

# **Advancing Family-Centered Care Coordination QI Project using a SPoC**

## **Learning Community**

October 22, 2019



## Advancing Family-Centered Care Coordination using a Shared Plan of Care QI Project

### Learning Community Call

October 22, 2019

12:00 – 1:00pm CST



#### Meeting Information:

Zoom Meeting Room: <https://zoom.us/j/3933567720>

To join by phone: 1-408-638-0968

Meeting ID: 393-356-7720, then enter Participant ID (shown on your screen)

<b>Welcome &amp; Introductions</b>	12-12:10
<b>Outcomes/Q1-Q3 Survey Data Highlights</b> <ul style="list-style-type: none"> <li>• Driver Diagram and Family of Measures</li> <li>• Survey Results and discussion</li> </ul>	12:10-12:20
<b>Using QI Framework to Advance Use of Shared Plans of Care (SPoC)</b> <ul style="list-style-type: none"> <li>• Sharing Experiences: <ul style="list-style-type: none"> <li>○ CHW/MCW-Rheumatology Department</li> <li>○ All teams: What's working well? What's challenging?</li> </ul> </li> </ul>	12:20-12:40
<b>Goal Setting with Families</b> <ul style="list-style-type: none"> <li>• Guest Speaker: Arianna Keil, MD <i>"Hopes and Dreams" and "Family Vision Statement" vs Actionable Goals</i></li> </ul>	12:40-12:55
<b>Wrap up &amp; Next Steps</b> <ul style="list-style-type: none"> <li>• Oct 28: Informational Call for 2020 competitive SPoC grant (12-1p)</li> <li>• Nov 1: Tribal Health Center Work Plans due (send to Leah Ludlum)</li> <li>• Nov 8: MOC Part 4 credits (Colleen will send email to interested Pediatricians to complete attestation forms)</li> <li>• Dec 2: Applications due for 2020 competitive SPoC Grant (online)</li> <li>• Jan 3: Q4 surveys due</li> </ul>	12:55-1:00

Health Center	Population
Amery Hospital and Clinic	Children with emotional/behavioral challenges
Children's Hospital of WI-Complex Care Clinic	Children with medical complexity who are 12 yrs old or older
Children's Hospital of WI-Rheumatology Clinic	Children/adolescents with chronic rheumatic disease
Forest Co Potawatomi Health and Wellness Center	Children/youth diagnosed with global developmental delays and/or Autism Spectrum Disorder
Gerald L. Ignace Indian Health Center	Children with ADHD
Lac Courte Oreilles	Children with special health care needs receiving care outside of the agency
Peter Christensen Health Center (Lac du Flambeau)	Children with chronic special health care needs including behavioral health

Health Center	Population
Prevea Pediatrics	Pediatric rheumatology patients
St. Croix Tribal Health Clinic	Children with special health care needs including emotional or behavioral health
Sokaogon Chippewa Health Clinic	Children with medical complexity/behavioral health
Stockbridge Munsee Health and Wellness Center	Children with asthma (0-18 yrs old)
UW Health AFCH – Pediatric Complex Care Program (Ehlenbach)	Children with medical complexity
UW Health AFCH – Pediatric Complex Care Program (Sodergren)	Children with medical complexity (ages 12-21)
Waisman Center – Newborn Follow-up Clinic	Children less than 36 mo of age who spent time in neonatal intensive care units

# Why SPoC? For Whom?

- >20% of **WI children and youth have some type of special health care need** anticipated to last at least a year and requiring services and supports beyond those of other children
- Fragmentation of care is common, and **families** often shoulder a disproportionate share of the care coordination burden
- Care plans developed with families may help reduce hierarchical relationships between health care providers and parents, improve reciprocal information exchange, and strengthen relationships

Wisconsin report from the 2001/12 National Survey of Children's Health.

Adams S, Cohen, E, Mahant S, et al. Exploring the usefulness of comprehensive care plans for children with medical complexity (CMC): A qualitative study. BMC Pediatrics. 2013; 13:10.

