

National Resource Center

**FOR PATIENT/FAMILY-CENTERED MEDICAL HOME**

***Meeting the Care Needs of CYSHCN and Their Families: Implementation of Equitable Care Coordination***

**Webinar**

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**Questions and Answer Document**

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The National Resource Center for Patient/Family-Centered Medical Home (NRC-PFCMH), in partnership with the National Center for Care Coordination Technical Assistance (NCCCTA) and Family Voices of Wisconsin and Wisconsin Title V, hosted a webinar on the role of care coordination in supporting equitable care for children and youth with special health care needs (CYSHCN) and their families.

This document notes questions asked by participants that were not answered during the live webinar due to time constraints. The faculty provided answers to these questions following the webinar

Questions	Answers
<p><b>What does CoIIN stand for?</b></p>	<p>“CoIIN” is the acronym for the Collaborative Improvement and Innovation Network.</p> <p>Wisconsin (WI) was one of ten states participating in the <a href="#">Collaborative Improvement and Innovation Network (CoIIN) to Advance Care for Children with Medical Complexity</a>. WI focused on two initiatives throughout the project:</p> <ol style="list-style-type: none"> <li>1) Improving enrollment in the Children’s Long Term Support waiver.</li> <li>2) Developing and implementing “Goal Cards” to spur discussions about goal that matter most to the child and family as part of the shared plan of care (SPoC).</li> </ol>
<p><b>How has the Wisconsin team, Family Voices and Title V, worked to build trust and relationships within Tribal Health Centers and Tribal communities within the state?</b></p>	<p>Wisconsin started working with the Tribal Health Centers in 2017. Over these years, it has been through ongoing individual team in-person and virtual meetings, team learning community calls, cultural respect and learnings, listening, and dedicated technical assistance/support. With this consistency, WI continues to build trust and relationships with the Tribal Health Centers. There has been significant staff turnover within the Tribal Health Centers which has made it challenging, especially during COVID-19.</p> <p>Grant Funding: The Title V Maternal and Child Health (MCH) Services Block Grant creates Federal-State-Local partnerships to develop state and local systems to meet the critical challenges facing women, children, and families. States are required to use at least 30% of the Title V Block Grant funds for preventive and primary care programs serving all children; and at least another 30% of these funds must support programs for children and youth with special health care needs in local and Tribal communities across WI.</p> <p>Funding is provided by the WI Children and Youth with Special Health Care Needs (CYSHCN) Program, located in the Family Health Section, Bureau of Community</p>

	<p>Health Promotion, in the Division of Public Health, Wisconsin Department of Health Services (DHS).</p> <p>Each WI Tribe (Tribal Health Centers/Clinics) is eligible for \$10,000 including \$10,000 to the Gerald L. Ignace Indian Health Center, Inc. in Milwaukee to support implementation of family-centered care coordination with children and youth with special health care needs. The <a href="#">WI Title V, CYSHCN Program</a> and the <a href="#">WI Medical Home Initiative</a> staff provide support and ongoing technical assistance to Tribal Health Center/Clinic staff. Most of the technical assistance is in the form of sharing expertise and program related ideas and implementation opportunities. Staff reports are appreciative of “thinking outside the box.”</p>
<p><b>How does the Wisconsin team define children with special needs?</b></p>	<p>In WI, CYSHCN are defined by the Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau (MCHB) as:</p> <p>“...those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”</p> <p>The WI CYSHCN Program works to improve systems of care for anyone from birth through age 21 with a chronic physical, developmental, behavioral, or emotional illness or condition. Some examples include attention deficit and hyperactivity disorder, asthma, autism spectrum disorders, childhood cancers, cerebral palsy, deaf or blind, diabetes, Down syndrome, heart disease, and mental health conditions.</p>
<p><b>How is the Wisconsin’s Health Information Exchange set up so SPoC are accessible to all providers involved in the care of CYSHCN?</b></p>	<p>Wisconsin’s health information exchange is called <a href="#">WISHIN</a> which includes more than 1,000 health care organizations including clinics, long term care providers, health plans, care coordinators and others who have access and can share information with WISHIN.</p> <p>Wisconsin healthcare maintenance organizations (HMOs) have requirements to share care plan information into WISHIN. In 2019, the WI Department of Medicaid Services (DMS) was working on a Care Plan Integration project that included</p>

