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Children's Health
Alliance of Wisconsin

Shared Plan of Care for Children and Youth With Special Health Care Needs

The purpose of a Shared Plan of Care (SPoC) is to achieve better, safer, more coordinated care resulting in improved outcomes for children and families. A core strategy is to strengthen the relationship through the creation and use of a plan of care. This tool can support communication, collaboration and comanagement between primary care, subspecialists and community partners, offering a complete picture of a child's health with a longitudinal view.

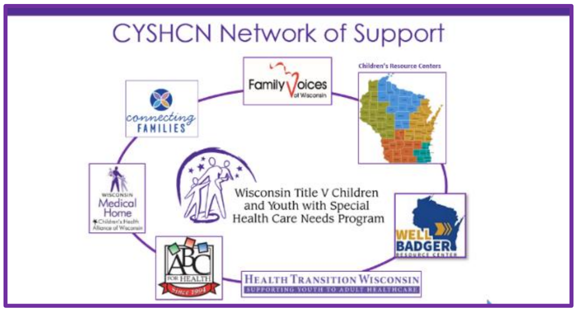
A **SPoC** is a living document completed by parents and health care providers that includes information necessary to assure issues affecting a child's health are identified and accessible across systems, and that activities and accountability for addressing those activities are documented.

Key Components include:
- Medical summary
- Family strengths and preferences
- Negotiated plan of action (including clinical and family goals, actions to address goals, responsible partners and timelines)
- Other necessary attachments such as emergency plans, chronic condition protocols and relevant legal documents (i.e., Individualized Education Programs [IEPs] or 504 plans)

In September 2014, the Wisconsin Department of Health Services' (DHS) Children and Youth with Special Health Care Needs (CYSHCN) program embarked on the Wisconsin medical home initiative's Systems Integration Grant (SIG) project, a three-year Health Resources and Services Administration (HRSA) grant initiative. This project had five overarching goals and sought to enhance Wisconsin's ability to coordinate policy, program development and collaborative partnerships at state and local levels to increase the number of CYSHCN who receive a family-centered medical home approach to comprehensive services and supports. The project team crafted the Wisconsin Medical Home State Plan which outlined short- and long-term objectives, and recognized care coordination as an essential element.

Between 2016-20, the CYSHCN program aimed to support testing the implementation of SPoCs. The goal was to have more families and clinicians aware of, and implementing, medical home standards of care for CYSHCN, in collaboration with professionals from other sectors. As part of the SIG, grant projects were made available to a total of five health care teams in 2016-17 (grant funding was provided by the Title V Wisconsin CYSHCN Program). Although advancing use of SPoC was not part of the original SIG project, the work evolved at a steady pace and grew to become a key initiative of the state's Maternal Child Health Title V block grant.

Over five years, 24 clinics from 18 different health systems and 11 Tribal Health Centers collectively participated in creating, piloting and implementing SPoCs within their clinical setting and with families. Each care team selected to focus on a population of children, addressing diverse health conditions such as Attention-Deficit/Hyperactivity Disorder (ADHD), down syndrome, Juvenile rheumatoid arthritis (JRA) and complex medical conditions. Some teams piloted for a single year, while others engaged in multi-year efforts.



Teams had flexibility in their approach, choosing to adopt an existing model or develop their own. Additionally, some teams incorporated a focus on youth health transition as part of their projects. This initiative allowed teams to tailor their work to meet the unique needs of populations they serve while fostering innovations to improve care coordination. Finally, to measure progress, teams were also required to complete quarterly surveys, and participating families were also invited to share feedback through anonymous quarterly surveys. Regular learning community calls and an annual in-person meeting supported learning.

This report summarizes five years of feedback from families, capturing progress, barriers, lessons learned and opportunities for improvement. Insights from surveys collected during the initiative are organized into three categories: 1) designing the tool, 2) challenges and 3) benefits.

Designing the Tool

Creating SPoCs begins with small-scale testing through quality improvement, alongside building a shared understanding with families of its purpose, use and benefits. The SPoC should incorporate clear, simple language accessible for various professionals and be thoughtfully developed over time in partnership with families. Consideration of its content and potential users are also important points of ongoing discussion.

Learning

- Engage families early to:
  - Gauge interest – developing a SPoC requires additional time
  - Discuss what a SPoC is, how it could be used and its benefits
  - Review what information is documented and potentially shared
- Consider what kind information is on the SPoC, and how it might be shared – sensitive information can't be shared and different families are comfortable with sharing different types of information

Development of the SPoC

- Introduce the SPoC at earlier stage of a child and family's journey
- Have a user-friendly layout that is readable – especially for those outside the medical community
- Use plain language
- Create a universal resource tailored to specific family goals and desires

Expanding Use

- Transitioning SPoCs to digital formats can increase accessibility
- Integrate SPoCs into other areas within your organization (like early intervention programs, specialty care and mental health services)
- Utilize SPoCs to bridge information gaps across departments or organizations (i.e., pediatric to adult health care transitions)

Potential Challenges

Developing and implementing SPoCs requires a period of testing and refinement for health care teams to understand their use and value, as well as how to engage families effectively. Over time, teams can adapt and adopt processes to incorporate SPoCs into visits – reviewing information, ensuring the plans remain relevant for families and a variety of situations they encounter, though not all families may find them useful.

