

Team Engagement for Quality Improvement

Welcome Booklet

An introduction for families and health care teams working together on *Advancing Family-Centered Care Coordination for Children and Youth with Special Health Care Needs using a Shared Plan of Care* to transform health care.

February, 2019



WISCONSIN DEPARTMENT
of HEALTH SERVICES



Wisconsin Title V Children
and Youth with Special
Health Care Needs Program



Parent Parent of Wisconsin

...making connections statewide

Funded in part by the Maternal and Child Health Title V Services Block Grant, Maternal and Child Health Bureau, Health Resources and Services Administration, U.S. Department of Health and Human Services.



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Welcome!

Thank you for joining a **quality improvement** Project Team that has committed to having **health care team members** (doctors, nurses, medical assistants, receptionists, and others) and **family representative team members** (adoptive or foster families, parents, grandparents, youth, or elders) work together to make health care better for everyone.

You may have questions about being on this team, such as:

“What is Quality Improvement?”

“How do we work well together?”

“Will family representative team members judge our practice if they see we may make mistakes?”

“Is the information I share private?”

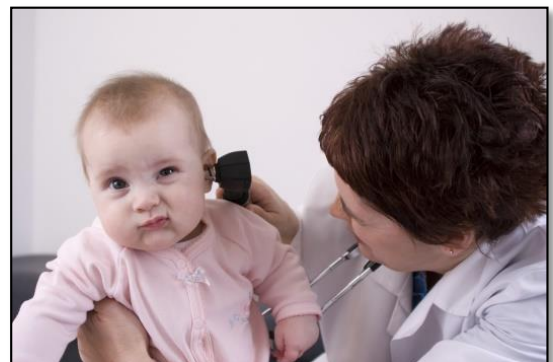
“What is my role?”

??

This booklet contains tips from health care team members and family representative team members to help you and your team. It has information about QI in health care, the Shared Plan of Care project goals, and your role on the team. Information in this booklet comes from evidence-informed best practices around family engagement and partnership with professional staff.

We appreciate your commitment to making health care better for families with children with special health care needs and their providers.

Thank you!



Children and Youth with Special Health Care Needs Program Goals

The team will be working on a specific QI project they have chosen to improve their clinical services. This project should align with the statewide Children and Youth with Special Health Care Needs Program goals. The Shared Plan of Care QI projects are part of the Wisconsin Medical Home Initiative.

Program Goals

The CYSHCN program promotes quality care for children and youth with special health care needs in Wisconsin. The program exists to assure that these children and youth:

- Are identified early.
- Receive high quality coordinated care.
- Receive, with their families, the supports they need.

CYSHCN collaborates with national, state and community-based partners to link children to appropriate services, close service gaps, reduce duplication, and develop policies to better serve families.

Vision for Advancing Family-Centered Care Coordination for Children and Youth with Special Health Care Needs

For children and youth with special health care needs, getting coordinated care within a medical home has been shown to positively impact health outcomes.

Use of a SPoC supports communication around coordinating care. It can improve family-clinician relationships, support family-centered care, and provide information that enhances services and supports to address medical and social needs of children, youth, and their families.



Shared Plan of Care

A living document completed and updated by parents and health care providers that includes information to assure issues affecting a child's health are identified and accessible across systems, and that actions for addressing those activities are recorded.

It includes:

- Medical summary.
- Family strengths and preferences.
- Plan of action (with goals, actions, responsible persons, and timelines).
- Attach emergency plans, chronic condition protocols, and IEPs or 504 plans.

Shared Plans of Care Quality Improvement Project Summary

The goal of the SPoC QI project is to enable project teams to advance high quality, family-centered care coordination for children and youth with special health care needs. Health care teams and family representative team members will be supported in the use of specific quality improvement tools in order to achieve this goal.

There are five main requirements of the project:

1. Pilot an SPoC

Clinic Activities:

- Pilot use of a SPoC with a minimum of 10 or 20 children (teams may choose which SPoC to pilot).
- Quarterly surveys to measure care team's perceptions of SPoC and its impact.
- Submission of two PDSA cycle worksheets each quarter.

