



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

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.”

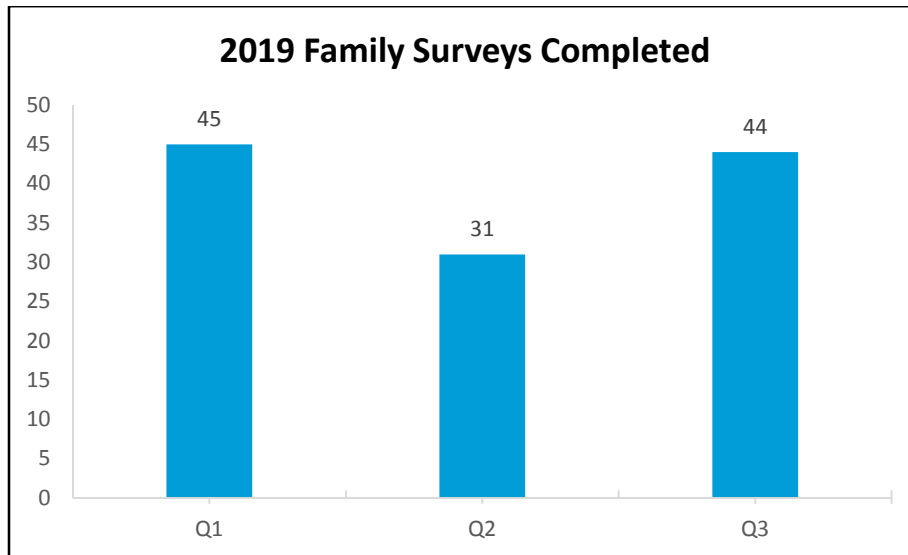
“It keeps all of the providers on the same page and keeps information accurate.”

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:

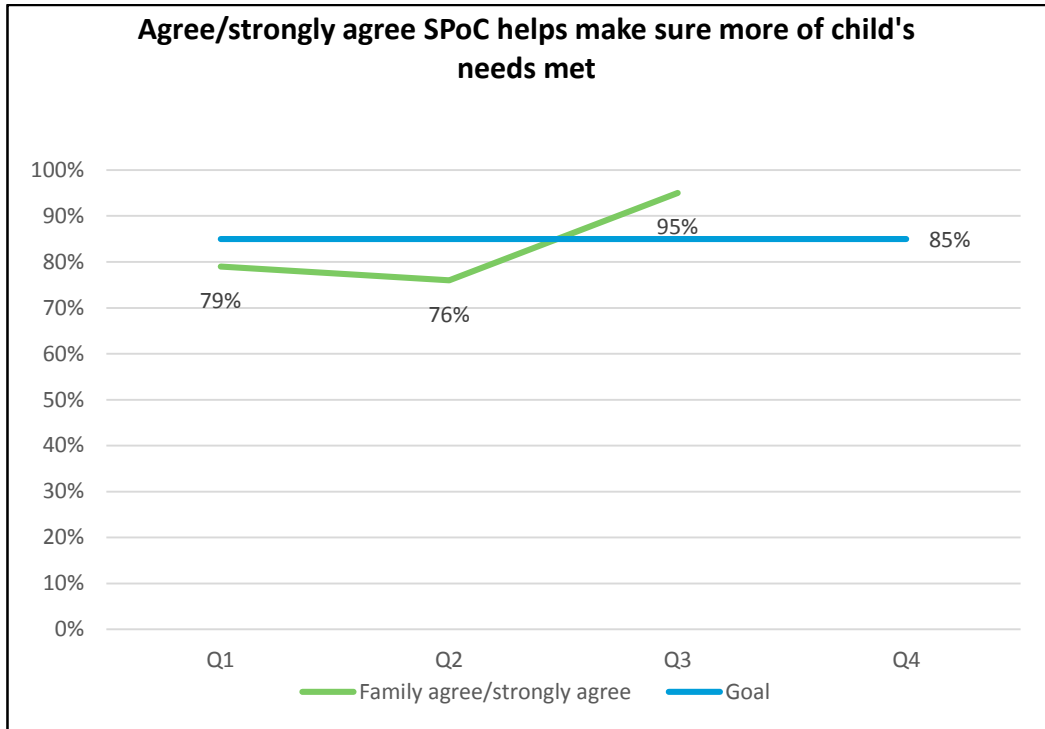
"It would be more helpful/useful if specific resources were provided for each family (and in a step-by-step format with checklist) towards reaching goals. My husband and I do this for ourselves, but not all families would have the background/resources/time to do so. For us a written plan is not as easy 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."

