategies for integrating care across child-serving systems to support CYSHCN
3:20–4:05 p.m.	**Integrated Care Group Discussion Breakouts** During this session, participants will be divided into three groups to discuss key components and strategies to advance integrated care and the role of high-quality, equitable care coordination for CYSHCN. Each group will include a facilitator and identify a reporter who will share key takeaways from the discussion. Each group will focus on one of the following topics and discussion questions: 1. **Interdisciplinary team-based communication** a. What innovative strategies are being implemented to support interdisciplinary cross-team communication through … i. Personnel roles, structures, and processes? ii. Technology? iii. Data and information-sharing? iv. Financing approaches? v. Shared decision-making and care planning? b. What are key considerations and opportunities for communicating and providing team-based care coordination for CYSHCN with providers that support social determinants of health? c. What additional policies, guidance, and/or resources are needed to advance team-based communication?

Time	Event

(continued)
3:20–4:05 p.m.
	2. Family engagement and partnerships
	    a. What innovative strategies are being implemented to support families as partners in care coordination for CYSHCN …
	        i. As a member of their child's care team?
	        ii. As peer support professionals?
	        iii. As a partner in design and implementation of integrated care coordination systems?
	    b. What are key considerations and opportunities to incorporate health equity into partnerships with families?
	    c. What additional policies, guidance, and/or resources are needed to improve family partnerships through integrated care coordination?
	3. Strategies for integrating care coordination across child-serving systems
	    a. What innovative strategies are being implemented to integrate care coordination across child-serving systems through …
	        i. Partnerships and collaborations?
	        ii. Alignment of screening and assessment?
	        iii. Financing strategies?
	    b. What are key considerations and opportunities to incorporating health equity into integrated care coordination systems?
	    c. What additional policies, guidance, and/or resources are needed to improve integrated care coordination across child-serving systems?

4:05–4:20 p.m.	**Review of Key Takeaways from Integrated Care Breakout Discussions** *Karen VanLandeghem* Each group's designated reporter will highlight key takeaways from the discussion.
4:20–4:50 p.m.	**Review and Discuss Key Recommendations** *Karen VanLandeghem* Facilitators will briefly review key recommendations highlighted during the presentations and discussions on integrated care coordination and workforce. Participants will then be asked to provide input on "what more is needed" beyond these topics to advance care coordination for CYSHCN.
4:50–5 p.m.	**Closing Remarks and Next Steps** *Karen VanLandeghem*

Appendix B – National Forum Participant List

Rishi Agrawal Lurie Children's Hospital, Northwestern School of Medicine	**Lia Jacobsen** Substance Abuse and Mental Health Services Administration
Richard Antonelli Boston Children's Hospital	**Dennis Kuo** University of Buffalo, Jacobs School of Medicine and Biomedical Sciences
Kayzy Bigler Kansas Department of Health and Environment	**Jennifer Kyle** UnitedHealthcare
Christina Boothby American Academy of Pediatrics	**Carolyn Langer** UMass Chan Medical School, Harvard School of Public Health
Jeffrey Brosco Florida Department of Health	**Eric Levey** The HSC Health Care System, Washington DC
Sandra Brown Virginia Department of Medical Assistance Services	**Ellen Marie-Whelan** Center for Medicaid and CHIP Services
Allegra Burrell Children's National Medical Center	**Margaret McManus** The National Alliance to Advance Adolescent Health
Susan Chacon New Mexico Department of Health	**John Morehous** University of Cincinnati College of Medicine
Adenike Chon Family Representative	**Molly Paul** Medical College of Wisconsin
Paul Chung Kaiser Permanente School of Medicine, UCLA	**Colleen Reuland** Oregon Pediatric Improvement Partnership
Cara Coleman Family Voices	**Heather Smith** Kansas Department of Health and Environment
Meg Comeau The Catalyst Center at Boston University	**Colleen Sonosky** Department of Health Care Finance, Washington, DC
Mary Daymont Children's National Health System	**Kate Taft** Association of Maternal and Child Health Programs
Deborah Garneau Rhode Island Department of Health	**Renee Turchi** Drexel University College of Medicine and School of Public Health
Holly Henry Lucile Packard Foundation for Children's Health	**Amy Zapata** Louisiana Department of Health

Endnotes

1 Breckenridge, Ellen D, Kite, Bobbie, Wells, Rebecca, and Sunbury, Tenaya M, "Effect of Patient Care Coordination on Hospital Encounters and Related Costs," *Population Health Management* 2019 October, 22(5): 406-414, https://pubmed.ncbi.nlm.nih.gov/30648928; Frandsen, Brigham R, Joynt, Karen E, Rebitzer, James B, and Jha, Ashish K, "Care fragmentation, quality, and costs among chronically ill patients," *American Journal of Managed Care* 2015 May, 21(5): 355-62, https://pubmed.ncbi.nlm.nih.gov/26167702.

