Background

In West Virginia, 24.1 percent of all children up to age 18 have special health care needs. Children and youth with special health care needs (CYSHCN) who meet eligibility criteria, including having a chronic and severe physical health care needs, functional limitations, and service needs, are served by West Virginia’s Title V CYSHCN Program, which is housed in the state’s Office of Maternal, Child, and Family Health. The CYSHCN program contracts with board-certified or board-eligible providers to deliver cardiology, nephrology, neurology, nutrition, orthopedic, and otolaryngology services across the state, and provides transition services to CYSHCN. The program’s care coordinators (made up of a registered nurse and a licensed social worker team) provide support (but not funding) to a statewide network of privately-run community clinics. Additionally, care coordination services are delivered within a partnership between the patient, family, and primary provider in cooperation with specialists and other community supports. Care coordination is provided to eligible CYSHCN using a tiered system. All enrolled CYSHCN are assessed for functional limitations and service utilization to determine their level of intensity for the care coordination services. There are three care coordination tiers, with Tier 1 serving children and youth with the least intensive and complex needs and Tier 3 serving those with the most intensive and complex needs.

Nearly half (44 percent) of CYSHCN in West Virginia are enrolled in Medicaid or the Children’s Health Insurance Program (CHIP). The majority of CYSHCN are served through the state’s Medicaid managed care program, which provides both medical and behavioral health services. Children enrolled in foster care are exempt from Medicaid managed care, and the West Virginia Title V CYSHCN program provides health care coordination to this population. Due to a strong relationship between Title V and Medicaid, especially in supporting the medical home model of care, Medicaid requires the four managed care organizations (MCOs) to establish roles and responsibilities for working with the state Title V program. Each MCO in the state is required to establish a detailed memorandum of understanding (MOU) to help “assure that all enrolled members with special health care needs, ages 0 to 21, have access to a medical home and receive comprehensive, coordinated services and supports pursuant to national standards for systems of care for children and youth with special health care needs.”

West Virginia’s Approach to SPoC Implementation

West Virginia’s Title V program developed its SPoC when it redesigned its statewide care coordination approach. Its SPoC is based on the report, Achieving a Shared Plan of Care with Children and Youth with Special Health Care Needs, as well as other CYSHCN screening tools and care summaries that have been used in medical homes. West Virginia created fillable PDF SPoC templates to correspond with the tiered care coordination system. Children
with less complex needs who are in Tier 1 care coordination receive a simplified version of the SPoC; those in Tier 2 and Tier 3 receive the full SPoC in order to accommodate their more complex medical needs. All 1,620 children enrolled as CYSHCN in the state have a SPoC in place.

The care coordinators in the state’s Title V CYSHCN program lead the development of SPoCs and collaborate with the MCO medical case managers, foster care services agencies, and primary care physicians to provide care coordination. When a child is initially referred to the CYSHCN program, the CYSHCN program enrollment specialist, West Virginia HealthCheck (West Virginia Medicaid’s child preventive health benefit) Foster Care Liaisons, and the MCO case managers complete the West Virginia CYSHCN Screener. The Title V CYSHCN Program developed and implemented the CYSHCN Screener to identify CYSHCN and gauge their families’ perspective and awareness of their children’s health care needs. The 15-question screener is used to determine eligibility for the Title V CYSHCN program, quantify and qualify the population of CYSHCN, and define care coordination activities and strategies.

Other information collected from the CYSHCN Screener includes functional limitations and service needs. This screener allows the providers/team members to base their patient and family assessments on a full understanding of a child’s and family’s needs, strengths, history, and preferences, and helps ensure that children, youth, and families are actively engaged in their care. The care coordinators also use the screening process as an opportunity to begin educating families on the purpose and content of SPoCs, and the information gathered from the screener is used to begin populating the SPoC. Once the SPoC is developed in coordination with the family, the family receives a printed copy, and providers and MCOs involved in the child’s care receive either a printed copy or an electronic copy sent via encrypted email, with the permission of CYSHCN and their families.

Currently, SPoC efforts are supported primarily by the state’s Title V Maternal and Child Health Services Block Grant program. However, MCOs’ higher reimbursement rates for CYSHCN enrolled in the Title V Program helps supports the additional time and resources needed to coordinate care and oversee care planning. Title V also receives Medicaid administrative dollars to support the program’s licensed nurses and social workers who provide the care coordination services to CYSHCN, including the development of SPoCs. While these Medicaid financing mechanisms are not specifically directed to SPoC implementation, they are critical sources of support for care coordination activities, which includes the development and updating of SPoCs.

**Cross-System Partnerships**

One of the critical contributors to West Virginia’s success with SPoC implementation is the strong partnership between the state’s Medicaid agency and Title V program. Through this partnership, the Title V program established MOUs with the four MCOs under contract with the state. The MOU outlines specific expectations and responsibilities for each entity serving CYSHCN, such as improving care coordination, monitoring the quality of care for CYSHCN, and coordinating performance measures. Through the MOU, MCOs and the Title V program are required to coordinate the care planning process for CYSHCN and designate the “lead team” (locus of care coordination) for the family and other team members on the child’s care team. The MOU also explicitly addresses SPoCs, requiring the use of plans of care for all members with chronic health conditions.6

In addition to its partnership with the state Medicaid agency, West Virginia’s Title V CYSHCN program collaborates with the state’s Title IV-E program (child welfare) to support SPoCs for foster care youth. Children in the foster care system in West Virginia are automatically eligible for the Title V CYSHCN program. The state Title V and Title IV-E programs have established an MOU to improve the coordination of services for this population. The MOU also supports coordination between the two programs in the development of SPoCs for the foster care youth. Significant challenges exist for full SPoC implementation due to the transient nature of this population and the
recent rapid growth in numbers from 4,000 children in 2016 to 6,800 in 2018.

The West Virginia Title V program has also partnered with two universities – Marshall University and West Virginia University. Marshall University’s School of Medicine currently provides training to medical residents on the medical home model of care and use of SPoCs. West Virginia University, under contract with the state, administers the Family-to-Family Information Center. The center employs parents of CYSHCN trained in the state’s system of care, including the medical home model and SPoCs, to provide education and support to other families and professionals.

Lessons Learned and Future Plans

Engagement of stakeholders was a key factor in successful implementation of SPoCs in West Virginia. Officials note the importance of leveraging the statutory requirement in the state’s Title V MCH Services Block Grant that mandates coordination between Title V and Medicaid. This requirement has promoted close collaboration between West Virginia’s Title V program and Medicaid agency and facilitated the state’s SPoC initiative. Additionally, engaging providers early in the implementation of the SPoC initiative and helping them to recognize the medical home model as an approach rather than a setting has supported their buy-in for this work.

Looking forward, West Virginia’s Title V program is working to establish data-sharing agreements with each MCO in order to obtain the necessary data to refine how SPoCs are implemented and understand their impact. The state continues to work on partnerships to lend support and expertise to SPoC implementation, including working with the American Academy of Pediatrics, medical advisory boards, and educational institutions. The state is exploring opportunities to establish an online platform for its SPoC, with the goal of improving the overall accessibility and functionality of the SPoC. The West Virginia Title V program also plans to develop a self-assessment for both children and families in order to monitor the use of SPoCs and increase overall engagement of the child or youth in their goals and activities.

Endnotes