## 2019 Advancing Family-Centered Care Coordination using a Shared Plan of Care Learning Community QI Project

AIM	Drivers	Tests of Change Ideas
By December 31, 2019, 85% of families will agree/strongly agree that the SPoC helps ensure more of their child's needs are met	Clinicians and care team members understand value of SPoC	<ul style="list-style-type: none"> <li>• Different versions of shared plans of care (previous vs plans containing 3 essential elements)</li> <li>• Use of SPoC with different groups within selected population (different levels of education, different economic resources, different condition severity)</li> <li>• Review best practice literature on development and use such as <a href="#">"Achieving a Shared Plan of Care with Children and Youth with Special Health Care Needs."</a></li> <li>• Partner with Family Voices, Regional Centers, Parent 2 Parent to provide support and resources for families</li> </ul>
	Families and youth understand value of SPoC	<ul style="list-style-type: none"> <li>• Use of strategies for communicating with families when enrolling in pilot, developing SPoC (such as <a href="#">letters of introduction</a> or recruitment, scripts for in-person conversations, <a href="#">cover pages on SPoC</a> to explain how families might choose to use document)</li> <li>• Explain "personal goals" section of SPoC using accessible language ("What matters to you?"/"What's important to you?" versus "What are your goals?")</li> <li>• Dedicated staff member to explain and develop SPoC</li> <li>• Promote WI Family Voices' <a href="#">Coordinating your Child's Health Care</a> training among enrolled families</li> </ul>
	SPoC improves the quality of communication	<ul style="list-style-type: none"> <li>• Use strategies to empower families to communicate with other health systems, agencies about the SPoC (test scripted language)</li> <li>• Share SPoC with emergency department clinicians and care team members, hospitalists, other clinical care providers</li> <li>• Share SPoC with school professionals, child care providers, early intervention</li> <li>• Develop and pilot a consent form to share the SPoC</li> </ul>
	Clinic has established processes for SPoC development, implementation and updating	<ul style="list-style-type: none"> <li>• Frequency of regular team meetings (Q2 wk. vs Q mo. vs other)</li> <li>• Team meetings are scheduled at convenient times/locations for families</li> <li>• Frequency of SPoC updates (Q3 mo. vs Q6 mo. vs other)</li> <li>• Roles for care team members in SPoC process (test different members leading different parts of process)</li> <li>• Families are engaged to provide feedback about SPoC clinic activities</li> </ul>

# Family of Measures

MEASURES	GOAL	Q3
1. Families agree/strongly agree SPoC helps ensure more of their child's needs are met	85%	95%
2. Care team meetings including family member	75%	33%
3. Families agree/strongly agree that SPoC helps them tell other service providers (schools, child care providers) about their child's needs	60%	89%
4. Teams neutral/disagree/strongly disagree use of SPoC helps their team communicate more efficiently	<20%	15%



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# 2019 Advancing Family-Centered Care Coordination for CYSHCN using a Shared Plan of Care

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Care Team and Family Survey Summary  
January-September 2019

## Background

Since 2016, over 20 clinics have participated in quality improvement work to advance family-centered care for children and youth with special health care needs using a Shared Plan of Care (SPoC). The SPoC is a tool designed to communicate and coordinate care, services and supports across systems and with families. In 2019, the aim is a family reported measure: 85% of families will agree/strongly agree that the shared plan of care meets their child’s needs.

## Summary

Coordination of services, supports and care is essential to meet the needs of children and youth while reducing the burden on families to navigate and coordinate services and supports on their own.

Communication, information sharing and active engagement with families and communities are critical elements of successful coordination. **This report primarily highlights how families may experience the benefits of a shared plan of care as well as opportunities for continued improvements.** The 2019 data for this report is aggregated from quarters one through three family and care team survey responses.