2 Abdi, Fadumo M., Seok, Deborah, Murphey, David, "Children with special health care needs face challenges accessing information, support, and services," *Child Trends,* February 2020, www.childtrends.org/wp-content/uploads/2020/02/CYSHCN-Brief_ChildTrends_February2020.pdf; Toomey, Sara L., Chien, Alyna T., Elliott, Marc N., Ratner, Jessica, Schuster, Mark A., "Disparities in Unmet Need for Care Coordination: The National Survey of Children's Health," *Pediatrics* 2013, 131(2): 217-224, https://publications.aap.org/pediatrics/article-abstract/131/2/217/31891/Disparities-in-Unmet-Need-for-Care-Coordination?redirectedFrom=fulltext?autologincheck=redirected.

3 Porterfield, Shirley L and McBride, Timothy D, "The Effect of Poverty and Caregiver Education on Perceived Need and Access to Health Services Among Children with Special Health Care Needs," *American Journal of Public Health* 2007 February, https://ajph.aphapublications.org/doi/full/10.2105/AJPH.2004.055921.

4 Skinner, Asheley Cockrell and Slifkin, Rebecca T, "Rural/urban differences in barriers to and burden of care for children with special health care needs," *Journal of Rural Health* Spring 2007, 23(2): 150-7, https://pubmed.ncbi.nlm.nih.gov/17397371.

5 Kuo, Dennis Z, et al., "Inequities in Health Care Needs for Children with Medical Complexity," *Health Affairs* December 2014, 33(2), www.healthaffairs.org/doi/full/10.1377/hlthaff.2014.0273.

6 Abdi, Fadumo M., Seok, Deborah, Murphey, David, "Children with special health care needs face challenges accessing information, support, and services," *Child Trends,* February 2020, www.childtrends.org/wp-content/uploads/2020/02/CYSHCN-Brief_ChildTrends_February2020.pdf.

7 Child and Adolescent Health Measurement Initiative, 2019–2020 National Survey of Children's Health data query, Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, accessed July 2022, www.childhealthdata.org; Williams, Elizabeth and Musumeci, MaryBeth, "Children with Special Health Care Needs: Coverage, Affordability, and HCBS Access," *Kaiser Family Foundation,* October 4, 2021, www.kff.org/medicaid/issue-brief/children-with-special-health-care-needs-coverage-affordability-and-hcbs-access.

8 Antonelli RC, McAllister JW, Popp J. Making Care Coordination a Critical Component of the Pediatric Health System: A Multidisciplinary Framework. New York, New York: The Commonwealth Fund; 2009; Council on Children with Disabilities and Medical Home Implementation Project Advisory Committee. Patientand family-centered care coordination: a framework for integrating care for children and youth across multiple systems. *Pediatrics*. 2014;133(5); "Care Coordination Measures Atlas Update," Agency for Healthcare Research and Quality, June 2014, www.ahrq.gov/professionals/prevention-chronic-care/improve/coordination/atlas2014/chapter2.html.

9 The National Academy for State Health Policy, "The National Care Coordination Standards for Children and Youth with Special Health Care Needs (CYSHCN)," October 2020, www.nashp.org/national-care-coordination-standards-for-children-and-youth-with-special-health-care-needs.

10 Association of Maternal and Child Health Programs, the National Academy for State Health Policy, and the Lucile Packard Foundation for Children's Health, "National Standards for Systems of Care for Children and Youth with Special Health Care Needs, Version 2.0," June 22, 2017, www.lpfch.org/publication/standards-systems-care-children-and-youth-special-health-care-needs-version-20.

11 Goodwin, Nick, "Understanding Integrated Care," *International Journal of Integrated Care,* 2016 October-December, 16(4): 6, doi: 10.5334/ijic.2530.

12 Innovation Center, "Integrated Care for Kids (InCK) Model," Centers for Medicare & Medicaid Services, https://innovation.cms.gov/innovation-models/integrated-care-for-kids-model.

13 The National Academy for State Health Policy, "The National Care Coordination Standards for Children and Youth with Special Health Care Needs (CYSHCN)," October 2020, www.nashp.org/national-care-coordination-standards-for-children-and-youth-with-special-health-care-needs.

14 Dunklee, Brady, "Community Health Workers in Rhode Island: Sustaining a growing public health workforce in the pandemic and beyond," Rhode Island Department of Health, January 2021, https://health.ri.gov/publications/reports/2021CommunityHealthWorkersInRhodeIsland.pdf.

