



# State Strategies to Advance Medical Homes for Children and Youth with Special Health Care Needs

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## Overview

Children and youth with special health care needs (CYSHCN) are a diverse population that require unique and special considerations when designing health care systems to serve them. Nearly 20 percent of US children up to 18 years old (14.6 million) have a chronic physical, developmental, behavioral, or emotional condition and need services and supports beyond what children require normally.<sup>1</sup>

In an effort to improve the delivery and quality of care that CYSHCN receive, the Health Resources and Services Administration (HRSA) funded a three-year initiative, *State Implementation Grants (SIG) to Enhance Systems of Services for CYSHCN through Systems Integration*. Through this initiative, 16 states received grants to implement quality improvement strategies to expand and improve medical homes – a family-centered, coordinated, and comprehensive approach to care – for CYSHCN.

This brief examines the strategies the 16 SIG states developed to expand the capacity of their medical homes to more effectively serve CYSHCN and their families and promote systems integration. It highlights state accomplishments and the resources they developed, and explores lessons learned in order to inform similar efforts in other states.

## Introduction

CYSHCN can have a wide-range of conditions and diagnoses, such as asthma, autism, attention-deficit/hyperactivity disorder, diabetes, and sickle cell anemia. Medicaid and the Children's Health Insurance Program (CHIP) play a significant role in financing their care, covering 44 percent of all CYSHCN.<sup>2</sup> The federal Title V Maternal and Child Health (MCH) Services Block grant program also plays a critical role in providing services and supports to CYSHCN and their families. Through the Title V MCH Block grant program, the federal and state governments partner to promote and improve the health and well-being of women, children, including CYSHCN, and their families. State Title V programs support a wide-array of activities including the development of family-centered, community-based systems of services and coordinated care for CYSHCN and their families.<sup>3</sup>

In addition to state Medicaid/CHIP and Title V programs, CYSHCN typically receive services and supports from multiple systems. CYSHCN, especially those with complex conditions, and their families may require services from primary and specialty health care, public health, education, mental health, social service and/or other systems and supports for their care.<sup>4</sup> Historically, care for CYSHCN has been highly fragmented with families bearing much of the responsibility for navigating complex systems, coordinating providers, and managing their child's care. This lack of coordination between systems can negatively impact access to care resulting in unmet needs.<sup>5, 6</sup>

The American Academy of Pediatrics (AAP) originally developed the medical home concept to reduce duplication and gaps in services caused by a lack of communication and coordination among providers

serving CYSHCN.<sup>7</sup> Since that time, the concept has evolved, and the medical home is now defined as a team-based approach to primary care that is easily accessible, family-centered, continuous from infancy through young adulthood, comprehensive, coordinated, compassionate, and culturally effective.<sup>8</sup> Research shows medical homes improve outcomes, reduce costs, and improve patient and family experience by more effectively and efficiently coordinating care.<sup>9</sup> The Maternal and Child Health Bureau (MCHB), HRSA and the National Standards for System of Care for CYSHCN, which defines an effective system of care for CYSHCN, have identified medical homes as a core component of a comprehensive system of care for CYSHCN.<sup>10, 11</sup> Additionally, medical homes have become a widely utilized approach to care for all populations.<sup>12</sup>

States and the federal government have a long history of promoting medical homes as an approach to primary care for CYSHCN. Since the 1980s, states have integrated medical homes into statewide plans to improve care for this population.<sup>13</sup> States have also integrated medical homes into their broader payment and delivery system reform efforts, including implementation of accountable care organizations and expansion of Medicaid managed care, that work to improve health care quality and outcomes while reducing costs.<sup>14</sup>

Over the past two decades, HRSA's MCHB has supported the advancement of the medical home approach of care for CYSHCN, most recently through its SIG initiative, which supported states in implementing these common strategies:

- Improve care coordination for CYSHCN through the development of shared plans of care, which can take a variety of forms, from their format (paper-based vs. electronic) to their customizability, to meet the needs of CYSHCN, their families, and providers and systems serving them.
- Establish infrastructures, policies, and/or procedures to improve access to care for CYSHCN, including centralized repositories of resources and services for CYSHCN and mechanisms to ensure referrals to additional services were successful.
- Formalize cross-system partnerships to promote better integration of care primarily using inter-agency agreements or agreements between providers, which align the partners in addressing gaps in the systems of care for CYSHCN and promote accountability in advancing the state's medical home efforts.
- Engage families of CYSHCN as partners and leaders, from serving as advisors to leading quality improvement activities, to ensure that states' efforts are guided by and meeting the needs of CYSHCN and their families.

### **State Implementation Grants to Enhance Systems Integration for CYSHCN**

From 2014 to 2017, 16 states received State Implementation Grants (SIG) to Enhance System of Services for CYSHCN through Systems Integration. The states (Alaska, Colorado, Connecticut, Indiana, Iowa, Kansas, Massachusetts, Minnesota, Mississippi, New Jersey, Oregon, Rhode Island, Utah, Vermont, Washington, and Wisconsin) were led by the state Title V CYSHCN program and worked to increase the proportion of CYSHCN who receive integrated care through a patient-centered medical home or health home approach. State Title V CYSHCN programs, Medicaid agencies, and stakeholders, including families of CYSHCN, came together to form collaborative partnerships to develop and implement policies and programs to advance SIG goals. In the first year of SIG, the states identified common goals across three cross-state strategy areas – developing a shared resource, promoting integrated care through the development of an interagency agreement, and improving cross-system care coordination – to support improvements in medical homes for CYSHCN. The grants that states received through SIG supported the planning and implementation of these strategies over the three-year initiative, and many states continue to implement these strategies as part of their MCH Title V Services Block grant programs.