### Successes

- ✓ Almost all families agree the SPoC helps make sure more of their child’s needs are met.
- ✓ All families and care teams have access to paper SPoCs.
- ✓ Families report how helpful the SPoC is in organizing information:

*“It’s great to have all names and numbers/addresses in one spot. I carry it around with her everywhere.”*

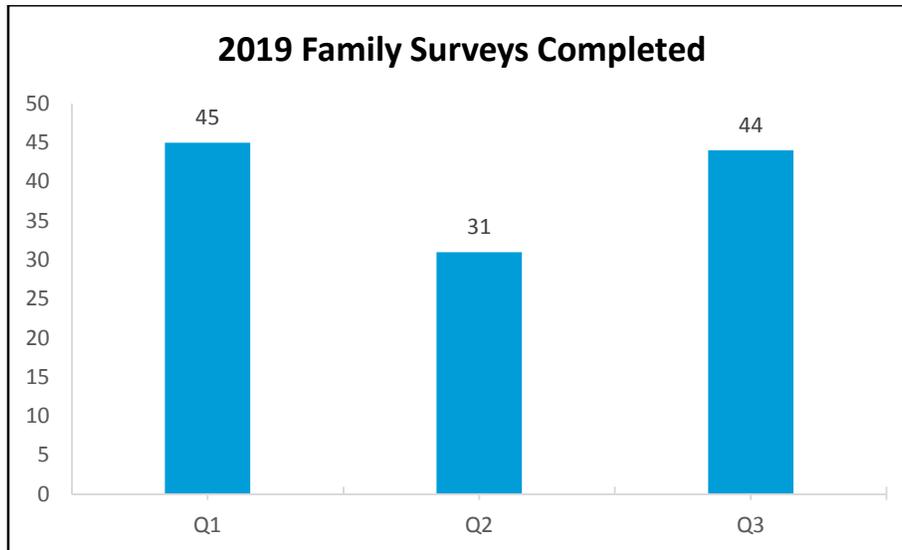
*“It keeps all of the providers on the same page and keeps information accurate.”*

### Opportunities for Improvement

- ✓ Ask families how they want to communicate their child’s needs with other clinical and community service providers. Inquire if they need assistance.
- ✓ Talk with families about how they may use their goals on the SPoC to coordinate needed supports and services.
- ✓ Invite at least one family representative to be a supported member of your QI team. If there is a family representative, arrange meetings so the meetings work with their schedule.

### For 2019 participating teams (Q1-Q3):

- ✚ 135 families have enrolled in the project
- ✚ 128 families have implemented SPoCs which were developed jointly



\*120 family surveys were completed in Q1-Q3 representing 10 teams. This data may not reflect unique responses as surveys are anonymous.

## KEY TAKEAWAYS: Family Experience with the Shared Plan of Care

### Communication

**Overall, care teams reported that the SPoC supported better communication including better communication with families (92%),** though families had a slightly lower level of agreement:

**78% families agreed/strongly agreed** that the SPoC helped them tell other health care providers about their child's needs

**79% families agreed/strongly agreed** that the SPoC helped them tell other service providers (such as school or child care) about their child's needs

Several families shared that the tool helps organize information *"It keeps all of the providers on the same page and keeps information accurate"* and *"It has been very helpful, especially when making appointments."*

A few parents reported that the SPoC was not supportive of better communication as *"we don't use it"* or *"I honestly don't feel that having the shared plan of care helps me out a ton. I really don't refer to it for anything..."*

## Coordination of Care

**An average of 75% of families felt that having a SPoC resulted in spending less time** they were coordinating their child's care and services.

Families shared *"It has freed up some of my time. I can focus on my child and not worry as much that all his needs (appointments being made & such) are being met. We are blessed to have this program,"* and *"I love having more time with my family and less time dealing with coordinating his care."*

The SPoC was reported to be a **valuable tool for 76% of families** to help navigate care and services needed for their child's and family's health. A few families offered a different perspective and commented *"the SPoC was out of date,"* or *"I honestly never look at it except to update it with the [team]. So I guess it helps them to coordinate when we are inpatient."*

## What's Important to Families

**Almost all families reported having helped to develop their SPoC,** though an average of **8%** of families indicated that their likes and dislikes were *not* included.

