Executive Summary

Children and youth with special health care needs (CYSHCN) and their families often use numerous systems, such as, education, health care, social services, and respite care, and require multiple providers, prescriptions, and home and community-based services and supports, which makes care coordination essential to a child’s health and quality of life. Care coordination can help facilitate access to medical and social services across a variety of systems to avoid duplication of services and unnecessary costs and improve outcomes for CYSHCN.¹

State Medicaid agencies are strengthening care coordination programs as part of their health care delivery transformation efforts to improve health care quality and outcomes and reduce costs. States are increasingly enrolling CYSHCN into their Medicaid managed care delivery systems.² As this shift occurs, it is critical to identify how managed care systems provide effective care coordination to CYSHCN. Care coordination can help managed care organizations (MCOs) make sure children’s needs are met through an organized, responsive, family-centered system of care. This requires a streamlined system that effectively identifies and screens CYSHCN, shares information, and measures care coordination quality.

This National Academy for State Health Policy (NASHP) issue brief describes how six states (Arizona, Colorado, Minnesota, Ohio, Texas, and Virginia) provide care coordination in their Medicaid managed care systems and partner with key stakeholders, such as state Title V CYSHCN programs, to meet the unique needs of their CYSHCN. NASHP found that while there is variation in the MCOs systems states have implemented, there are many common approaches to how they provide care coordination. State Medicaid agencies have focused on several strategies including, using risk assessments to set a baseline determination for care coordination need for newly-enrolled children, identifying the qualifications of care coordinators, and setting minimum standards for reaching out to enrollees to coordinate their care. States use a variety of Medicaid funding options to pay for care coordination within managed care and in some cases have established quality measures for care coordination.

States interested in improving care coordination services that CYSHCN receive through Medicaid managed care may consider these strategies:

- **Develop a standard approach to risk assessment and risk assignment** to ensure consistency across MCOs so MCOs and providers do not have to develop their own risk assessment methods.
- **Encourage or require MCOs to enter into agreements** with community-based providers to share data about enrollees or coordinate services to support coordination of care and establish trust with families who have longstanding relationships with these providers.
- **Require MCOs to designate a specific care coordinator** within the MCO for each individual child in order so families know whom to call with problems and questions. In addition, families would benefit from clear information from MCOs about the availability of and services provided
by care coordinators.

- **Establish tools, policies, and systems to facilitate information sharing among providers** to support care coordination. These approaches include shared plans of care, which can help families and providers better coordinate care; universal referral forms to reduce some of the administrative burden when connecting children with services and supports; and procedures for ensuring that referrals are successful and results are communicated back to the referring provider.

- **Leverage existing quality measures** to monitor and assess the impact of care coordination. Several validated and reliable measures for care coordination exist, such as those included in the Family Experience with Care Coordination survey.

## Introduction

More than 20 percent of all US children ages birth to 18 years (14 million children) have a chronic and/or complex physical, developmental, behavioral, or emotional condition (e.g., asthma, diabetes, spina bifida) requiring health care services and supports beyond what children require normally. A smaller but increasing group of children have complex medical conditions that require the highest levels of services. There are an estimated 3 million children – about 4 percent of all children -- with medical complexity in the United States.  

Care coordination can help facilitate access to medical and social services across a variety of systems, avoiding duplication of services and unnecessary costs, and improving outcomes for CYSHCN. The most effective care coordination is patient- and family-centered and comprehensive, emphasizing cross-system relationships and enhancing skills and capabilities of the child and family. Care coordination activities typically include conducting a needs assessment, developing care plans for the child and family, facilitating communication among providers, and managing and tracking referrals and outcomes. Comprehensive care coordination can be an intensive service and may not be available, or necessary, for all children or even all CYSHCN. Care coordination is most appropriate for those using multiple services and/or with recent or frequent hospitalizations and costly care.