In addition to providing funding to state grantees, HRSA funded the National Academy for State Health Policy (NASHP), in partnership with the National Improvement Partnership Network (NIPN), to establish a cross-state learning collaborative for the 16 states, called the Systems Integration Academy (SIA). NASHP and NIPN provided targeted technical assistance and support to the SIG states in the development of the collective goals, the use of quality improvement (QI) approaches to test interventions, and sharing of resources and experiences.

## Improving Care for CYSHCN through Medical Homes

In 1967, AAP first introduced the concept of a medical home as a model of care specifically to address the unique and complex needs of CYSHCN and their families. AAP described the medical home as a centralized source for pediatric records as a means to address the challenges of having multiple providers in various locations serving this population of children without having an effective means to communicate and coordinate care. The medical home concept has since evolved from a centralized medical record to a model of providing primary care that addresses the needs of the whole child and family.<sup>15</sup> In March 2007, AAP, the American Academy of Family Physicians, the American College of Physicians, and the American Osteopathic Association released the *Joint Principles of the Patient-Centered Medical Home* to establish an operational definition for providing comprehensive primary care for children, youth, and adults in a health care setting.<sup>16</sup> Today, a medical home is defined as a team-based approach to primary care that should be easily accessible, family-centered, continuous from infancy through young adulthood, comprehensive, coordinated, compassionate, and culturally effective.<sup>17</sup>

Patient- or family-centered medical homes are recognized as an essential component of an effective system of care for CYSHCN, and are designed to coordinate care across both clinical and non-clinical settings.<sup>18</sup> Care coordination within medical homes promotes care integration for CYSHCN by creating linkages and facilitating collaboration between health care providers, community agencies, educators, and other professionals involved in the child's care.<sup>19</sup> Evidence shows that medical homes positively impact CYSHCN and their families, including reducing unmet needs, improving access to care, decreasing avoidable or preventable emergency department visits, reducing burden for the family in coordinating care, and increasing patient and family satisfaction.<sup>20</sup>

A medical home is a team-based approach to primary care that should be easily accessible, family-centered, continuous from infancy through young adulthood, comprehensive, coordinated, compassionate, and culturally effective.

## State Strategies to Advance Medical Homes for CYSHCN

Medical homes are a core component of a comprehensive system of care for CYSHCN, and a well-integrated system effectively serves CYSHCN and their families. Achieving a more seamless and well-functioning system of care facilitates coordination and linkages between services and programs, which enables medical homes to provide comprehensive, coordinated, and family-centered care. The SIG states implemented a common set of strategies to advance medical homes for CYSHCN while promoting systems integration:

- Supporting care coordination through a shared plan of care;
- Improving access to services and supports through a shared resource – a one-stop shop for resources and services for CYSHCN – and policies designed to close the referral feedback loop;
- Forming cross-system partnerships to promote better integration of care; and
- Partnering with families in the development of medical home policy and practice for CYSHCN.

While the SIG states shared these strategies, their implementation varied. To support care coordination through a shared plan of care, nearly all states developed and implemented a shared plan of care template. Yet, they differed in their target populations, the content of their template, and whether the shared plan of care was electronic or paper-based – all of these decisions were guided by the needs of families in each state and the systems serving them. In developing the shared resource – a one-stop shop for resources for CYSHCN – states recognized the challenge of maintaining and sustaining such a repository. As a result, nearly all SIG states incorporated their shared resources into an existing state

infrastructure, or they sought to leverage an existing national platform for their shared resources that could be tailored to their state. As they sought to promote the integration of care across systems, a common approach among the SIG states was to establish interagency agreements between the state Title V MCH program and other state agencies to allow for coordination and alignment of activities to improve care for CYSHCN. Most states focused on the systems-level, creating formal linkages between providers to promote better-coordinated and integrated care.

Below is an in-depth examination of effective strategies used by SIG states to expand the reach of medical homes serving CYSHCN and their families, and ultimately, to improve access to care and health outcomes. The Appendix provides an overview of the strategies implemented by each SIG state.

## Supporting care coordination through a shared plan of care

Successful care coordination is key to the medical home approach to care. Care coordination is a family-centered, team-based activity designed to meet the needs of CYSHCN and enhance the caregiving skills of the family. Care coordinators create linkages between families and needed services and supports, facilitate communication between providers, and ensure the child and family receive the care they need. Providing effective care coordination can be challenging and complex, especially for children with the highest needs who receive care from numerous providers and systems.<sup>21</sup>

To support improved care coordination for CYSHCN, states worked to develop, implement, and expand the use of a shared plan of care. A shared plan of care is a family-centered, comprehensive, and dynamic document that facilitates communication and collaboration across the child's entire care team, and is guided by patient and family input. A shared plan of care captures a child and family's medical and social needs, goals, and planned activities to achieve their desired outcomes. It is developed in partnership with the family, and is continually reviewed and updated to reflect the child's progress and evolving care needs. The shared plan of care is shared across multiple providers – in both clinical and nonclinical settings – to give them a comprehensive view of the family's needs. It also ensures that all services are coordinated and aligned with the family's goals.<sup>22</sup>

The shared plan of care was different in every SIG state as officials worked to meet the needs of their target populations and address the challenges of their states' unique systems. Yet, states took similar approaches to developing and implementing their shared plans care. Working closely with participating providers, which included private practices and federally qualified health centers, and, most importantly, families of CYSHCN, each state determined the components to be included in a shared plan of care template and how the information would be compiled by the site serving as the medical home. After designing a template, states made the shared plan of care available to providers and families through a variety of mechanisms, depending on what would be most conducive to sharing the document. These mechanisms included integrating the shared plan of care into an electronic medical record, providing a downloadable form to be shared with providers and families, or placing it on an easily-accessible, state-based electronic platform. While some states provided the shared plan of care as a standardized form for providers and care coordinators to complete as part of their care coordination activities, others allowed providers to adapt the template to better align with their practice processes.