2. Promote family and youth engagement

Quarterly surveys to measure family's perceptions and experience with their child's SPoC and its impact on care (completed by families).

3. Partner with family representatives in QI project work

- At least one family representative will be identified, and will be a supported member of the QI project team
- Family representatives participate in three calls with other family representatives of health care project teams.
- Family representatives participate in April in-person meeting.

4. Participate in the ongoing learning community

- Health care project team members participate in three learning community calls with other health care teams throughout the state to learn about successful strategies.
- Health care project team members participate in April in-person meeting.

5. Health Care Teams select at least one additional focus area from the list below:

- Pilot the use of the Care Coordination Measurement Tool.
- Promote the understanding of medical home with families.
- Promote the understanding of care coordination with families.
- Implement strategies to support youth health transition.

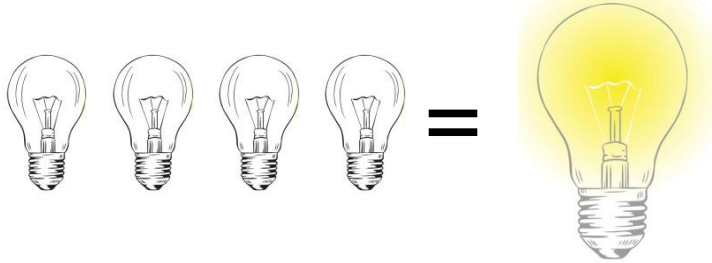


Information about Quality Improvement

Value of Improving Care as a Team

A team approach can offer valuable experience and insight to improve care. Patients and families experience health care differently from providers and administrators. **Family representative team members** share knowledge about what it is like to receive care. **Health care team members** share knowledge about providing care. All team members should be active on the project team from the beginning.

This collective knowledge is powerful.



A **family representative team member** shares the experience they have, and also strives to represent a wide variety of family voices. The goal is to share a broad family perspective with providers to help them see through the eyes of patients and family members.

A **health care team member** shares the experience they have, and also strives to represent the diversity of views of other providers. The medical assistant's experience may differ from the doctor's experience, which may differ from the nurse's and the receptionist's experience.

Team Engagement

A partnership between health care team members and family representative team members working together to improve health care

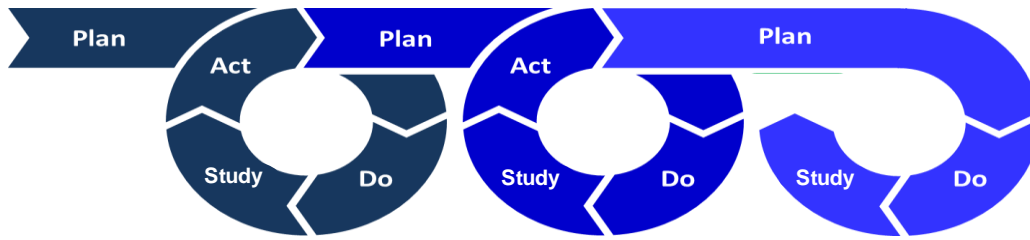
Quality Improvement

Planned and routine actions that lead to better health care services and health

My Motivation

Why am I participating on this team? What do I hope to change?