Medicaid and the Children’s Health Insurance Program (CHIP) play a prominent role in providing coverage for CYSHCN, insuring 44 percent of all CYSHCN in 2009-2010. Approximately two-thirds of children with medical complexity are enrolled in Medicaid, with many eligible for Medicaid due to their disabilities or medical conditions. State Medicaid agencies are strengthening care coordination programs as part of their health care delivery transformation efforts to improve health care quality and outcomes and reduce health care costs. A recent NASHP nationwide analysis found 47 states and Washington, DC, now use some form of managed care to serve all or some children and adults enrolled in Medicaid today. Of states with managed care delivery systems, all enroll at least some of their CYSHCN into some type of Medicaid managed care. Most enrollment is in risk-based managed care, where the MCO assumes financial risk. The recent Medicaid and CHIP Managed Care Final Rule issued by the Centers for Medicare & Medicaid Services (CMS) in April 2016 underscores the importance of care coordination. It requires that enrollees in managed care have access to the care they need, regardless of its source, and that care be coordinated across settings, orchestrating services provided outside the MCO and by community and support service providers.

Care coordination can help MCOs meet the needs of children through an organized, responsive, and family-centered system of care. This requires a system of identification, risk screening, information sharing, and measurement of care coordination quality, which state Medicaid agencies have designed
structuring care coordination services for children and youth with special health care needs in medicaid managed care

in various ways.

eligibility and risk screening

under medicaid managed care, MCOs are responsible for identifying those enrollees at highest risk of adverse health outcomes and in greatest need of care coordination. In states, such as Minnesota and Ohio, where CYSHCN are integrated into standard managed care plans, the plans generally use an algorithm, which is a set of well-defined rules or procedures, based on utilization data or other identifiers (such as a history of foster care) to identify children who are at highest risk and should receive care coordination. The specialized managed care plans may use risk screening to stratify children based on their level of need, with those with the highest level of need receiving the most intensive level of coordination. This is the case in Arizona, for example, where all children eligible for the Children’s Rehabilitative Services program are enrolled in a single, specialized managed care plan. The MCO uses a risk stratification tool based on claims data to identify and refer children who are in need of high-risk care coordinators.

After this initial screen, MCOs typically conduct a needs assessment to better identify the needs of each enrollee and his or her family. These screens may be conducted over the phone or in-person, and may use a standard form developed collaboratively by the state Medicaid agency and MCO (as in Ohio) or a form developed by each MCO (as in Minnesota). Some states use screening forms specifically tailored to CYSHCN:

- **Ohio**’s Pediatric Needs Assessment, for example, is a 26-question form covering children’s needs and diagnoses, use of medications and hospitalization, mental health, and use of community services.
- **Texas** STAR Kids program, a specialized managed care program for children and youth with disabilities and complex conditions, uses a 40-page screening and assessment form to identify the child’s living situation and existing support services, goals for care, diagnoses, health care utilization history and medications, mental health concerns, current treatment plan, functional status, and need for nursing care. The form also assesses parental concerns and challenges faced by the caregivers.

Colorado, while not a fully capitated system, utilizes an accountable care model under which health plans, called Regional Care Collaborative Organizations (RCCOs), are required to coordinate care for...
enrollees. One RCCO uses a two-page general survey for all children and adults enrolled in Medicaid to assess the enrollee’s health status and potential care coordination needs. The survey asks about specific health conditions (e.g., asthma, diabetes, high blood pressure, mental health condition, or other conditions); whether the enrollee needs help managing the condition; hospitalizations and emergency department use in the past 12 months; need for housing or food assistance; whether the family has a child with special health care needs; concerns about the child’s growth and development; and health goals for the year.

Based on initial screens, MCOs typically assign children to levels of risk and intensity of care coordination needed, and a care plan is developed. Texas uses three levels or tiers to identify levels of need, while one Colorado health plan utilizes four levels. Stratifying children into different tiers for the purpose of care coordination helps to ensure that the level of care coordination matches the enrollee’s needs and condition. The tiered system in Colorado is designed with the following goals:

- At four, the highest level of need, the focus is on improving quality of life;
- At level three, the focus is on self-management and preventing emergency department visits, and addressing the social determinants and mental health needs that allow children to move down to level two.