States conducted provider outreach and training to obtain buy-in for the use of the shared plan of care and ensure that the shared plan of care was effectively implemented and co-created with families. Approaches to outreach and training included developing and disseminating educational materials, holding webinars, and convening in-person meetings that taught providers what a shared plan of care is, how to develop and maintain it, and the role of families in its development. Additionally, states explored

opportunities to implement policies that could promote the use of a shared plan of care, such as including shared plan of care requirements in their medical home recognition programs or integrating shared plans of care into state programs for CYSHCN.

**Iowa's Title V CYSHCN program** developed an electronic shared plan of care using ACT.md, a team-based care coordination technology. Its electronic shared plan of care is designed to serve as a central hub, organizing family, youth, provider, and community partner goals for CYSHCN across Iowa. The electronic shared plan of care can also be printed for caregivers or other providers who might not have access to the electronic platform. Iowa is currently implementing and evaluating the electronic shared plan of care in its Title V CYSHCN specialty clinics and eventually plans to expand it to other geographic locations and care settings across the state.

**New Jersey's Special Child Health Services (SCHS) Case Management program** is a free and voluntary service that provides care coordination to CYSHCN from birth to 21 years. Licensed nurses and social workers, who serve as case managers, address and provide resources and referrals to CYSHCN and their families in the following five domains: health care, developmental, educational, rehabilitative, and social-emotional and economic. To support the care coordination activities of the case managers, New Jersey's Title V CYSHCN program has created a standardized, paper-based [shared plan of care template](#). The state Department of Health undertook a robust process to develop its shared plan of care. This process included numerous roundtable meetings with state leadership, in addition to focus groups and individual interviews with youth and caregivers of CYSHCN. Once they had developed the template, they piloted it in three counties, providing trainings to the SCHS case managers, developing a guide on the use of a shared plan of care for youth and families, and partnering with the AAP New Jersey Chapter and the Statewide Parent Advocacy Network to provide technical assistance to providers. New Jersey is in the process of expanding the shared plan of care to be used in all SCHS case management units throughout the state.

## Improving access to services and supports through a shared resource and improving referral feedback loops

Effective medical homes link families of CYSHCN to needed services and supports, and aid them in accessing those services and supports in the right place and at the right time. However, systemic barriers can prevent these linkages from occurring. Providers and families of CYSHCN may not be aware of existing resources and services available in their communities. When a referral is made, families of CYSHCN may struggle to navigate complex systems on their own, and they may experience language, literacy, or cultural barriers to receiving care. Additionally, providers may not have mechanisms in place to ensure a family accessed and received the critical services needed.

States are tackling some of these barriers through the development of a shared resource. SIG states focused on establishing and expanding an electronic platform, or “one-stop shop,” to serve as a statewide shared resource, providing current and well-vetted information to improve health care delivery for CYSHCN and their families. The SIG states designed their shared resources to contain information that could be used by CYSHCN, their families and caregivers, clinicians, and other service providers, and that conveyed the information in languages that were accessible for all and reflected cultural and ethnic diversity. Some states paired their shared resource with a call center, allowing CYSHCN, families, and providers to connect with trained staff who could provide additional support in finding and accessing services. Creating this up-to-date shared resource provides needed resources to families and providers, and it helps states evaluate the status of needed services and supports for CYSHCN.

**Minnesota's Title V CYSHCN program** developed and integrated its shared resource, [Children and Youth with Special Health Needs \(CYSHN\) Navigator](#), into an existing state resource [website](#), which allows the state to leverage an established and tested infrastructure, as well as support the shared resource's long-term sustainability. The CYSHN Navigator consists of a navigable directory of resource listings for providers and families of CYSHN. It also includes call and chat functionality that allows families and providers to connect with a resource specialist and family-to-family peer support navigator. The CYSHN Navigator site receives an average of 117 views per day.

**Utah** has a well-established shared resource, [Medical Home Portal](#), which the University of Utah Health launched in 2001 to improve family and provider knowledge of local resources for the care of CYSHCN, support case managers in linking families to resources, and disseminate best practice guidelines for common chronic conditions in children. Under SIG, Utah's Title V program partnered with the University of Utah to continue to refine the content contained in the Medical Home Portal, and developed and incorporated enhanced features, such as generating customizable lists and providing phone and e-mail support. As of 2017, the Medical Home Portal has more than 500 pages of content and resources and 5,000 links to other reliable and valuable websites or downloadable information for providers and families.<sup>23</sup> Currently, five states – Idaho, Montana, New Mexico, Nevada, and Rhode Island – are partnering with Utah to implement state- and region-specific versions of the Medical Home Portal.<sup>24</sup>

Maintaining a shared resource can require significant time and resources to ensure it is up-to-date, that providers and families are aware of it, and that it is of value to CYSHCN, families, and providers across the state. Several states incorporated their shared resource into existing state infrastructures, such as state-based websites, and others opted to contract with an existing, tried-and-true shared resource platform. All states tracked usage, such as website visits and number of calls received, and a majority incorporated surveys into their shared resources to assess user experience. Most SIG states are using their Title V MCH Services Block Grant to sustain their shared resource and have secured or are exploring additional funding streams, including state general funds, Medicaid, Individuals with Disabilities Education Act (IDEA) Part C formula grant program, and other federal grant programs.

