State Strategies for Shared Plans of Care to Improve Care Coordination for Children and Youth with Special Health Care Needs

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Care coordination is an essential component of state efforts to transform health care systems and improve value and outcomes. When successfully implemented, it can improve care quality, reduce costs, and avoid fragmented and duplicative care,[1] especially among children and youth with special health care needs (CYSHCN). Care coordination has also been shown to improve health care utilization and family functioning and satisfaction, and reduce families' financial burden and unmet needs for services.[2]

As states work to provide quality care coordination for CYSHCN, adopting shared plans of care (SPoCs) can enhance patient- and family-centered care delivery and overcome barriers to controlling costs and ensuring quality. This issue brief by the National Academy for State Health Policy (NASHP) identifies approaches and strategies states can use to promote the use of SPoCs as a key component of care coordination for CYSHCN and their families. It also includes case studies showcasing the efforts of four states – Iowa, Oregon, Utah, and West Virginia – to implement SPoCs for CYSHCN.

Background

CYSHCN make up nearly 20 percent (14.6 million) of the US population up to age 18. Many CYSHCN require significant care coordination across physical health, behavioral health, early care and education, early intervention, education, community organizations, social services, and financial supports.[3,4] A subset of CYSHCN – children with medical complexity – are the smallest yet most rapidly growing population of these children, comprising approximately 0.5 percent of US children.[5] This subpopulation may have multiple ongoing medical and social needs requiring extensive care planning and care coordination, and they account for as much as one-third of all health care spending on children.[6]

States play a significant role in coordinating care for CYSHCN. In 2015, state Title V programs served nearly 4.2

What is pediatric care coordination?

Pediatric care coordination is a patient- and family-centered, assessment-driven, team-based activity designed to meet the needs of children and youth while enhancing the caregiving capabilities of families. Care coordination addresses interrelated medical, social, developmental, behavioral, educational, and financial needs in order to achieve optimal health and wellness outcomes.[7]

The benefits of providing care coordination to CYSHCN are widely recognized.[8] Care coordination reduces emergency department visits and hospitalizations, improves health outcomes, and improves families' experience with care.[9] Families of CYSHCN receiving care coordination also report lower financial burden, less impact on their employment, and fewer school absences.[10] In particular, children with medical complexity experience significant benefits from a team-based approach to care coordination, including decreases in hospitalizations and other unnecessary, high-cost health care visits.[11]

million CYSHCN with multiple states supporting care coordination services.[12] Nationally, Medicaid and the Children's Health Insurance Program (CHIP) provide health insurance to 48 percent of all CYSHCN, with variations in coverage across individual states ranging from 23 percent to 67 percent.[13] States are increasingly serving CYSHCN through Medicaid managed care delivery systems, and federal regulations require managed care organizations (MCOs) to assess the needs of CYSHCN and develop care plans for them. Yet, states can face significant barriers to providing quality care coordination to CYSHCN. Within a clinical care setting -- especially community-based provider practices -- access to well-organized care coordination services may be limited. Health care delivery systems are often fragmented and may lack mechanisms to coordinate services and supports for CYSHCN and their families. Inadequate financing and low or absent reimbursement rates for care coordination services can also impede efforts to provide quality care coordination.

To improve care coordination for CYSHCN, health care delivery systems are increasingly turning to the use of integrated health care teams, health information technology, and the development of an actionable, individual, and comprehensive plan of care, referred to as a shared plan of care (SPoC).[14,15] Preliminary research findings indicate using a SPoC within a care coordination model is a feasible and effective approach for managing the needs of CYSHCN, especially children with medical complexity, and improving family outcomes.[16] Several examples of SPoC templates developed and used by states are available.[17,18,19,20] Guided by the family and child's care team, a SPoC compiles both clinical and non-clinical information about a patient.[21] Continually reviewed and updated in partnership with the family, the document describes shared goals, negotiated actions, and assigns responsibility for overseeing the various activities to address the medical and non-medical needs of the child. The multiple providers engaged in providing services and supports, such as primary care, schools, mental health, and others, may be given access to the shared document, if permitted by the family.