**Provision of Care Coordination Services**

Generally, states contractually require MCOs to provide care coordination for their high-risk enrollees. However, in some states, MCOs may delegate the provision of care coordination to provider entities such as medical homes or accountable care organizations (ACOs), or they contract with community agencies to provide care coordination. In Texas and Virginia, MCOs take the lead in providing care coordination, while in Colorado and Minnesota, health plans provide care coordination or they contract with provider entities (ACOs in Minnesota and medical homes in Colorado). In Ohio, comprehensive primary care practices may also provide care coordination. These practices take the lead in providing care coordination for members enrolled in managed care. In Minnesota, an MCO is developing contracts with Federally Qualified Health Centers and other community agencies that provide care coordination to their patients so as not to duplicate services. Arizona’s multi-specialty interdisciplinary clinics, which were established to meet the needs of children in the Children’s Rehabilitative Services (CRS) program, are responsible for coordinating their enrollees’ care.

How care is coordinated and by whom – MCOs or provider entities – are important considerations for state Medicaid programs, as designation of the coordinating entity has significant implications for the delivery of care coordination services. In Ohio, for example, when the hospital-based ACO provides care coordination for its enrollees, the coordinator attends rounds with physicians and can be present at medical appointments. In Virginia, an MCO is experimenting with embedding care coordinators in physician offices in order to bring coordination closer to the patients. In these innovative practices, MCOs report that patient outcomes are improving.

In general, care coordinators within an MCO are generally nurses or social workers, depending on the primary needs of the child. Colorado’s model allows for flexibility in the type of professional providing care coordination services at the local level, and some MCOs have implemented multidisciplinary models to include medical assistants, social workers, and counselors. Ohio’s ACO includes a quality outreach coordinator in its care coordination team -- a community health worker who conducts home visits and provides transportation and logistical support to make sure enrollees can keep their appointments.
Care Coordination Across Systems

One of the major challenges of coordinating the care of CYSHCN is coordinating the diverse range of medical and community-based support services across systems, including education and early intervention services, long-term services and supports, and other community-based supports. The integration of services including physical health, behavioral health, and support services -- a strategy increasingly used in state Medicaid programs -- can result in one entity coordinating services that were previously provided across several systems. Arizona, for example, is integrating physical and behavioral health care into a single managed care plan under a recent Section 1115 Medicaid demonstration waiver, and Virginia is integrating physical, behavioral, and long-term care services for CYSHCN under its CCC Plus program.

In systems that are not yet fully integrated, MCOs and state agencies use a number of strategies to facilitate coordination across systems. In Arizona, for example, an MCO that serves CYSHCN meets monthly with the state’s Division of Developmental Disabilities to review individuals who are enrolled in both programs for better coordination of their care. In Virginia, the services provided outside of the managed care system that each member uses are identified during the assessment process. The care coordinator then requests permission from the family to contact the relevant agencies to coordinate services. One MCO also employs “community relations liaisons” to network with community agencies that may provide services that members need. In New Jersey, the Title V CYSHCN program helps to link families with resources and facilitates information-sharing across systems, as the care coordinators within the managed care plans do not have a formal lead care coordinator role.

The ability to share information between providers and across the myriad of systems that serve CYSHCN is critical to coordinating care. In Arizona, the state Medicaid agency contractually requires MCOs to participate in the statewide Health Information Exchange (HIE) and to encourage providers to use the HIE to support care coordination. To this end, providers within the system share a common electronic medical record and the clinics that serve CYSHCN submit data to the HIE. In Ohio, the hospital-based ACO has an electronic medical record that is shared with providers outside of the hospital system as well, and an MCO in Texas has developed an online platform to share data and document communication. In Minnesota, enrollees are asked to sign releases to share information with providers outside of the managed care network as part of their consent to care management. Other states have taken different approaches. In Virginia, for example, the MCO’s care coordinator requests permission from the parent to contact other agencies involved with the child’s care.

Additionally, CYSHCN may receive services from programs, such as Part C Early Intervention programs, schools (e.g., special education programs), and Medicaid waiver programs that also provide care coordination. In these cases, the MCO must be notified not only about the services the enrollee is receiving, but also about care coordinators from whom they receive support. Many states address this...
challenge by designating the MCO’s care coordinator as the “lead care coordinator,” responsible for coordinating all services and orchestrating the care coordinators that other systems may employ as well. However, in some states, such as Colorado and Virginia, the family may choose a lead care coordinator from another source outside of the MCO.