In addition to establishing and maintaining shared repositories to improve access to resources and information about services and supports, states are also taking steps to improve the referral feedback loop. Once referred, CYSHCN may not access the recommended service for a variety of reasons, such as difficulty in obtaining timely appointments and transportation challenges.<sup>25</sup> States are examining the referral process and establishing procedures to:

- Confirm that CYSHCN and their families are able to access the additional services;
- Provide follow-up options if referrals are not successful; and
- Ensure timely receipt of information between providers once the referral is completed.

To improve referrals to needed services, half of the SIG states established universal referral forms for state services, such as early intervention, to provide a convenient and streamlined mechanism that captures all of the information needed for a family to access the service and obtain necessary consent for the sharing of patient information. Additionally, several states established formal agreements between medical homes and other programs or services in order to define processes and standard guidelines for closing the referral loop and tracking the outcomes of the referral, such as whether an appointment was made and occurred and documenting the results of screenings.

**The Oregon Center for Children and Youth with Special Health Needs** developed an agreement template for medical homes to use to support the timely receipt of patient information related to a referral to an education entity (e.g., early intervention) or behavioral health agency. To inform the development of the agreement template, Oregon conducted a thorough review of referral workflows within medical homes, education entities, and behavioral health agencies, and identified the facilitators and barriers to closing the referral loop between these various entities. The results of this review are captured in the issue brief, "[Closing the Referral Loop for Medical Homes Serving Children and Youth with Special Health Needs](#)."<sup>26</sup>

The agreement template stipulates that the medical home will use the universal referral form developed by the state, including obtaining consent for the referral from the parent/caregiver and the child or youth. It also requires that the education entity or behavioral health service provider use the universal referral form to document the outcome of the referral -- including eligibility status, appointment status, and services being received -- and the return the referral form to the medical home within 90 days of when they received the initial referral. Oregon has been partnering with several primary care sites to pilot the agreements and identify any needed modifications before implementing it statewide.

### **Forming cross-system partnerships to promote better integration of care**

Cross-system collaboration within states is necessary to advance medical homes for CYSHCN, given the myriad of services and supports that CYSHCN and their families typically need. Aligning state programs and providers with medical home efforts can promote high-quality and consistent care, while minimizing inefficiencies and duplication of services.<sup>27</sup> When various systems work together to reduce barriers to and fragmentation of services, medical homes are also better able to coordinate care for CYSHCN.<sup>28</sup> States are taking a variety of approaches to cross-system collaboration, such as establishing interagency agreements, promoting data sharing between agencies and systems, and convening cross-system workgroups or task forces.

**Alaska's Title V CYSHCN program** worked to bridge health and education systems by piloting a school nurse care coordination program. Under the program, school nurses in one Alaskan school district have established written agreements and enhanced communication protocol with a high-performing pediatric medical home. The long-term goal is to give school nurses access to electronic medical records for children with complex needs who are participating in the pilot, which will be expanded to additional schools and pediatric providers. Historically, sharing patient information between health care providers and the education system has been fraught with issues due to Health Insurance Portability and Accountability Act (HIPAA) and Family Educational Rights and Privacy Act (FERPA) laws.<sup>29</sup> To overcome these barriers, Alaska established a memorandum of agreement between the participating school and pediatric primary care practice, and also supported the pediatric practice in obtaining the necessary consent from families to allow for the sharing of patient information. With access to a child's medical record, a school nurse will be better able to coordinate with health care providers, care coordinators, and families, and participate in the development of the shared plan of care. This cross-system collaboration also supports the inclusion of health and educational goals of children and their families in the shared plan of care.

**Connecticut's Title V CYSHCN Program** is using several mechanisms to advance medical homes through cross-system collaboration. The Connecticut Departments of Public Health (Title V) and Social Services (Medicaid) have executed a memoranda of agreement in order to share data and the shared plan of care through MAVEN, a state-based electronic platform that is designed to support disease surveillance and case management. While the MAVEN data platform has not yet been

used for data sharing while the state evaluates privacy concerns in information sharing, Connecticut plans to use MAVEN to better track and coordinate care for the CYSHCN they serve, and to ensure that the shared plan of care is the single record of service for both agencies. The agreement also specifically calls for the state Medicaid agency to engage its patient-centered medical home program in care coordination activities.

The Connecticut Department of Public Health has also convened a work group to develop a state-wide model for efficient care coordination that meets the needs of families and minimizes duplication of services across agencies, programs, and providers. This work group includes representation from the state Title V CYSHCN program, Medicaid, Connecticut Family Support Network, Child Development Infoline (a shared resource), regional care coordination centers and collaboratives, Office for Early Childhood, and Department of Children and Families. As a result of this work group, care coordination for CYSHCN is now included as a requirement for primary care practices participating in the state's State Innovation Model program, which is a federal initiative supporting state-led, multi-payer payment and delivery system reform.