Multiple federal and state agencies and programs have recognized the SPoC as a standard of care and an invaluable care coordination tool to support team-based and person- and family-centered care for both children and adults with complex or chronic health conditions.[22] The Centers for Medicare & Medicaid Services, Agency for Healthcare Research and Quality, and National Committee for Quality Assurance, for example, have all cited individualized shared care plans for Medicare and Medicaid beneficiaries as an essential ingredient for quality integrated care.[23,24,25] The National Standards for Systems of Care for CYSHCN, a core set of system standards for serving CYSHCN based on research and national consensus for use by national,

What are shared plans of care?

A shared plan of care (SPoC) is a living document created in partnership with the family and made available across systems that "includes the information necessary to assure issues affecting a child's health and health care are identified and that activities and accountability for addressing them are documented." The SPoC results from a family-centered, team-based process, involving families, clinicians, and coordinators. The goal of the document is to ensure that services provided are comprehensive, coordinated, and aligned with the CYSHCN's and family's identified needs, priorities, and goals. SPoC key components include:

- Medical summary (e.g., history, background, family preferences and strengths, treating providers, medications, immunizations, etc.), and child and family personal, educational, and social circumstances;
- Negotiated actions or plan of actions (e.g., family's personal and clinical goals, agreed-upon strategies, assignment of responsibilities, and anticipated timeline) based on a patient's, family's, and the provider/team's shared goals and identified strategies; and
- Other necessary materials, such as an emergency plan, legal documents, chronic condition protocols, or action plans.

Once created by the care team, the success of the SPoC rests on effective implementation. This requires that the document is, with the family's permission, shared with or available to all those involved in the care of the CYSHCN to ensure clear communication. Progress towards the goals is monitored, and the plan is regularly reviewed in partnership with the family and modified as needed.

Source: Jeanne W. McAllister, "Achieving a Shared plan of Care with Children and Youth with Special Health Care Needs," Lucile Packard Foundation for Children's Health, May 2014, https://www.lpfch.org/publication/achieving-shared-plan-care-children-and-youth-special-health-care-needs.

state and local stakeholders, includes the recommendation for SPoCs for CYSHCN.[26] A dozen State Title V Maternal and Child Health (MCH) Services Block Grant programs have also prioritized the creation of SPoCs for CYSHCN within their state plans.[27]

Opportunities to Promote Shared Plans of Care in State Health Care Delivery Transformation

Multiple states have adopted SPoCs as part of their efforts to improve coordination of care for CYSHCN and their families.[28] The types of SPoC models used and groups targeted vary across states. As health care systems increasingly work to implement more effective care coordination, state agencies and organizations have opportunities to incorporate SPoCs within new or existing health care reform efforts. SPoCs, for example, can be integrated into state patient-centered medical home (PCMH) initiatives, health home models, Medicaid managed care arrangements, Section 1115 waivers, and state accountable care organizations. The examples below describe several current state care coordination initiatives that either currently use SPoCs or can be adapted to implement SPoCs for CYSHCN.

State patient-centered medical homes. State PCMH initiatives prioritize comprehensive, coordinated, and whole-person care with patients and families functioning as core members of health care teams. To meet practice certification or credentialing requirements as a medical home, multiple states currently require the use of a comprehensive care plans created with the family.[29,30] Other states provide financial incentives, such as care management fees and performance-based payments, to support efforts to improve care coordination within medical homes.[31] These PCMH requirements and funding supports can be utilized to develop and use SPoCs for CYSHCN.

- **Arkansas's** Medicaid Health Care Payment Improvement Initiative, led by the state Medicaid agency, is working with two of the largest private payers to transition the state to a "patient-centered" health care system and ensure Arkansans have access to patient-centered medical homes. The initiative's use of shared savings and episodes of care payments allows providers to share in the excess costs or savings for each episode and aims to reward effective care coordination. Participating practices receive non-capitated, risk-adjusted, quarterly payments to support ongoing operational expenses for care coordination services and PCMH transformation, including development of individual care plans.[32]

Health homes. Health homes are an optional Medicaid benefit, established by Section 2703 of the Affordable Care Act, that allows states to implement a coordinated and comprehensive model of care specifically for Medicaid beneficiaries with chronic conditions.[33] The population served by health homes can particularly benefit from enhanced care coordination and formal, comprehensive plans of care. Though the majority of state health home programs target chronic conditions that are more common among adults, state Medicaid agencies have the opportunity to tailor health home programs for CYSHCN and incorporate the SPoC as a required tool within the programs. (See the Iowa Case Study).