15 Center for Medicaid & CHIP Services, Centers for Medicare & Medicaid Services, Department of Health and Human Services, "Rhode Island State Plan Amendment (SPA) 21-0012," www.medicaid.gov/medicaid/spa/downloads/RI-21-0012.pdf.

16 Kansas Division of Public Health, "Bridges: Bridging Services for Children & Families," Kansas Department of Health and Environment, accessed July 2022, www.kdhe.ks.gov/DocumentCenter/View/6162/Bridges-Information-PDF.

17 Kretzmann, J. and McKnight, J, "Discovering Community Power: A Guide to Mobilizing Local Assets and Your Organization's Capacity," Asset-Based Community Development Institute, School of Education and Social Policy, Northwestern University, 2005, https://wlcvs.org/wp-content/uploads/2015/07/ABCD_and_organisations.pdf.

18 Dunklee, Brady, "Community Health Workers in Rhode Island: Sustaining a growing public health workforce in the pandemic and beyond," Rhode Island Department of Health, January 2021, https://health.ri.gov/publications/reports/2021CommunityHealthWorkersInRhodeIsland.pdf.

19 Chesapeake Regional Information System for Our Patients (CRISP), "CRISP," accessed July 2022, www.crisphealth.org.

20 Chesapeake Regional Information System for Our Patients (CRISP), "Connected Providers," accessed August 2022, www.crisphealth.org.

21 Children's Wisconsin, "Special Needs Program," accessed July 2022, https://childrenswi.org/medical-care/special-needs-services.

[22] Antonelli, Richard C., Huth, Kathleen, Rosenberg, Hannah, and Bach, Ashley, "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.

[23] Children's Wisconsin, "Bridge to Independence," accessed July 2022, https://childrenswi.org/medical-care/special-needs-services/bridge-to-independence.

[24] Randi, Olivia and Gould, Zack, "Medicaid Financing of Care Coordination Services for Children and Youth with Special Health Care Needs (CYSHCN)," National Academy for State Health Policy, July 2022, www.nashp.org/wp-content/uploads/2022/06/NASHP_CYSHCN_July2022.pdf.

[25] Randi, Olivia, Girmash, Eskedar, Honsberger, Kate, "State Approaches to Reimbursing Family Caregivers of Children and Youth with Special Health Care Needs through Medicaid," National Academy for State Health Policy, January 2021, www.nashp.org/wp-content/uploads/2021/01/Family-Caregivers-for-CYSHCN-PDF-1-15-2021.pdf.

[26] The National Academy for State Health Policy, "The National Care Coordination Standards for Children and Youth with Special Health Care Needs (CYSHCN)," October 2020, www.nashp.org/national-care-coordination-standards-for-children-and-youth-with-special-health-care-needs.

[27] The National Academy for State Health Policy, "States Use Appendix K and Emergency Waivers to Support Home- and Community-Based Services in Response to COVID-19," updated May 22, 2022, www.nashp.org/states-use-appendix-k-waivers-to-support-home-and-community-based-services-in-response-to-covid-19; The National Academy for State Health Policy, "Map: ARPA Initial Plan Proposed Supports for Family Caregivers," updated December 23, 2021, www.nashp.org/map-arpa-initial-plan-proposed-supports-for-family-caregivers.

[28] The National Academy for State Health Policy, "The National Care Coordination Standards for Children and Youth with Special Health Care Needs (CYSHCN)," October 2020, www.nashp.org/national-care-coordination-standards-for-children-and-youth-with-special-health-care-needs.

[29] Randi, Olivia, Gould, Zack, and Honsberger, Kate, "The National Care Coordination Standards for Children and Youth with Special Health Care Needs (CYSHCN)," The National Academy for State Health Policy, June 2022, www.nashp.org/national-care-coordination-standards-for-children-and-youth-with-special-health-care-needs-cyshcn-implementation-guide.

[30] Randi, Olivia and Gould, Zack, "Medicaid Financing of Care Coordination Services for Children and Youth with Special Health Care Needs (CYSHCN)," National Academy for State Health Policy, July 2022, www.nashp.org/wp-content/uploads/2022/06/NASHP_CYSHCN_July2022.pdf.

[31] Girmash, Eskedar and Honsberger, Kate, "Aligning Quality Measures with the National Care Coordination Standards for Children and Youth with Special Health Care Needs (CYSHCN)," National Academy for State Health Policy, June 2022, www.nashp.org/aligning-quality-measures-with-the-national-care-coordination-standards-cyshcn.

Contributing Author

Olivia Randi