The overall approach to establishing formal cross-agency and system partnerships depended on the goals of the SIG states. Some focused on improving coordination between state programs, such as the state Title V MCH and IDEA Part C, while others worked to improve linkages between different provider types. Regardless of the approach used for cross-system collaboration, all SIG states acknowledged the value of creating formal partnerships and establishing formal agreements to help align the priorities of the participating entities and promote accountability in advancing systems' integration efforts.

## Partnering with families to develop medical home policies and practices for CYSHCN

Families of CYSHCN, as experts in their child's needs and the systems serving them, are invaluable partners and leaders in the development of medical home policies and practices. Their insights help promote appropriate care and improved care experiences. As states design resources for families and CYSHCN, such as a shared plan of care, input from families is critical to ensure the materials are appropriate, accessible, and meet their needs.<sup>30</sup> Families can also inform state or community needs assessments and support outreach work.<sup>31</sup>

Building partnerships with families requires going beyond conducting surveys and focus groups. To achieve true partnerships, families must have opportunities to serve as leaders in systems integration efforts, having both power and responsibility in decision-making processes that influence the design and implementation of medical homes.<sup>32</sup> Among the SIG states, engaging families as partners and leaders was a fundamental strategy for their medical home efforts. The SIG states partnered with families in setting agendas and priorities, integrated and trained them to serve as leaders in quality improvement teams, and/or ensured they had seats on advisory committees that informed policymaking.

**Washington's Title V CYSHCN program** facilitated a quality improvement project to improve family-centered care within three maxillofacial review boards across the state, which provide care coordination to CYSHCN with maxillofacial conditions, such as cleft lip or cleft palate. With technical assistance from the CYSHCN Program's Family Engagement Coordinator, each maxillofacial review board recruited families as key participants in their quality improvement activities. The Family Engagement Coordinator also provided training to families on the components of a medical home and the role of a family advisor in a quality improvement project. This training was conducted in both English and Spanish. Each maxillofacial site then conducted a workgroup with their respective family leaders to identify any needed changes to support continued improvements in their care.

**Wisconsin's Title V program** engaged family partners in a variety of ways through SIG. Families of CYSHCN were key members of the Wisconsin Medical Home Implementation Team, which oversaw the state's SIG activities. As part of the team, the family partners provided strategic direction and guidance to the project, including developing, implementing, and evaluating the state plan for increasing the number of CYSHCN served through medical homes. One activity the team recommended was analyzing the strengths and gaps of the current systems of care for CYSHCN in the state. The state not only interviewed families as part of this analysis, but they also used the findings to identify strategies and opportunities to better engage families in their children's care and as advisors on system policies and procedures. The culminating report, [Wisconsin Care Coordination for Children and Youth Mapping Project](#), captures the families' feedback, which the state is using to improve care coordination, including continuing to build family partnerships.

Additionally, Wisconsin established, [Leading Together](#), a learning collaborative of nearly 30 family-led and family-supporting programs across domains. Leading Together focuses on mapping family leadership development opportunities throughout the state, conducting cultural competence assessments for member organizations, and developing family leadership competencies for organizations/agencies. All of the activities are designed to equip families with the skills needed to serve as leaders or advisors and support their integration into decision-making processes within the systems that serve their children, including medical homes.

## Key considerations for systems integration efforts

Strengthening systems of care for CYSHCN through the implementation of medical homes is a priority in many states. While states face significant challenges in establishing well-integrated systems that support effective medical homes, they continue to make progress in improving care for CYSHCN, as evidenced by the impact and outcomes of the MCHB, HRSA *State Implementation Grants (SIG) to Enhance Systems of Services for CYSHCN through Systems Integration*. The following key considerations reflect lessons learned from the SIG states and are critical to any systems integration effort.

**Assess the status of systems integration for CYSHCN within the state:** Before undertaking their systems integration efforts, the SIG states first conducted a needs assessment to understand the various components of the existing systems serving CYSHCN, including local and community services that are involved in supporting the children and families' medical, social-emotional, behavioral, and developmental needs. They also assessed how the system is currently functioning. Needs assessments reveal a system's strengths, as well as its gaps and areas requiring improvement. Each state is unique and its needs assessments will have varied results. Some states will already have well-integrated systems in place for CYSHCN and can focus their efforts on more targeted aspects of medical home implementation. Others' system integration efforts may be in their infancy, and they will have to start with improving fundamental components, such as promoting collaboration between Title V CYSHCN programs and Medicaid to advance medical home implementation for CYSHCN. Ultimately, the needs assessment is instrumental for states as they set priorities and develop a plan to improve systems integration.

**Strategically engage diverse stakeholders who may successfully influence integration of services and supports for CYSHCN and their families:** An integrated system requires successful coordination and collaboration across multiple state agencies, health care professionals, service providers, and an array of other community-based organizations and systems serving CYSHCN. States have numerous partners that can be involved in system integration efforts. Partners can have different levels of influence on various components of systems serving CYSHCN, and the levels of existing collaboration between these partners and systems vary across states. As a result, engaging a diverse range

of partners early and often is key to bringing about meaningful and sustainable change. It is critical to obtain buy-in from those systems and programs that can support systems change and strengthen stakeholders' capacity to advance quality improvement for CYSHCN through medical homes. Typical stakeholders include the state Title V CYSHCN program, state Medicaid agency, managed care organizations, pediatric primary care providers, specialty providers, and state chapters of AAP. States may also engage early intervention programs, schools, child welfare agencies, and social service organizations. Systems mapping was a successful tool used by the SIG states to identify key partners for engagement in medical home efforts.