Quality Measurement
Few states have quality measures specifically focused on assessing the effectiveness of care coordination. On the national level, these measures are emerging, and a wide range of measures have been catalogued by the Agency for Healthcare Research and Quality in its Care Coordination Measures Atlas. Measures that specifically address care coordination for CYSHCN include:

- Boston Children Hospital’s Care Coordination Measurement Tool;
- University of Colorado Denver’s Care Transitions Measure;
- Family Voices’ Family-Centered Care Self-Assessment Tool;
- Institute for Child Health Policy’s Care Coordination Services in Pediatric Practices survey; and
- Primary Care Questionnaire for Complex Pediatric Patients.13

In addition, since the publication of the atlas, the Family Experiences with Care Coordination measure set, which focuses on care coordination for children with complex needs, was released.14

In spite of the lack of measures, many MCOs and providers monitor the outcomes of care coordination for children in their care. The Partners for Kids ACO in Ohio provides care coordination to Medicaid-enrolled children whose MCOs have delegated their care coordination to the ACO. The ACO monitors the provision and effectiveness of care coordination closely, using both process measures (e.g., frequency of contact with care coordinators, the completion of assessment forms and the quality of the data, location of visits, and the level of engagement of the patient and family) and outcome measures (e.g., emergency department use, length of stay for admitted patients, readmissions, and surveys of patient satisfaction and engagement).

These measures are shared with the Medicaid agency and the MCOs that enroll the children. In addition, specific clinics have been asked to select an outcome indicator that is meaningful for their particular clinical area, such as patient BMI for the weight management clinic, or the completion of developmental screens for children in the neonatology clinic. Finally, the program recently conducted an evaluation of its care coordination program that examined changes in inpatient admissions, length of stay, 30-day readmissions, and emergency department use for program enrollees before and after enrollment. The study found significant reductions in inpatient admissions, bed days, and 30-day readmissions for children who received care coordination.15

Arizona’s multi-specialty interdisciplinary clinics in Phoenix and Tucson that serve CYSHCN have value-based payment agreements with their MCOs that are based on standard quality measures. In Colorado, RCCOs receive a per-member-per-month payment for providing care coordination. While the state does not use a statewide measure related to care coordination, one RCCO monitors process measures for their care coordinators, including number of clients served and the completeness of their records. In addition, an MCO in Virginia uses the 12-question, SF-12 survey to assess CYSHCN’s quality of life before, during, and after enrollment in a disease management program.
How State Medicaid Agencies Finance Care Coordination

State Medicaid programs support care coordination through a variety of financing mechanisms. The most common source for care coordination for children is through administrative case management under Early and Periodic Screening, Diagnosis, and Treatment (EPSDT), the Medicaid benefit that provides comprehensive and preventive health care services for children under age 21. Administrative case management may include activities such as informing eligible families about EPSDT; providing or arranging for screening services; arranging for assessment and follow-up (either directly or through referral); and arranging for transportation to services at clinics, schools, or other community settings.\(^{16}\)

In addition, states may establish programs under state plan amendments or waivers to provide care coordination under other vehicles. Options for providing care coordination under state plan amendments include:

- **Targeted case management.** This optional service allows states to provide care coordination services to specific, defined groups of enrollees, such as pregnant women, people with mental health conditions, or CYSHCN. Unlike administrative case management, which cannot be used to assist enrollees in accessing non-Medicaid services, targeted case management can be used to help enrollees access a broader range of services and supports to meet their care needs.

- **Section 2703 health homes.** This state plan amendment allows states to operate health homes that integrate physical, behavioral, and long-term care services, for enrollees with chronic conditions. Services required under this program include care coordination.