- Launched in 2016, the **New York** State Health Home Serving Children program focuses specifically on the needs of Medicaid-enrolled, high-needs children with at least two chronic conditions or a single qualifying condition (HIV/AIDS, serious emotional disturbance, or complex trauma).[34] New York's Health Home program requires participating providers to establish systems and policies that support the creation of an initial comprehensive plan of care within 60 days of member enrollment, with input from the parent or guardian. Health home care coordinators are expected to support the child and family/caregivers in participating in the care planning process.[35]

Section 1115 waivers. Section 1115 waivers provide states with an avenue to test new approaches within their Medicaid programs to better serve Medicaid and CHIP beneficiaries.[36] State 1115 waiver demonstrations can be designed to engage beneficiaries in their health care planning, strengthen provider

networks, improve access to high-quality, person-centered services, or other priorities. Though Section 1115 waivers are generally initially approved for a five-year period, states may receive three- to five-year extensions if requested.

- **New York** is using a Section 1115 waiver to implement a Delivery System Reform Incentive Payment (DSRIP) initiative, through which providers establish integrated, comprehensive care management plans, team-based care models, and patient-engagement strategies.[37] The group of entities responsible for creating and implementing a DSRIP project are called performance provider systems (PPS). A PPS must meet specific milestones that could be impacted by care coordination, such as reducing potentially preventable readmissions and potentially avoidable emergency department visits.[38] PPS must also provide education to patients and family/caretakers to enable them to participate in creating their care plans.[39]

Medicaid managed care. Forty-seven states and Washington, DC enroll some or all populations of CYSHCN in some form of a Medicaid managed care program.[40] Medicaid managed care regulations issued by the Centers for Medicare & Medicaid Services in 2016 broadened care coordination requirements within managed care contracts, requiring that each enrollee have an identified care coordinator to coordinate care across multiple settings, including community and social support services.[41] States can also use their contractual agreements to arrange higher reimbursement rates for CYSHCN and set specific quality or performance targets including a requirement for plans to participate in the development and use of SPoCs. (See the West Virginia case study.)

- **Texas's** Medicaid agency integrated specific requirements for individualized service plans as part of the contract for STAR Kids, the state's Medicaid managed care plan that exclusively serves children and youth under the age of 21 with disabilities and complex conditions.[42] Participating STAR Kids providers are given detailed instructions about the method for collecting the information to be included in the comprehensive individual service plan.[43]

State accountable care organizations. Accountable care organizations (ACO) are a group of health care providers who share financial responsibility for managing the health care needs of a set group of patients. ACOs are designed to control health care costs by promoting effective care coordination as a means to deliver more efficient and effective care. Through the use of financial incentives, ACOs hold physicians accountable for improving outcomes and patient satisfaction.[44] To date, 12 states have active Medicaid ACOs, with 10 working to create programs.[45] In states developing Medicaid ACOs or engaged in overseeing accountable care activity, using SPoCs can help align activities with ACOs' quality goals and support efforts to deliver effective care coordination.

- Eligibility to receive a population-based payment in **Minnesota's** Medicaid ACOs, known as Integrated Health Partnerships (IHP), is in part dependent on the quality of the care coordination, effective patient engagement, and creation of partnerships across multiple providers, community organizations, and social services.[46] The effective implementation of SPoCs for CYSHCN served by IHP has the potential to positively impact a number of the quality measurements reported to the IHP (e.g., measures of patient-centered care).

The Role of State Title V Maternal and Child Health Services Block Grant Programs

State Title V Maternal and Child Health (MCH) Services Block Grant programs play a central role in the promotion and implementation of SPoCs.[47] Administered by the Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration(HRSA), the MCH Services Block Grant program is a state-federal partnership designed to improve the health of pregnant women, mothers, and children. State Title V programs are tasked with promoting family-centered, community-based, coordinated care for CYSHCN. The HRSA, MCHB has supported efforts by states to adopt SPoCs in the care of CYSHCN. Sixteen states, for example, completed a multi-year effort to ensure SPoCs were available to either all or a subset of the CYSHCN in their state.[48] Ten states are currently working to increase the use of SPoCs specifically for children with medical complexity and their families.[49] As evidenced in Title V State Action Plans, multiple state Title V programs have specifically cited SPoCs as a priority need and are actively collecting information about their use (e.g., Alaska, Colorado, Indiana, Iowa, Kansas, Massachusetts, Mississippi, New Hampshire, s Rhode Island, Utah, and Washington).[50]