**Engage and sustain family partnerships through ongoing opportunities, training, and financial compensation:** Families of CYSHCN are key partners in systems integration efforts based on their expert capacity to identify the gaps and barriers in systems serving CYSHCN, inform strategies and policies to better serve CYSHCN, and lead continuous quality improvement efforts to support medical home implementation. However, it is not enough to engage them as partners during implementation, these partnerships need to be sustained. Sustaining family partnerships requires a multi-pronged approach, which includes:

- Creating a range of opportunities for families to serve as partners that have varying levels of commitment;
- Training families of CYSHCN to build their capacity to serve as leaders in systems integration efforts; and
- Compensating families for their participation in systems integration activities, such as providing stipends for their time and child care and reimbursing for travel expenses.

Additionally, family partners should reflect the diversity of the state or region, factoring in race and ethnicity, language, socioeconomic background, gender, and geographic locations. Sustaining and engaging diverse family partners is challenging for states. It requires substantial time and resources to cultivate relationships with families, support them in their involvement in systems integration activities, and provide materials, resources, and meetings in culturally and linguistically appropriate ways. However, all SIG states recognized that partnering with families was a critical component of their efforts. A majority leveraged their state's Family to Family Health Information Center, which is a family-staffed, nonprofit organization that assists CYSHCN and their families in navigating health care systems and programs, in their efforts to support and sustain family engagement.

**Develop the data and information systems needed to support systems integration for CYSHCN within the state:** Supporting systems integration requires the collection, tracking, and reporting of data and quality metrics to promote continuous improvement and ensure that these efforts are generating positive outcomes. To support data and quality measurement, many SIG states considered the availability of existing data, gaps in data, and strategies to address those gaps. State data about issues that are critical to the care of CYSHCN, such as referrals, may already exist but it may not be accessible or fully utilized to evaluate and improve the system. The data needed to track and assess specific components of the system, such as the use of a shared plan of care or the quality of care coordination, may not exist, necessitating a new measure to be implemented, tested, and/or collected.

Additionally, challenges to the exchange of data and information exist and are often compounded for CYSHCN due to the complexity of the systems serving them. For example, interagency data systems often are not linked, limiting the ability to share data across agencies that could be used to monitor and improve care quality and outcomes for CYSHCN. At the health system level, providers might lack integrated lab, pharmacy, or diagnostic systems, which can perpetuate fragmentation in care and impede their care coordination efforts. Providers may also lack an understanding of what is allowed by HIPAA

and FERPA, which are federal laws regulating the use and disclosure of information. To address such barriers, states can explore opportunities to develop interagency data-sharing agreements – a common approach used by the SIG states – and support technological systems improvements, such as access to electronic medical records.

**Promote coordination and communication as the cornerstone of systems integration for CYSHCN:** In advancing medical homes for CYSHCN, states are emphasizing the need for improved care coordination across various systems and providers serving CYSHCN and their families. Using care coordination to achieve improved coordination and communication may require a culture shift for providers and families as they adapt to this new model of care. The SIG states recognized the necessity and benefit of educating families of CYSHCN, providers, and others involved in their care about the value of care coordination, as well as training them in their roles within the care team and, in states implementing shared plans of care, in the development and use of the shared plan of care. Improved communication may also require states to address language and cultural barriers. They can do so by applying Culturally and Linguistically Appropriate Services (CLAS) standards to their systems integration efforts, including making tools and resources, such as the shared plan of care, available in multiple languages and at appropriate literacy levels, and providing interpreters.

**Align medical homes for CYSHCN with ongoing health system transformation reform efforts:** Payment and delivery system reform initiatives are underway across states, many with a focus on advancing medical homes. As states work to integrate systems serving CYSHCN, they can explore opportunities to align or leverage these efforts with other health reform initiatives that may be active in the state. For example, as states increasingly enroll CYSHCN into Medicaid managed care programs, they have the opportunity to work with managed care organizations to strengthen the provision of care coordination services for CYSHCN and help connect them to medical homes.<sup>33</sup> Additionally, states are implementing alternative payment models that can support critical activities that have not traditionally been covered under fee-for-service systems, such as care coordination. One such initiative is the federal Comprehensive Primary Care Plus (CPC+), which is a multi-payer payment reform program that is strengthening the delivery of primary care by providing care management fees and performance-based payments, and emphasizes the role of medical homes and care coordination.<sup>34</sup> In aligning with and building on these initiatives, states can ensure that their efforts to advance systems integration for CYSHCN and improve quality and outcomes for broader populations are moving toward shared goals, and will help to promote efficiencies and sustainability of these efforts.

## Conclusion

The SIG states continue to make progress in advancing the use of medical homes for CYSHCN by strengthening care coordination, supporting the integration of services and supports, and improving access to them. They demonstrated that a multitude of approaches can be applied to systems integration efforts. In developing shared plans of care, the SIG states tailored their design and implementation strategies to ensure the shared plans of care could facilitate effective care coordination within their state's system of care. While nearly all states implemented a shared resource that was functionally the same, they took different approaches to their development in order to maintain and sustain the shared resource within their unique state environments. The SIG states also formed cross-system partnerships either between state agencies or between providers based on where they identified the need for more effective integration of care. A common thread underlying all of these strategies across all SIG states was the engagement of families as partners and leaders in this work. The strategies pursued represented significant undertakings by the states, and while none of these strategies alone are sufficient for moving the needle on medical homes forward for CYSHCN, their culminating effects can lead to the improved health and well-being of CYSHCN and their families.