*"Having outlined interaction dialogue in the SPOC has been a huge help in how my son's health care provider, and others, choose their words when talking with him so he can better understand what is being said and what is going on."*

*"We don't use the tool, but the benefit of the tool is for clinics."*

## Recommendations and Thoughts from Families:

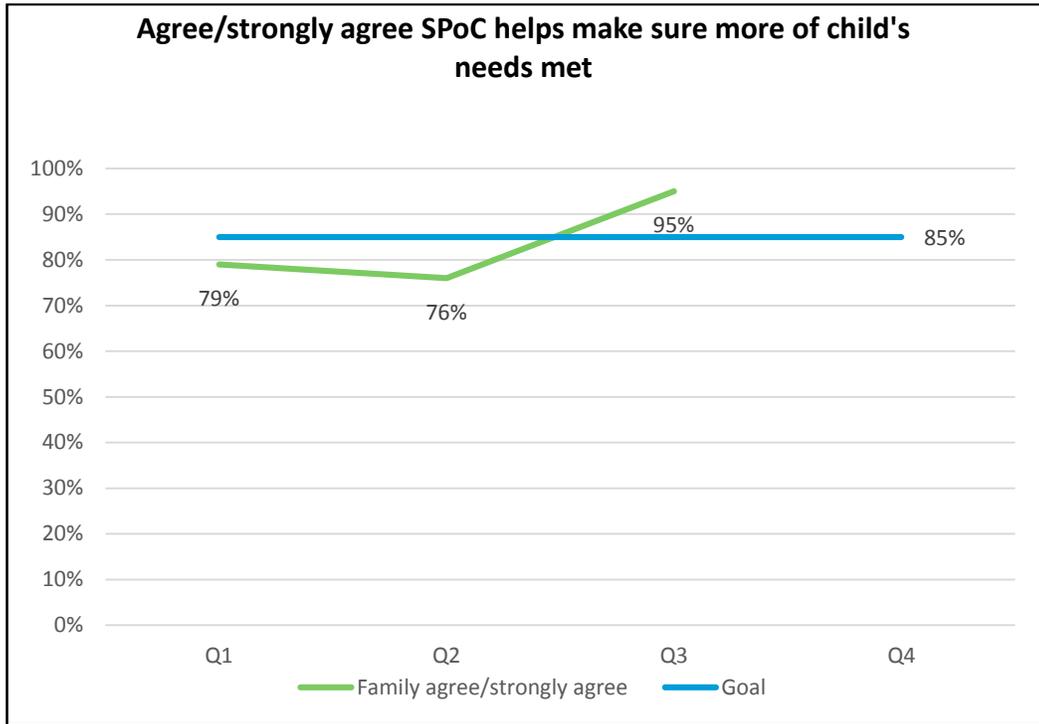
*"It would be more helpful/useful if specific resources were provided for each family (and in a step-by-step format with checklist) towards reaching goals. My husband and I do this for ourselves, but not all families would have the background/resources/time to do so. For us a written plan is not as easy to follow as a checklist with timelines. Could make one universal resource guide and highlight per family's needs for efficiency."*

*"It feels empowering to have a plan, as a family. To take note of issues that my daughter is experiencing, but to have help to make a plan to make things better."*

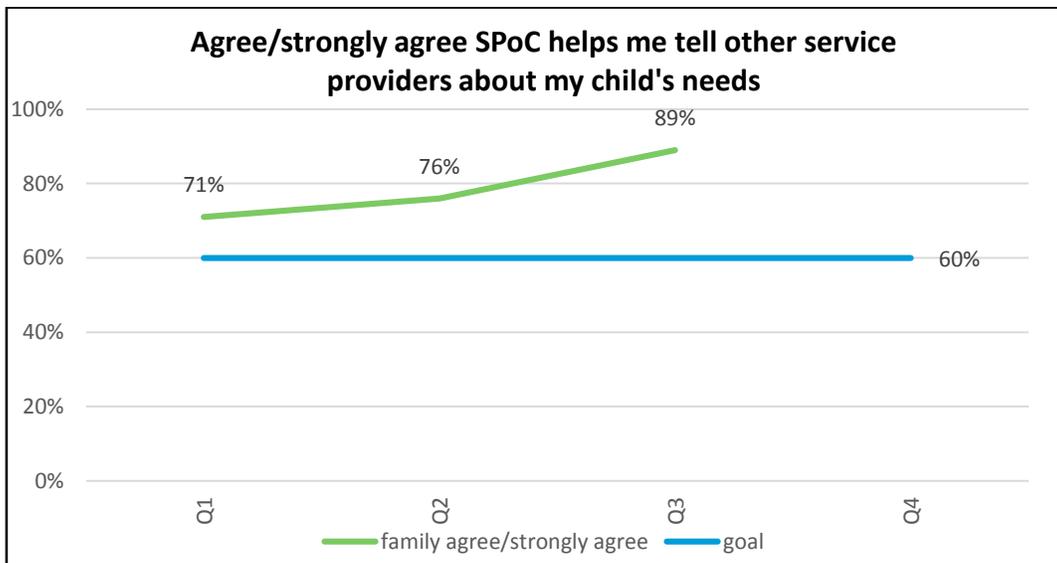
*"The shared plan has helped us to work together to best manage our daughter's care and prolong her quality of life!"*