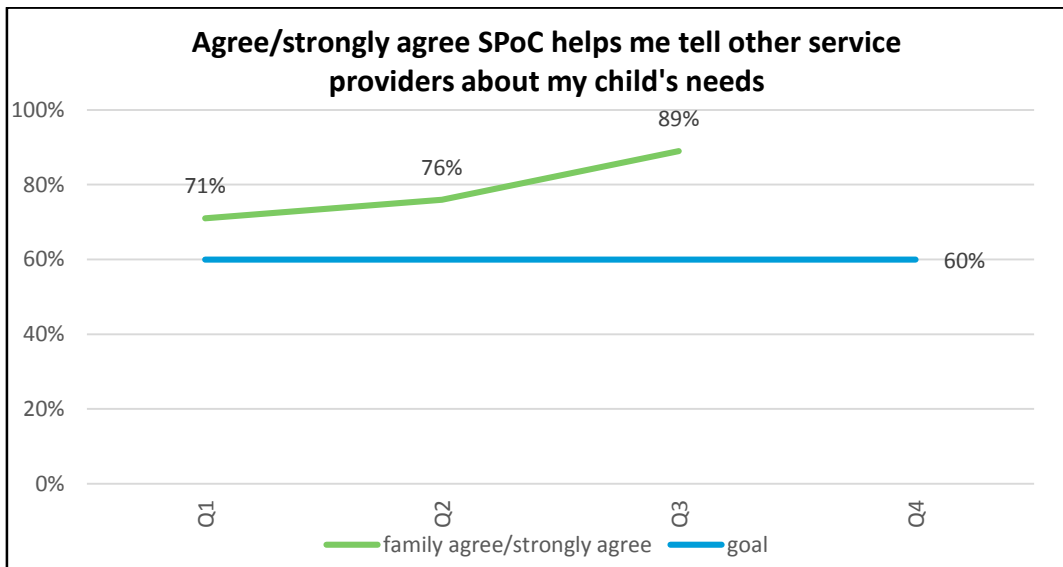
"The shared plan has helped us to work together to best manage our daughter's care and prolong her quality of life!"

2019 FAMILY OF MEASURES (Q1-Q3)

Families Say:

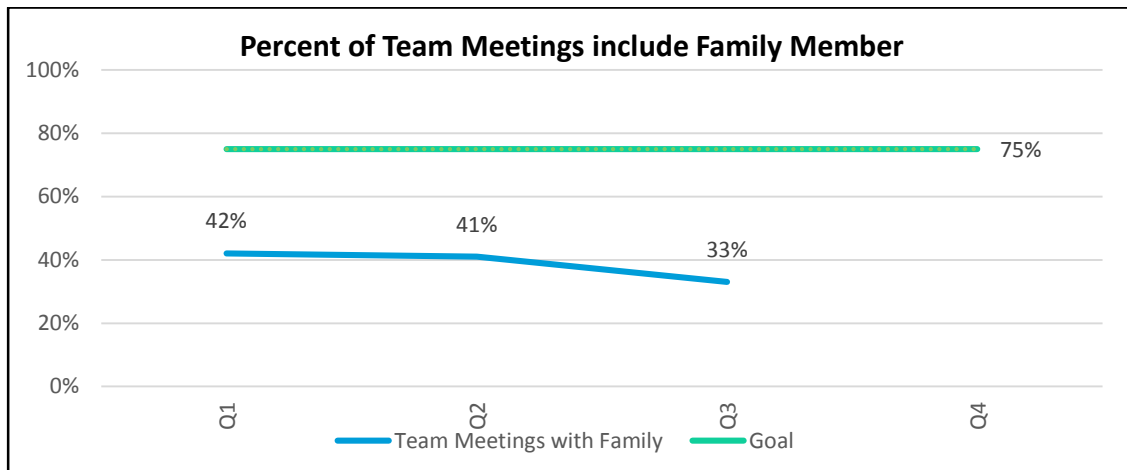


From Q1- Q3, the percent of families agree/strongly agree that the SPoC helps ensure more of their child's needs are met slightly decreased to 76% followed by an increase to 95% in Q3.

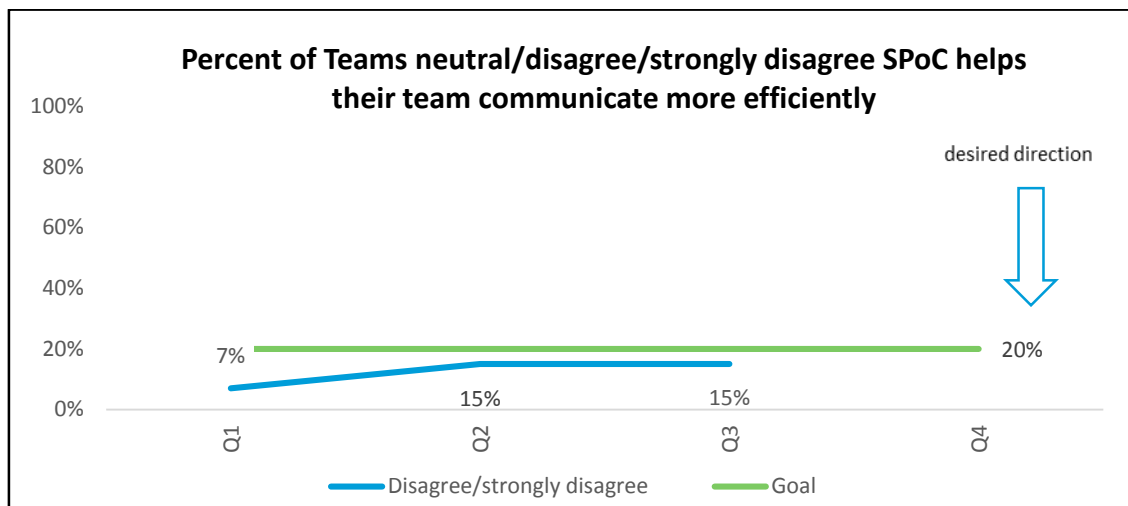


The agreement rate has steadily increased each quarter.

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.