State Title V programs can promote the use of SPoCs for CYSHCN and their families through a variety of approaches. They can create a standardized SPoC document for use or adaptation by state Title V program staff, health care providers, local health department officials, clinicians, and others who serve CYSHCN. In cases where states contract with local health departments and clinics for services, Title V programs can contractually require use of SPoCs. State Title V programs can also work within their programs or with outside entities to help modify existing approaches to care plans to ensure they meet SPoC standards. For example, existing care plans used for CYSHCN may only focus on one provider's specific treatment approach to a patient's medical condition. State Title V programs can provide recommendations on how to develop a plan that is comprehensive, co-produced with families, identifies individuals to monitor the progress towards agreed-upon goals, and is also accessible to those involved in the care of the child or youth.

State Title V programs can also impact activities at the systems level to support the use of SPoCs for CYSHCN. For example, when a state Title V program is responsible for the development and oversight of SPoCs, they can develop specific policies and procedures concerning the use of SPoCs for CYSHCN to ensure consistency and fidelity to the SPoC model. (See the Utah case study.) State Title V programs can also work in partnership with Medicaid in the Medicaid managed care contracting process to provide expertise on care coordination and encourage the use of SPoCs as the standard of care for CYSHCN served by MCOs. Strong partnerships between state Title V programs and Medicaid can provide numerous opportunities for Title V programs to provide guidance and recommendations for use of SPoCs for CYSHCN. (See the West Virginia case study.) Given Title V's extensive role in family and community engagement and education, these state programs can also play a key role in the development and dissemination of trainings and educational material on SPoCs for health care providers, health plans, patients and families, program staff, and others.

- **Iowa's** Title V CYSHCN program developed an electronic SPoC using ACT.md, a web-based platform that serves as the central hub for SPoCs.[51] The state Title V program is also using multiple strategies to improve care coordination through the expanded use of SPoCs for CYSHCN.[52] These strategies include developing and implementing trainings on and protocols for the use of SPoCs for both families and providers, and disseminating SPoC templates to specific entities for their use. (See the Iowa Case Study.)

How States Finance Shared Plans of Care

Securing adequate funding and reimbursement for care coordination services for CYSHCN can be challenging.[53] Financing for care coordination is currently provided by an array of private and public sources, including commercial insurers, Medicaid, CHIP, state Title V programs, and other state agencies or entities.[54] State Title V programs are a primary funder of SPoC initiatives in some states and, in some cases, these programs may partner with Medicaid agencies to support the use of SPoCs. One promising opportunity to support SPoCs is through Medicaid financing of care coordination services. Currently, two-thirds of state Medicaid/CHIP programs provide some funding for care coordination services, although it varies widely across individual states.[55] Medicaid-targeted case management funds may also be used to help families participate in multidisciplinary team meetings, and Medicaid administrative dollars may be used to support personnel involved in using the SPoC.

To help reimburse for the time required to create and use SPoCs, states can educate providers on specific Current Procedural Terminology (CPT) billing codes that may be available to secure reimbursement.[56,57] In January 2015, Medicare provided additional CPT codes for complex and non-complex chronic care management (CCM).[58] These CCM codes allow the physician to supervise and bill for clinical staff who are providing care coordination management services outside of a visit; this service must include the development of a comprehensive person-centered care plan. Even though these reimbursement codes exist, payers determine whether providers will be reimbursed. Currently, routine reimbursement for these CPT codes by many public and private payers is limited. States can encourage payers to reimburse for these CPT

codes and provide some financial support for the time and effort required for effective SPoC use.

In addition to traditional fee-for-service payments using CPT codes, some state programs are providing per member per month (PMPM) payments to support the use of SPoCs, adjusted to account for a patients' complexity. Providers overseeing more complex CYSHCN, for example, would receive enhanced PMPM payments to cover the additional time required to create and use a comprehensive care plan such as a SPoC. The use of adjusted payments by state programs is one way to encourage establishing payment policies that optimize resource allocation that aligns with individual patients' needs.[59]

- The **New York** State Health Homes Serving Children program provides preliminary and ongoing care management PMPM rates to providers based on a three-tiered PMPM rate structure (Low, Medium, or High).[60] Tiering is guided by an algorithm to determine which tiered PMPM rate a provider will receive; it is based on the acuity, functional capability, and other characteristics of the enrolled child, and provides higher payments for the care of more complex children and youth.