- **Voluntary managed care programs.** States may establish primary care case management (PCCM) or capitated managed care programs, which include care coordination services, under Section 1932(a) as a state plan amendment. For CYSHCN, enrollment under this authority must be voluntary.\(^{17}\)

Additionally, federal Medicaid waiver programs may include care coordination for eligible beneficiaries. Medicaid Section 1915(c) Home and Community-Based Services waivers allow states to provide long-term care services and supports at home and in the community to enrollees in need of institutional-level care, and these programs may include care coordination services. Medicaid Section 1915(b) waivers also allow for managed care programs for specific groups of enrollees or specific geographic areas, and Section 1115(a) Research and Demonstration waivers allow for statewide managed care programs. Both of these may include care coordination among their benefits.\(^{18}\)

Care coordination is generally included in the per-member-per-month capitation rate paid to MCOs. This financing strategy is used in Minnesota, Ohio, Virginia and Texas. In some states, this payment may then be passed on to subcontractors or delegated providers, such as ACOs or community agencies, on either a fee-for-service or capitation basis. For example, in Arizona where one MCO serves all children enrolled in the CRS program, the multi-specialty, interdisciplinary clinics that care for these children can bill the MCO for care coordination using a special code. In Ohio, when MCOs delegate care coordination for their enrollees to ACOs, this service is included in the capitation rate that the ACOs receive. Including care coordination in the capitation rate gives MCOs the flexibility to invest in care coordination at their discretion. However, a designated payment for care coordination has the appeal of directly covering the costs associated with this service, as was noted by some plans and providers. A provider in Minnesota
suggested that a separate payment for care coordination, ideally from both private- and public-sector payers, would allow them to invest in infrastructure, and a plan in Virginia also made this suggestion to better fund its “high-touch” model of intensive care coordination.

The overall impact of care coordination on health care costs is under study. Because care coordinators connect enrollees to services they might not otherwise have received and work to ensure that appointments are kept, care coordination has the potential to increase expenditures for care, both within and outside the MCO, in the short term. However, the potential for cost savings exists as well, due to reductions in length of hospital stays, readmissions, and emergency department use, allowing MCOs (or delegated providers) to benefit financially from care coordination.

## The Role of Title V and Families in Care Coordination

State Title V CYSHCN programs have a long history of providing care coordination to children and youth with special health care needs and this role is increasing as many states move away from providing direct health care services in favor of systems development, quality assurance, and policy development.

- **The Minnesota Title V CYSHCN program** has taken a leading role in this area with its Mapping Care Coordination effort. Using a Systems Integration Grant from the Maternal and Child Health Bureau of the Health Resources and Services Administration, the agency held stakeholder meetings in five regions to assess the strengths, weaknesses, redundancies, and gaps in care coordination systems across the state, and developed recommendations for a more rational, effective system.

- **The Colorado Care Coordination Collaborative (4C) project**, funded by the state Title V program, is a pilot initiative in one region of the state. One of the state’s health plans, a RCCO, is working together with the Department of Health Care Policy and Financing (the state Medicaid agency) and the local health department to support communication and collaboration between programs that provide care coordination for children and youth. The pilot has produced a data-sharing agreement between the RCCO and the local health department. The lessons learned from this effort were used to inform Title V medical home policy strategies that focus on CYSHCN.

- **The Virginia Department of Health and the Department of Medical Assistance Services (DMAS)**, the state Medicaid agency, are examining the provision and payment for care coordination, and how the two agencies can better coordinate and maximize their resources. DMAS officials participate in various meetings convened by the Title V program to better learn about the program’s leadership and Title V activities and ensure that their care coordination activities are aligned.

Title V may also maintain a role in providing care coordination to CYSHCN.

- **Virginia’s Title V program continues to coordinate care for specific groups of CYSHCN**, including children with sickle cell disease, bleeding disorders, and developmental and behavioral conditions. Additionally, Care Connection for Children, a program for CYSHCN funded by Title V,
serves children with a range of physical conditions through Centers of Excellence. If an enrolled child is also eligible for Medicaid, the Title V program works in partnership with the MCO’s care coordinator, but the family can designate one coordinator as the lead.

• In Ohio, the Bureau of Children with Medical Handicaps (BCMH) program provides treatment services and service coordination for children with specific physical conditions, such as cystic fibrosis, craniofacial anomalies, cancer, and hemophilia. To receive service coordination through BCMH, a child must be receiving treatment through a multidisciplinary team at a BCHM-approved hospital. However, if a BCMH-eligible child is also eligible for Medicaid, the MCO or comprehensive primary care practice will work with the child’s BCMH service coordinator.