Quality Improvement: Plan, Do, Study, Act

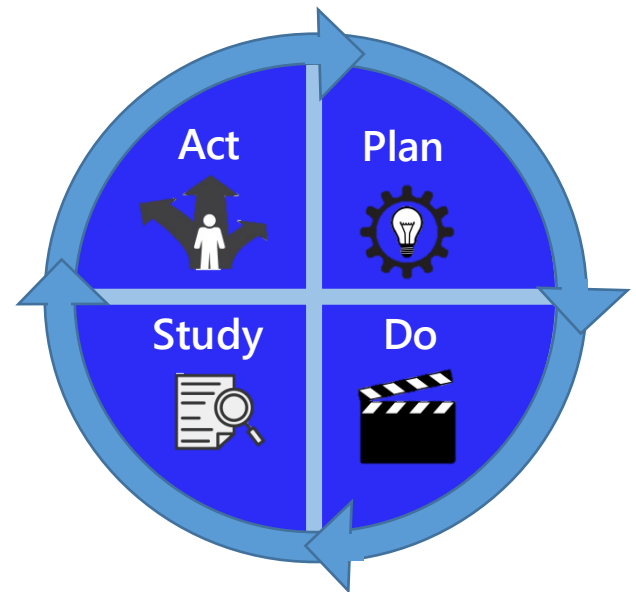


Plan

- Questions and predictions about what will happen.
- Who, what, where, when?
- What do you predict will happen?
- How will you know that the change is an improvement?

Do

- Implement the change.
- Document results with data and observations.
- What did you observe that was not part of your plan?



Study





- Analyze the data.
- Did the results match your predictions?
- What did you learn?

Act

- Refine the change.
- Plan for the next cycle.
- Decide to adapt, adopt, or abandon.



Plan, Do, Study, Act Examples

Steps	Questions to consider	Example
Plan 	What change will you test?	During the pre-visit call with the family, the nurse will introduce the SPoC using a standard script.
	What question are you trying to answer?	Will adding introduction of the SPoC to the call script result in more families enrolling in the project?
	What do you predict will happen (one per question)? Predict time and accuracy score.	The SPoC will be introduced at 10 pre-visit calls conducted January 1– March 31. Five additional families will enroll by the end of quarter one.
Do 	What did you discover while testing? What did you note that was expected or unexpected?	SPoC introduction script developed. Nurse used script during seven pre-visit calls with families.
Study 	Go back to the measures and questions in your plan. What are the results of your test for each?	An additional three families were enrolled during quarter one.
	What did you learn in this test cycle?	Although the script was used with fewer families than expected (seven vs. 10 predicted) and fewer families enrolled (three vs. five predicted), adding the introduction of the SPoC to the pre-visit call appears valuable.
Act 	Decide whether to adapt—and how—adopt or abandon.	Adopt—edit script to emphasize value of SPoC to families.
	Was anything uncovered that could be an alternative change to test?	Some families expressed interest in reviewing the SPoC before enrolling. Consider mailing a hard copy SPoC example as a possible subsequent test of change.

Plan, Do, Study, Act Worksheet



Plan

Light blue rounded rectangular area for notes related to the Plan phase.



Do

Light blue rounded rectangular area for notes related to the Do phase.



Study

Light blue rounded rectangular area for notes related to the Study phase.



Act

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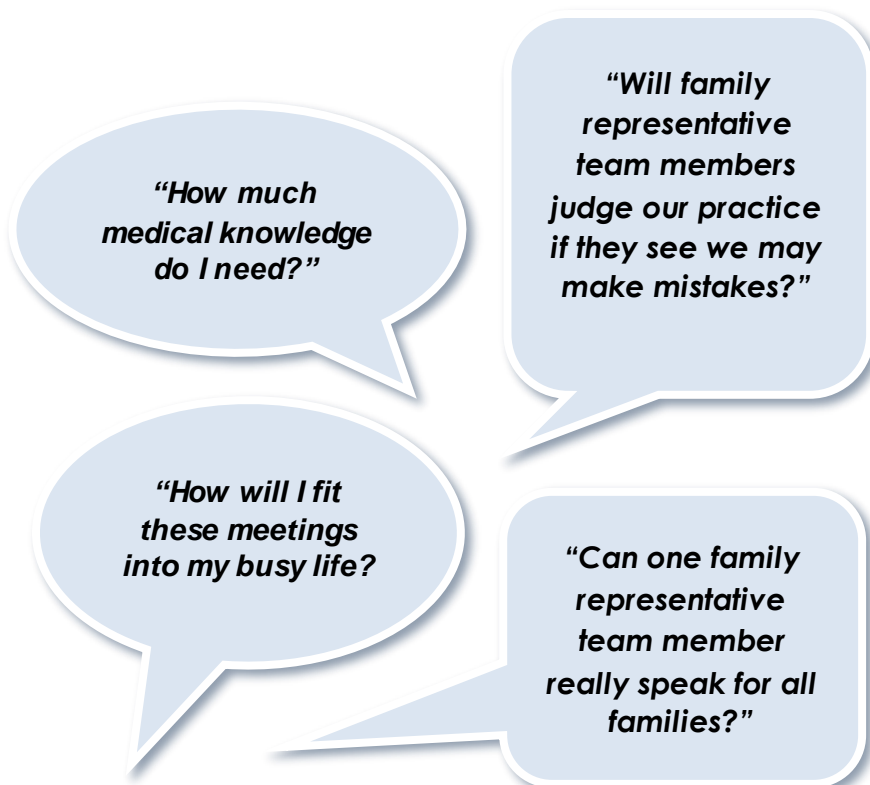
Family Partnership Commitment