## 2019 FAMILY OF MEASURES (Q1-Q3)

### Families Say:

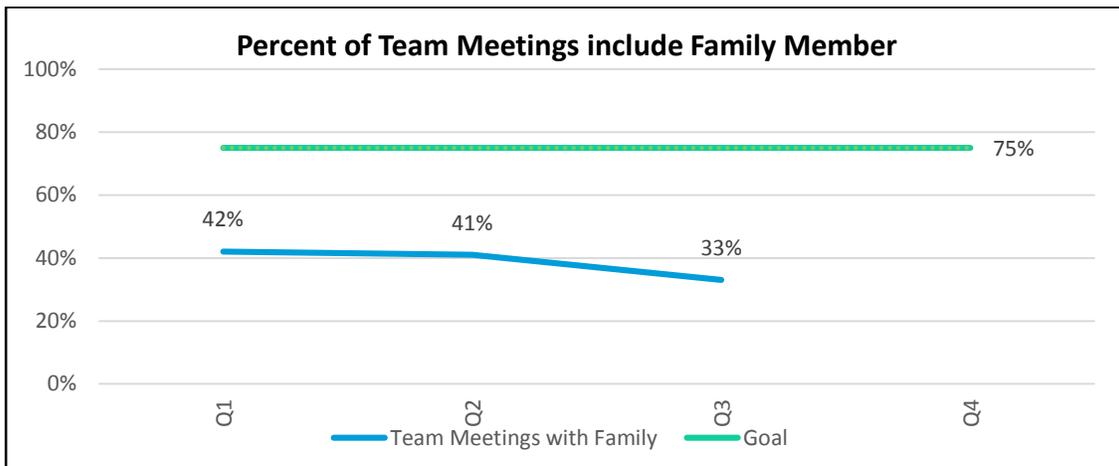


From Q1- Q3, the percent of families agree/strongly agree that the SPoC helps ensure more of their child's needs are met slightly decreased to 76% followed by an increase to 95% in Q3.