As evidenced by New York State's Health Homes Service Children program, support for care coordination and the use of SPoCs may increase as health care reform continues to move towards the use of alternative payment models. Such models prioritize efficient, high-quality, and patient-centered care, and stress coordination and collaboration across systems and providers. Alternative payment models are also linking financial incentives to a provider's performance on measures directly impacted by the provision of quality care coordination and patient engagement. As states explore global budgets, shared savings methodologies, and the use of bundled payments, the resulting financial incentives may help direct attention to the use of SPoCs as a valuable care coordination tool for CYSHCN.

CPT codes for care planning and coordination

Examples of codes related to care plan oversight and coordination include:

- CPT 99339/99340 Care Plan Oversight can be used monthly by physicians and qualified non-physician practitioners and also annually with specific documentation.
- CPT 99367 Medical Team Conference Without Direct Contact with Patient and/or Family can be reported for a medical team conference of three or more qualified health care professionals with the family present.
- CPT 99215 Highly Complex Office Visit can be used when facilitating a care conference up to 45 minutes. Providers can add a prolonged service visit code if additional time is needed.
- CPT 99490 Chronic Care Management (CCM) covers time for care management services and requires a comprehensive care plan to be established.
- CPT 99487 Complex Chronic Care Management (Complex CCM) covers non-face-to-face services by clinical staff for up to one hour per month and requires a comprehensive care plan to be established.
- CPT 99489 Complex Chronic Care Management (Complex CCM) can be used for each additional 30 minutes of clinical staff time per calendar month when CPT 99487 is also reported.

State Strategies to Advance Use of SPoCs

In addition to securing reimbursement for SPoC efforts, states are using a variety of strategies to advance the use of a SPoC with CYSHCN and their families. Generally, states will determine which populations of CYSHCN will be offered a SPoC and, when overseen by the state, which care team member will act as the lead coordinator. They will also ensure that a strong partnership with the family and the care team is established. Buy-in from key stakeholders at the local and state level is critical, both early on when considering the use of SPoCs and throughout the process of integrating them into the state health care delivery system. Data sharing and privacy concerns, health information technological requirements, and data collection to support and enhance SPoC use are some of the strategies that can support and increase the adoption of SPoCs. Key considerations in the design and use of SPoCs are reviewed below.

Determine which subpopulation/s of CYSHCN should have a SPoC. The creation and use of SPoCs is a time-consuming and potentially costly undertaking, and states are taking different approaches to their use.

States are targeting the use of SPoCs to selected subpopulations of CYSHCN, implementing pilot projects for children with either specific diagnoses (e.g., serious emotional disturbance) or a specific level of complexity or for all CYSHCN within a specific region of the state.[61] In some cases, all CYSHCN, including foster children receiving services through the state, may be eligible for SPoCs.

Identify and train specific individuals or entities to serve as the lead coordinator. Once an eligible population is determined, specific individuals need to be identified and trained to serve as lead coordinators in the development and oversight of a SPoC. They must also be trained in how to discuss the option with families and establish the strong partnerships required to jointly create and implement the comprehensive plan. Individuals serving as lead care coordinators typically reside within a primary care physician's practice or may be social workers, public health nurses, or coordinators employed by the state or another entity.

Partner with family-led organizations to ensure families of CYSHCN are engaged in the design, testing, and use of SPoCs. Family-led organizations can play a key role in the successful state adoption and implementation of SPoCs for CYSHCN.[62,63,64] Consumer and family organizations, such as Family Voices and Family-to-Family Health Information Centers, can provide expertise on the diverse needs of CYSHCN and their families and can help ensure that SPoC initiatives are meeting these needs. States can partner with such family organizations, for example, to develop both the SPoC template and the SPoC education and training materials for families and health care providers. Family Voices of Indiana, for example, has developed a series of online videos for families that describes care coordination and the value of SPoCs.[65] Videos can provide guidance on how to create and use a SPoC, and advise families on how to fully participate as partners in goal setting. Family organizations can also help states obtain feedback from families on their experience with SPoCs to identify opportunities to improve their use.