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## Appendix

The following table provides an overview of the strategies implemented by State Implementation Grant states in order to effectively develop a shared resource, improve cross-system care coordination, and promote integrated care through the development of an interagency agreement. It also includes links to select resources that states have developed or are using to support medical homes for children and youth with special health care needs (CYSHCN) and to advance systems integration.

State	Improving Cross-System Care Coordination		Developing a Shared Resource	Integrating Care through Interagency Agreements	Additional State Resources to Advance Systems Integration for CYSHCN
	Target Population	Approach to the Shared Plan of Care (SPoC)			
Alaska	Children with complex needs in pilot elementary schools served by the pediatric medical home partner	Short-term: Increase school nurse coordination with medical home partner through written agreement and established protocol  Long-term: Electronic SPoC via an electronic platform	<a href="#">Help Me Grow Alaska</a>	Alaska leveraged its partnership with Help Me Grow to establish referral feedback loop procedures as part their contract.	<a href="#">Alaska CYSHCN State Plan 2016-2021</a>
Colorado	CYSHCN receiving services through HCP (the state Title V-funded care coordination program).	Both paper-based and electronic SPoC, including electronic medical records (EMRs), format varies	Colorado leveraged the statewide 2-1-1 information and resource system to enhance information and strengthen referrals for CYSHCN and their families.	Colorado promoted the development of care compacts that strengthen communication between State Innovation Model (SIM) primary care practices that serve CYSHCN and behavioral health service providers. Care compacts are essentially a communication tool that defines roles, responsibilities, and processes to coordinate care between health care team members.	<a href="#">What is the Value of a SPoC?</a> <a href="#">How Does HCP Support a Medical Home Approach?</a> HCP Universal <a href="#">Referral Form</a> and <a href="#">Consent and Release Form</a> <a href="#">Consent and Release HCP Talking Points</a> <a href="#">Tips for Providers When Using Interpreter Services</a>
Connecticut	CYSHCN with high CT HOMES Complexity Index (a tool used to determine the complexity of care required for a child)	Piloted an electronic version of the SPoC	<a href="#">Child Development Infoline</a> (CDI)	Connecticut established a memorandum of agreement (MOA) between the Departments of Health and Social Services to allow for collaboration and data-sharing through MAVEN, a state-based electronic platform that supports case management. The MAVEN data-sharing platform inclusive of SPoC has not yet been launched as the state is evaluating privacy concerns in sharing information.	<a href="#">CT Shared Plan of Care Template</a> <a href="#">CT's Care Coordination Collaborative Infrastructure</a>

State	Improving Cross-System Care Coordination		Developing a Shared Resource	Integrating Care through Interagency Agreements	Additional State Resources to Advance Systems Integration for CYSHCN
	Target Population	Approach to the Shared Plan of Care (SPoC)			
Indiana	CYSHCN with a neuro-developmental diagnosis targeted for care coordination in eight participating practice sites	Paper-based SPoC, which is scanned into EMRs	Using social media and listservs to share resources with families and providers	Indiana focused on formalizing a relationship between the Department of Health and Medicaid agency, and has been exploring a memorandum of understanding (MOU) to support care coordination.	<a href="#">Care Coordination Resources</a> , which include a series of short videos explaining care coordination, the SPoC, and how to set care coordination goals.
Iowa	CYSHCN enrolled in Child Health Specialty Clinics' Pediatric Integrated Health Home program	Electronic SPoC via an electronic platform	<a href="#">Iowa Child Health Connections</a>	Iowa implemented MOAs with its SPoC Implementation Workgroup members who represent health plans, providers, and cross-system agencies, in order to obtain commitment to develop and implement a strategy to expand the use of SPoC in the state.	<a href="#">Iowa's State Plan for Integration of Services for CYSHCN, 2015</a> <a href="#">SPoC Flyer for Families</a> <a href="#">SPoC Flyer for Care Team Members</a> <a href="#">ACT.md Flyer</a>
Kansas	Children (ages 8–12) with ADHD, asthma, or obesity	Paper-based SPoC that are scanned into EMRs	Help Me Grow Kansas	Kansas is establishing an MOA between three agencies (Departments of Health and Environment, Education, and Children and Families) that incorporates the National Standards for Systems of Care for CYSHCN into a shared vision for early childhood programs and systems in the state.	<a href="#">Kansas SPoC and Action Plan Template</a>
Massachusetts	CYSHCN in two pilot practices: family medicine practices and a specialized program for CYSHCN in a community health center	Developing and testing SPoC tool on paper and in an EMR	The Resource Place (an online searchable resource directory)	Massachusetts developed an MOU between its Department of Public Health Title V Division for CYSHN and Part C Early Intervention Program, and piloted a referral feedback loop protocol.	<a href="#">Care Coordination for Children and Youth With Special Health Needs</a>
Minnesota	Children with medical complexity with pilot testing in four primary care practices	Provide examples of SPoC that meet best practices to clinics. Clinics use both paper-based and electronic SPoC.	<a href="#">Children and Youth with Special Health Needs Navigator</a>	Minnesota is revising a Title V Interagency Agreement with the state Medicaid agency in order to facilitate data-sharing to improve population health for CYSHCN populations.	<a href="#">Interagency Consent and Release of Information Form</a>
Mississippi*	CYSHCN enrolled in the MS Children's Medical Program	Developing a SPoC that can be piloted through an EMR	<a href="#">Mississippi Families for Kids</a>	Mississippi is pursuing interagency agreements between the University of MS Medical Center (Complex Care Medical Clinic), Part C Early Intervention, and the Division of Medicaid to advance care coordination for CYSHCN.	<a href="#">Child &amp; Adolescent Health Referral Form</a>
New Jersey	CYSHCN served by Special Child Health Services Case Management Units (SCHS CMUs)	Paper-based SPoC, with a printable template available online in English and Spanish	<a href="#">Special Child Health Service Case Management Units</a>	New Jersey developed linkage agreements for use between SCHS CMUs and providers and between the Statewide Parent Advocacy Network and providers in order to strengthen referral systems for CYSHCN.	<a href="#">New Jersey SPoC</a> <a href="#">SPoC Guides for Families and Youth</a>