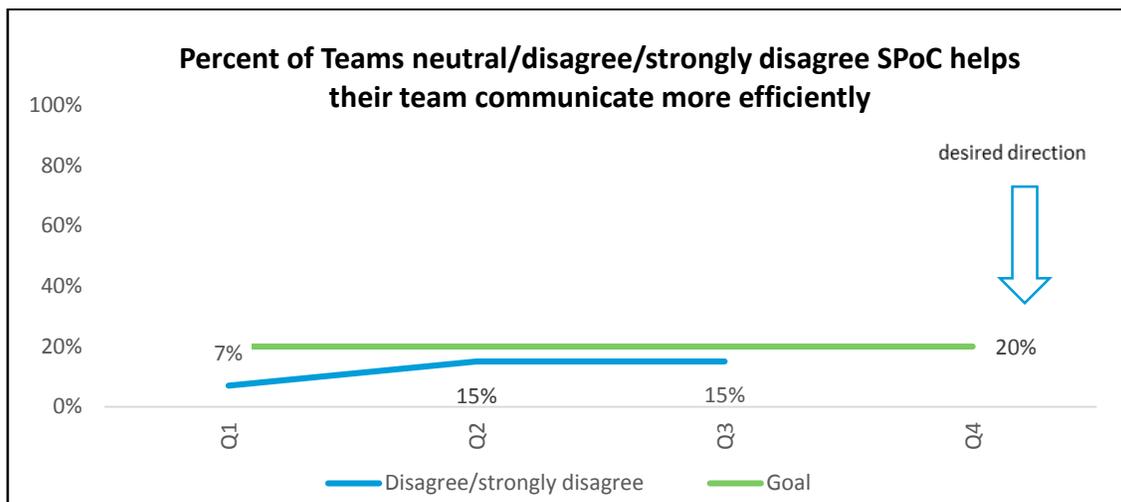


The agreement rate has steadily increased each quarter.

## Care Teams Say:



As of Q3, 11 of 13 teams report having at least one family representative. By the end of Q3, 33% of all reported team meetings included a family representative (3 teams did not have team meetings); throughout Q1-Q3, 6 - 8 teams have coordinated at least one meeting that included a family representative. Barriers to having family representatives involved in team meetings include identification of family members to participate and competing family priorities.



Balancing Measure: Over time, the direction of goodness or desired direction is to decrease. In Q1, 7% teams of teams disagree/strongly disagree that the SPOC helps their teams communicate more efficiently. In Q2, rather than decreasing, this increased to 15% and remained at 15% for Q3.

# Team PDSA Sample



## Children's Hospital of WI-Rheumatology

- **Plan**

- Discuss steps to address weight gain with newly diagnosed patient/parents (secondary to prednisone therapy)

- **Do**

- During next appt, discussed with patient and parent. Provided info regarding health eating, asked patient to complete 3-day diet history form for dietician, encouraged 3 scheduled exercise activities/week for both patient and family to engage in.

- **Study**

- For next 2 appts, patient only gained 1 pound. Patient riding bike & walking with parents, forgot to complete 3-day diet history; reminded and gave new form.

- **Act**

- Set up appt for patient/parents to work with dietician, scheduled another rheumatology visit. Gave patient positive encouragement in gaining only 1 pound and exercising more. Continue to monitor.

# ***"Hope and Dreams" and "Family Vision Statement" vs Actionable Goals***

**Arianna Keil, MD**

Children's Health Alliance of Wisconsin  
*Quality Improvement Director, WI Department of Health  
Services' Family Health Section*

# Your Child's Shared Plan of Care

*"Hopes and Dreams" and "Family Vision Statement" Versus Actionable Goals*

## Hopes and Dreams, Family Vision Statements

Most people have hopes and dreams for the future. Many parents of children, especially children with conditions that require frequent medical care, have ideas of how they would like this care provided. These ideas can guide decisions for treatment selection and more. Some parents think of these ideas as a "Family Vision Statement."

Examples of hopes and dreams for a young child:

- Ali wants to be an astronaut someday.
- Ben wants to go to college at UW-Madison.

Examples of family vision statements:

- We want Cameron to be as comfortable as possible and to know that he is loved.
- We want Felicity to be as independent as possible so that she can grow into a competent young adult.

Both of these might be located in your child's Shared Plan of Care in the "Who Am I?" section. Including these ideas helps remind plan readers what's important to you and your child. They can, and often do, change over time.

**Actionable goals** are different. These are steps that you and your child's care team can take together to improve his/her health or quality of life.

Examples of actionable goals:

- David will see a dentist within 2 months.
- Eve will be able to leave and enter the house easily using her wheelchair.

Actionable goals are found in the "Goals" section of the care plan. This section is sometimes called the "Negotiated Actions" section. Your child's care team will likely check this section of the care plan often to make sure goals are being met, or if they need to be changed.



# Reminders

- **Oct 28:** 2020 Competitive Grant informational call (12-1pm)
- **Nov 1:** Tribal Health Center Work Plans due (send to Leah Ludlum)
- **Nov 8:** MOC Part 4 credits (Colleen will send email to interested pediatricians)
- **Dec 2:** Applications due for 2020 Competitive Grant
- **Jan 3:** Q4 surveys due

# Thank you!



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