• In New Jersey, the Title V program maintains case management units in each of the state’s 21 counties, which link families of CYSHCN with medical, educational, rehabilitative, developmental, and support services, including help with enrollment in Medicaid. The Title V case managers advise families about requesting a care coordinator from their MCOs.

Families also play a critical role in the coordination of their children’s care. MCOs and providers acknowledge the importance of the family on the care team, and states create various opportunities for families to be involved throughout the care coordination process. In Arizona, families are included in planning sessions between the MCO and the providers. MCOs in Minnesota, Ohio, and Virginia reported they include families on their care teams. In Ohio, families provide feedback and recommendations for improving care through participation on family advisory councils organized by MCOs. In Texas, providers serving people with disabilities are required to complete a training course in “person-centered planning” and family members are invited to participate in these trainings as well. In New Jersey, the Title V program has taken on the role of educating families as they make the transition to managed care and provide a brochure Finding Your Way Through Medicaid Managed Care that explains the program’s requirements and advises families about common problems and how to resolve them.

Opportunities to Strengthen Care Coordination in Medicaid Managed Care

The following strategies may be helpful as states examine ways to strengthen their care coordination within Medicaid managed care:

• Develop a standard approach to risk assessment and risk assignment to help ensure consistency across MCOs. This relieves MCOs and providers of the need to develop their own risk assessment methods, which can vary between practices. Identifying the needs of CYSHCN is crucial to effectively coordinate their care. Without a standard approach to assessing the needs of children, the quality of the care coordination provided by MCOs could vary.

• Encourage or require MCOs to enter into agreements with community-based providers to share data or orchestrate services to support coordination of care. Children and youth with special health care needs often receive services from a variety of providers, those covered by Medicaid and those covered by other sources. MCOs should receive information about the services children are receiving from community providers to most effectively coordinate their care.

• Require MCOs to designate a specific care coordinator within the MCO for each individual so families know whom to call with problems and to whom to turn first with questions. If a parent has a designated person to contact with questions or requests, that person is more likely to be familiar with a child’s care needs and be better equipped to coordinate care. In addition, families of CYSHCN benefit from having clear information from an MCO about the availability of and services provided by care coordinators so that they can be active partners with MCOs in the coordination of their child’s care.
Structuring Care Coordination Services for Children and Youth with Special Health Care Needs in Medicaid Managed Care

- Leverage existing quality measures to monitor and assess the impact of care coordination. Several validated and reliable measures for care coordination exist, such as those included in the Family Experience with Care Coordination survey. While quality measures for care coordination can be challenging for states to implement, they are critical to ensure that care coordination is meeting the needs of CYSHCN and their families and is leading to improved outcomes and quality of life.
- Establish tools, policies, and systems to facilitate information sharing among providers to support care coordination. Strategies for promoting seamless information-sharing can include tools such as shared plans of care, which can help families and providers collaborate and coordinate care; universal referral forms to reduce some of the administrative burden of connecting children with services and supports; and procedures to ensure referrals are successful and results are communicated back to the referring provider. Another key strategy is developing or securing the data and technology infrastructure that could support data sharing across providers and systems, which would enable care coordinators to better track and manage CYSHCN’s needs. However, this strategy represents a significant undertaking and requires substantial investments.

Conclusion

States are increasingly implementing managed care programs for CYSHCN to better organize complex health care systems, improve the quality and outcomes of care, and reduce costs. While states have taken a variety of approaches for delivering, financing, and assessing care coordination for CYSHCN within managed care, care coordination plays an essential role in these programs. Care coordinators oversee the system as a whole by developing comprehensive care plans; facilitating communication among providers; assisting with transportation and other supports so that appointments are kept; monitoring follow-up protocols to prevent emergency department visits or readmission; and generally assuring that children’s needs are met cost-effectively.

As care coordination programs evolve, state Medicaid agencies, MCOs, and providers are identifying and addressing the structural challenges inherent in these programs, including developing and sustaining community partnerships, involving families, establishing systems for information sharing, and measuring the effectiveness of care coordination.

Notes


17. Ibid.

18. Ibid.


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