Considerations

- Developing and implementing SPoCs requires significant time and effort, with a learning curve for both health care teams and families
- Families placed an emphasis on SPoCs being most beneficial when they are regularly updated with the most relevant information
- Not every family found utility in the SPoC; some participants found it very helpful, others mention not using the SPoC, or not referring to them frequently

SPoC Benefits

A SPoC supports families by facilitating the exchange of information across organizations and situations. It allows families to share relevant details with key organizations such as schools, children's long-term support programs, legal entities and emergency responders. As a central source of information, the SPoC can simplify communication, reduce the burden on families to share details and ensure critical information is accessible to all team members. This support can be especially vital during a child's hospitalization or transfer between entities, or helping bridge gaps between departments like primary care and mental health.

69%

Families reported improved communication with health care providers and 61% with other service providers (schools, social services)

84%

Care teams reported improved communication and collaboration with families

65%

Families reported the SPoC helps make sure that more of their child's needs are met

Family-Centered Care

- SPoCs help families clearly outline their goals, document child's medical information, identify team members and share preferences

Improved Communication and Coordination

- Facilitates sharing of medical information, reducing the need for families to repeat details – especially in emergency situations
- Facilitates shared expectations, where parents said they knew what to expect

- Provides support for families managing special situations allowing them to share information in a variety of situations including: camps, schools, travel, emergency situations, etc.
- Informs other health care providers about the child's medical history and goals

Adaptability

- SPoCs can be customized for children with diverse health conditions and tailored to family goals and desires, such as: ADHD, down syndrome, JRA and complex medical conditions
- Families were able to integrate the care plan with school systems, legal settings, therapists, program requirements and others
- Involves various professionals including doctors, therapists, school staff and community workers

Conclusion & Testimonials

The implementation and use of SPoCs over the five-year period has demonstrated progress in enhancing care coordination and communication for CYSHCN. A core strategy is to strengthen the relationship among children, families and their health care team, through the creation and use of a plan of care. Key findings highlighted that having a SPoC was beneficial for some families, but does not work for everyone. Additionally, feedback revealed that using these plans with schools, early intervention and other agencies helped to strengthen communication, and in some cases, a more seamless experience for families. Despite the challenges inherent in developing and implementing SPoCs, the initiative highlighted the potential for improvements in communication, accessibility and family engagement.

Provider Testimonials

"The shared plan of care has allowed us to reach out to teachers, school counselors, siblings and other family members to help them understand the patient's ADHD issues more fully and ask clarifying questions to help the child at their level."

"By having a SPoC, our organization has been able to communicate the families' high priority items more efficiently to the health care team. It allows for more seamless communication between all members of the care team."

"This year was challenging to get families to enroll. I struggled all throughout the year to get the 10 families to enroll. The diagnosis that was chosen did not have a large population of patients with severe illness. The mild illness patients voiced that they didn't feel the care plan would be very useful for them. This year I feel that the shared plan of care was not very useful for my patient population."

"It has been difficult to get a family to commit to this project, as they all are busy.; I think the more I am understanding what this tool is the easier it is to explain to families."

"It's been difficult getting parents/caregivers interested with partnering with this project. It also takes a while to finalize the SPOC. Families are following up with several different appointments and changes are always made with their plan of care. It's almost difficult to keep up with the constant changes."

Family Testimonials

"It's helpful to have it listed out who is in charge of managing what and to have to do lists spelled out as to what is our responsibility to do versus what the care team is working on for our child.”

“Hospice can access his plan of care which means that I have a smaller role in coordination and devote my time to other issues regarding my son.”

“It was easier to just send the care plan with him then have to explain things over and over.”

“I honestly never look at it except to update it with the Complex Care team. So, I guess it helps them to coordinate when we are inpatient.”

“It is such a good model, but the layout is difficult to read and comprehend for people outside the medical community who know my child. Also, the font, spacing and readability is hard... could it look more like the inpatient discharge papers - those are blocked, bullet Pinter and easier to follow.”

References and Links

1) Lucille Packard Foundation. Achieving a Shared Plan of Care with Children and Youth with Special Healthcare needs accessed on Oct 10, 2024 from https://lpfch.org/resource/achieving-a-shared-plan-of-care-with-children-and-youth-with-special-health-care-needs/

2) America's Health Rankings analysis of National Survey of Children's Health, U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB), United Health Foundation, AmericasHealthRankings.org, accessed 2024.