	<p>researching care plan templates and a process to identify core elements of the care plan. This is a requirement for WI HMOs; and WI DMS wanted to open the opportunity for a variety of stakeholders to inform the process (in addition to HMOs). Wisconsin’s two complex care clinics participated in these efforts. At this time, we are not aware of any pediatric clinic/health system that is sharing SPoC’s through the health information exchange.</p>
<p><b>What agency/department within WI does the Medical Home Initiative reside?</b></p>	<p>The Medical Home Initiative with Children’s Health Alliance of Wisconsin is funded by the WI Department of Health Services’ Title V CYSHCN Program and the Maternal Child Health Program located in the Division of Public Health.</p>
<p><b>Did Wisconsin identify “family navigators” that can support the family in SPoC?”</b></p>	<p>In the Medical Home SPoC Quality Improvement grant project, we worked with 24 health clinics/systems over a 5-year period. Each team was unique. Some of the teams had family navigators on staff. Each team had one pediatric primary care clinician, (pediatrician, family physician, pediatric nurse practitioner or physician assistant), one care team member (nurse, medical assistant), and at least one family member. Teams were strongly encouraged to have support from administration and include personnel from the following areas: social work, care coordination, information technology, and quality improvement. This included family navigators if the clinic/system had available. <a href="#">Family Voices of Wisconsin</a> and the <a href="#">Regional Centers for Children and Youth with Special Health Care Needs</a> provided connection to services and supports for families and the health care providers.</p>
<p><b>Could someone explain a bit more about care mapping that the families are taking to the providers? Is there a standardized care mapping tool that was used that could be shared with this group? Was the care mapping tool changed as a result of this project and from family input?</b></p>	<p>A Care Map is a visual way to show all the people and services involved in caring for and supporting a child with special health care needs. Each family’s care map may look different as each family decides how many details to include. Sharing their care map is one-way families may communicate their family’s needs and goals with their provider. It is a tool to use to show all the organizations the family is working with and how their health care team may help coordinate many of the services their child needs. When creating a care map, families are encouraged to think about who they may want to share the care map with and who would benefit from the information (provider, home health, school, daycare, other agencies).</p>

	<p>Wisconsin developed the <a href="#">C.A.R.E. Medical Home Series for Families</a> to support families who have children or youth with special health care needs. It is a series of four presentations and discussions:</p> <ul style="list-style-type: none"> <li>○ <b>Caring for the Whole Family</b></li> <li>○ <b>Assembling a Care Notebook</b></li> <li>○ <b>Requesting a Shared Plan of Care</b></li> <li>○ <b>Exploring Care Mapping</b></li> </ul> <p>The <i>Exploring Care Mapping</i> presentation includes <a href="#">sample care maps</a> and <a href="#">care map categories</a> to consider.</p>
<p><b>Can you describe how school nurses were involved in the project (for school aged children)? For example, were school nurses invited to team meetings or were the SPoC provided to school nurses so they could incorporate them into their nursing care plans?</b></p>	<p>In the Medical Home SPoC Quality Improvement grant project, we worked with 24 health clinics/systems. Teams encouraged families to share their child’s SPoC with their schools, camps, home health and other agencies. In one instance, health care team members accompanied a family and their child to a meeting with the school nurse and teacher to discuss potential side effects of the child’s medications.</p>
<p><b>Any plan to focus on health systems within the state to teach them about care coordination and how to implement within the systems?</b></p>	<p>The SPoC Quality Improvement grant project (2016-2020) focused largely on supporting health care systems to coordinate care within or across the health care system. The WI CYSHCN Network provided a variety of support for health care teams to advance their care coordination goals. This included funding, training, convening a learning community and an annual conference each year. In 2021, our focus pivoted to support clinics to coordinate and connect families to organizations outside of the health care system. Many health systems in our communities have mechanisms to share information within the healthcare system and this is not the case when a family needs to be connected to services outside of the health care system (early intervention services, food, nutrition, etc.).</p>
<p><b>Have you found a way to identify a standard RN care coordinator to patient ratio that allows for equity for all families served?</b></p>	<p>As a Network, we did not conduct a review on nurse patient ratios needed for effective care coordination services. There is significant variation in how coordination services are offered, when available. In two of WI’s Complex Care clinics, there are nurses and social workers who are coordinating care. Other clinics that we worked with did not have a dedicated staff person to coordinate care. Nurses are one category of care coordinators and work with kids and families who have more complex or specialized health conditions. For kids who have chronic</p>

	<p>health conditions, a family navigator could provide coordination services. For families and children who have chronic health conditions and experience complex social and economic circumstances, a community health worker could provide coordination services.</p>
<p><b>A lot of the care coordination and transition planning programs occur in large health care systems. How can we integrate these activities into smaller settings?</b></p>	<p>There may be several ways to integrate these activities into smaller settings. Consider reaching out to other organizations in your community to determine how you could coordinate services for a shared population of kids. This might include community health worker groups or organizations in your community that have relationships and trust with community members.</p> <p>Teach families to advocate for this type of care. In small, rural communities start a parent advisory board to gain family/caregiver trust and direction.</p>

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