State	Improving Cross-System Care Coordination		Developing a Shared Resource	Integrating Care through Interagency Agreements	Additional State Resources to Advance Systems Integration for CYSHCN
	Target Population	Approach to the Shared Plan of Care (SPoC)			
Oregon	CYSHCN with asthma, who are medically and/or socially complex, and/or who live in rural areas.	Both paper-based SPoC and electronic versions (the format varies based on the participating practice)	<a href="#">Oregon 211</a>	Oregon developed agreements to support its pilot of referral feedback loop protocol with education service districts, medical homes, and behavioral health agencies.	<a href="#">Oregon SPoC Template</a> <a href="#">SPoC Tools and Resources</a> <a href="#">Closing the Referral Loop for Medical Homes Serving Children and Youth with Special Health Needs</a>
Rhode Island	All CYSHCN in the following state programs: Cedars, Pediatric Practice Enhancement Project (PPEP), and PCHM-Kids	Using both paper-based SPoC and electronic versions embedded in an EMR	<a href="#">RIPIN Call Center using the RI Medical Home Portal</a>	Promoted the use of KIDSNET (a statewide health data database) that supports care coordination for CYSHCN to community providers through the establishment of MOUs between the Department of Health, Department of Education, and the Executive Office of Health and Human Services.	<a href="#">Rhode Island State Plan 2015-2020 -Supporting Children and Youth with Special Needs</a> <a href="#">RI Medical Home Portal Web-Based Resource for Children and Youth with Special Needs</a> <a href="#">KIDSNET Reference Guide for Care Coordinators</a>
Utah	CYSHCN who receive direct clinical services from the Utah Bureau of Children with Special Health Care Needs	The SPoC is created within the EMR and shared with families as a printed copy or via a patient portal built into the EMR.	<a href="#">Medical Home Portal</a>	The Utah Department of Health developed MOUs with the Up to 3 Early Intervention Program, Utah Valley University Melisa Nellesen Center for Autism, and Utah Valley University to ensure collaboration and communication throughout the referral and feedback process.	<a href="#">Medical Home - School Information Release</a> <a href="#">Medical Home/School – Evaluation and Services Form</a> <a href="#">Pediatric Care Coordination Information Checklist</a> <a href="#">Utah Policy and Procedures for Creating SPoC</a>
Vermont	CYSHCN receiving care through the 14 participating practices	Using paper-based SPoC and electronic versions embedded in the EMR and via an electronic platform	<a href="#">Help Me Grow Vermont</a>	The Vermont Department of Health’s (VDH) Maternal Child Health (MCH) Division developed an agreement with the Department for Children and Family (DCF) Children’s Integrated Services (CIS) to strengthen collaboration between CIS staff and CYSHN social workers. An MOU between VDH MCH and DCF has been drafted that will ensure that on a regular basis a list of all children in DCF custody will be provided to VDH for the purpose of notifying involved care coordinators. VDH MCH and the Department of Aging and Independent Living Children’s Services Division are also working to refresh the process by which families can chose to bundle various funding streams into one unified services plan or “disability services waiver.”	<a href="#">Care Coordination Payments Guide-VT</a> <a href="#">Family Health Partner Fact Sheet-VT</a> <a href="#">Help Me Grow VT Referral Form</a> <a href="#">“Six Ways to Medicaid” resource for families</a>

State	Improving Cross-System Care Coordination		Developing a Shared Resource	Integrating Care through Interagency Agreements	Additional State Resources to Advance Systems Integration for CYSHCN
	Target Population	Approach to the Shared Plan of Care (SPoC)			
Washington	CYSHCN receiving services from three maxillofacial review boards	Using both paper-based SPoC and electronic versions embedded in EMR	<a href="#">WithinReach</a>	Washington developed an agreement between the Departments of Health and Early Learning to implement a policy for closing the feedback loop between family resource coordinators and primary care providers.	<a href="#">Practice Guide for Medical Homes for Washington's Early Support for Infants and Toddlers (ESIT) Program</a>
Wisconsin	Children with medical complexity, ADHD, and juvenile rheumatoid arthritis	Using both paper-based SPoC and electronic versions embedded in EMR	<a href="#">Wisconsin MCH First Step</a>	Wisconsin established an MOA between the Departments of Health Services and Early Learning to facilitate communication between physicians and the early intervention program.	<a href="#">Wisconsin Care Coordination for Children and Youth Mapping Project</a> <a href="#">Wisconsin State Plan to Serve More Children and Youth with Medical Homes</a> <a href="#">What is a Medical Home?</a> (brochure for families)

\* The information NASHP compiled about this state was not confirmed by the state's MCH/CYSHCN Title V program.