Provide education and training to obtain buy-in from health care providers and other key stakeholders. Many states emphasize the importance of early and regular engagement of key stakeholders including health care providers and state health officials as essential to obtaining buy-in, and informing and guiding state efforts. For many states, implementing SPoCs within care coordination programs may require a significant culture change for an organization or health care practice. Providers, in particular, may benefit from education and training as they transition to a more family-driven approach to care and adopt processes and workflows to accommodate jointly creating SPoCs with families. To ensure they are effectively implementing SPoCs, providers need to understand the purpose of the SPoC, how to develop and maintain it, and the role of the family in its creation, use, and updating. Many states are partnering with provider entities, such as state chapters of the American Academy of Pediatrics, medical advisory boards, health plans, and academic medical centers, to facilitate provider engagement and provide education, training, and support to providers in the use of SPoCs.

Implement strategies to address real or perceived concerns for patient privacy to promote the exchange of information across an array of services and support systems. Engagement with state-level legal experts early on to identify potential issues and solutions related to privacy and data sharing can help inform where specific barriers exist and how they can be addressed. State and federal efforts to address the challenges around health information exchange have led to multiple strategies states can employ to facilitate health information sharing and overcome legal barriers.[66,67,68] Educating health care and other service providers about existing state and federal privacy law, for example, can address potential misperceptions about restrictions. The creation of standardized and universal consent forms for sharing information also minimizes potential confusion about what can be shared under existing privacy laws, and streamlines what often is a complicated and time-consuming process for patients and providers.

Address technology requirements to facilitate the seamless exchange of patient information across multiple settings. Federal efforts are underway to determine the technological requirements and provide

technical assistance to support the use of comprehensive shared care plans.[69] Ideally, the system to exchange information would include interoperability across electronic platforms, the ability to obtain structured and unstructured data from different sources, and the capacity to update and share a care plan. However, establishing the infrastructure and achieving the required interoperability that can support the sharing of SPoCs remains a challenge. State strategies to work around technological limitations may vary depending on whether the SPoC is developed and overseen by health care providers or managed by state agencies. Among health care providers, SPoCs may be housed in a patient's electronic medical record (EMR) and either shared electronically with other providers or provided to the family as a paper document to be shared with the CYSHCN team. Patient access to the document may be made available through patient portals.

Outside the physician's office, state agencies may elect to contract with a commercial platform to support an electronic SPoC or leverage an existing state-based electronic platform. Both approaches can potentially provide greater access to the document by families and state, community, and health care service providers. States may also house the SPoC on an existing Medicaid or Title V state electronic platform already used to serve CYSHCN. Utah's Title V program, for example, uses an in-state EMR system, CaduRX, to house the SPoC and provides patient access to the document through a patient portal.[70] (See Utah case study.) Given the variations in state resources, individual states may need to be flexible about who hosts the SPoC and how it is shared.

Evaluate the process of creating a SPoC and the outcomes for CYSHCN and their families to improve their effective and expanded use. Strategies to examine families' experience with SPoC implementation can include interviews and surveys with measures drawn from tools designed to examine family experience with care coordination. A recent study, for example, describes efforts to collect data from families specific to a SPoC care coordination intervention and used measures from the SPoC, the Family Experiences with Coordination of Care Survey (FECC),[71] and the National Survey of Children with Special Health Care Needs (NS-CSHCN).[72,73] These findings included preliminary evidence that the use of a SPoC within a care coordination model is an effective approach to enhance care coordination and results in improved family outcomes. Obtaining information about SPoCs from care coordinators can also serve to track the number of SPoCs in place and assess their experience with the implementation process itself. This gives states valuable information on the use of the SPoC and potential areas for process improvement. Oregon, for example, has created an instrument for local health departments to collect key information biannually to evaluate their SPoC implementation.[74]

Examining the impact of a SPoC on key outcomes, such as increased family confidence and navigation skill-building, decreased hospitalization rates, emergency room visits and other outcome measures, can provide states with important information to promote its use among policymakers. Given the potential cost and effort for SPoC implementation, collecting data may be critical to obtain the necessary buy-in from providers, payers, and other state-level stakeholders. Segregating the impact of the SPoC from other interventions and variables may be difficult. Though no one tool specifically addresses SPoCs, the Care Coordination Measures Atlas, developed by multiple national organizations, provides a list of existing measures related to care coordination, which could be used to assess the impact of SPoC use.[75] As increasing numbers of states utilize SPoCs and collect data on impact, results from outcomes data may become more available to support its use.

Summary of key considerations for states implementing SPoCs

- **Assess the key opportunities and potential barriers to providing SPoCs for CYSHCN and their families.** Each state will have its own experience with care coordination and issues related to SPoC implementation. A review of available care coordination services will uncover the strengths, gaps, and challenges at the local, community, or state level to help maximize the use of resources and limit unexpected challenges to implementation.

- **Select population/s to target and how to identify eligible children.** States may provide SPoCs for all CYSHCN receiving services or select a subpopulation as an initial pilot. Once the target population is identified, states will need to determine how to identify eligible CYSHCN and partner with families to ensure access to a SPoC.

- **Engage multiple stakeholders in the creation of the SPoC document.** Stakeholders needed to create a SPoC template can include family representatives, health care providers, state Title V and Medicaid staff, care coordinators, and others. The group may choose to adopt existing templates or create and pilot a specific state form.

- **Prioritize patient and family engagement.** SPoCs serve as valuable tools to build a family-professional partnership and promote shared decision-making among providers and families. Families should be involved in both the program and policy process leading to the adoption and implementation of the SPoC approach, and in the creation and use of an individual SPoC for their child.

- **Leverage multiple federal and state funding streams to support the use of SPoCs.** State agencies can offer education to providers about billing opportunities and explore how the state can leverage existing state health payment and delivery system reforms to support the creation and use of SPoCs.

- **Designate the lead coordinator responsible for SPoC oversight.** At the systems level, states can designate a lead coordinator to provide oversight and support for the policies related to SPoCs. At the patient level, states or health care entities can designate a lead coordinator who is eligible for care coordination payments, responsible for partnership with the family on SPoC development, and able to provide continued oversight and modification as needed.

- **Develop and disseminate SPoC training and education.** The use of a SPoC may require a major culture shift and training for some providers, agencies, and care coordinators. Families in particular can benefit from understanding the SPoC process and their role as a partner in the development of the plan. Leveraging existing materials already developed using state, federal, or private financial sources may help expedite the process of creating needed materials.

- **Examine the technological infrastructure needed to support SPoCs.** Federal and state programs are working to create an interoperable electronic system with the ultimate goal of electronically embedding the SPoC within an electronic health record in order to seamlessly share a SPoC. In the interim, using multiple mechanisms, including existing electronic health record systems, patient portals, and state and private platforms -- in addition to paper documents -- can promote access to the document for those involved in the care of the CYSHCN.

- **Address privacy issues that impede the exchange of information.** Privacy laws, or a lack of understanding of what is allowed under these laws, may pose barriers to the exchange of health information and other data through SPoCs. These barriers can be addressed at both the provider and systems level to ease the flow of needed information for CYSHCN.

- **Establish policies and procedures to support SPoC use.** To ensure consistent and appropriate use of SPoCs, states can establish specific policies and procedures for those state agencies overseeing SPoC implementation. Health care delivery transformation efforts, such as Medicaid managed care, can promote the use of SPoCs as a standard of care and require education to ensure their correct use.

- **Monitor experience and outcomes associated with use of SPoCs.** The collection of data on SPoC use and its impact on outcomes is an important activity to help states refine and expand the use of SPoC for CYSHCN. Data also has the potential to create a body of evidence supporting the inherent value of SPoCs to families, providers, health plans, and state agencies as well as provide valuable evidence about the return on investment both financially and for the health and well-being of the CYSHCN and family.

Conclusion

State Medicaid agencies, Title V programs, health care providers, and others have long recognized the value of providing quality care coordination for CYSHCN and their families. Improvements in care coordination, particularly for children with complex medical conditions, result in measurable improvements in family satisfaction, lower costs, and more efficient and effective health care delivery. The creation and sharing of an individualized and comprehensive care plan, in partnership with the family and with input from those whose services impact the health and well-being of the child or youth, are essential to provide care coordination and effectively address the multiple needs of CYSHCN and their families.

State implementation of SPoCs requires collaboration across the public and private entities involved in the state's child health policy, programs, and practices. The process of implementing a SPoC will vary widely among individual states as they rely on differing funding sources, varied levels of engagement and buy-in of key stakeholders, and the availability of technological resources. As states promote care coordination and incorporate SPoCs as a valuable care coordination tool, they can communicate lessons learned from their efforts to help other states. These efforts can further be aided by states' ability to demonstrate the impact of SPoCs on care and outcomes for CYSHCN and their families.

Endnotes

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