Partnering with patients and families is integral to the success of program design and implementation.

Teamwork (partnership) requires trust. There are many ways to build trust on teams. For example, teams build trust by sharing their concerns at the beginning. Another way is to commit to ground rules for meetings. It is also important to use good listening skills and follow through on commitments.

Possible Concerns

The **Concerns and Actions** section contains common concerns that **family representative team members** and **health care team members** have, and possible actions. Consider talking about these at your first meeting, or during any meeting, if you think they are impacting the conversation.



What do I need to know to commit to this teamwork?

Family Partnership Principles

Family Partnership Principles help teams keep their commitment to each other.

These principles—**Representation, Access to Information, Results, and Commitment**—are explained in detail on the next page.

Representation



Access to Information



Results



Commitment



Family Partnership Principles

Good teamwork, to improve care for children and families, benefits from partnership principles.⁷ Consider the questions below as you work together. Revisit them once in a while to make sure your partnership is on track.

Representation



- Start at the beginning of the project.
- Reflect the diversity of the community.
- Partner with family-led and community-based organizations.

- Who needs to be on the project team?
- What groups or organizations in your community should be included?

Access to Information



- Provide relevant knowledge.
- Practice partnership in all parts of the process.

- How does the team communicate?
- What information do I need?
- Where should I go to get answers to my questions?

Results



- Identify what has changed and what the organization system of care is doing differently because families were involved.

How are families making a difference?

Commitment



- Promote engagement as a core value.
- Establish engagement at all levels, in all systems of care

- How can families stay involved?
- Where else can families be involved?

Adapted from: A Framework for Assessing Family Engagement in Systems Change. Issue Brief. Lucile Packard Foundation for Health

Family Partnership Principles in Our Work

Work together to record the ways your team practices the Family Partnership Principles:



Representation

Empty text box for recording ways your team practices the principle of Representation.



Access to Information

Empty text box for recording ways your team practices the principle of Access to Information.



Results

Empty text box for recording ways your team practices the principle of Results.



Commitment

Empty text box for recording ways your team practices the principle of Commitment.

Tips for Successful Team Engagement

Tips for All Team Members

- Be curious and learn about your team members.
- Listen for details about what matters to each team member.
- Seek common ground.
- Be yourself and share your opinions.



Honor Storytelling

Often, family members have a story about their child and their family's journey that they are eager to share. Health care team members may also have stories that they want to share.

Remember, **everyone** has a lot to share, and it may or may not include their stories. When making room for storytelling at meetings, it is a good idea to link those stories to make a point and keep the storytelling relative to the meeting topic.



Make room to honor the story.

Qualities of Effective Team Members

- The passion to improve the health care experience for all patients and providers
- Willingness to share insights and experience
- Ability to see beyond personal experience and opinion and seek other providers' and family's ideas
- Comfort with asking questions:
 - *What do you mean with that acronym?*
 - *Please give more details about the current process.*
- Respect for diverse opinions
- Good listener
- Works well with others
- Speaks up if the meeting is not staying on track



Being a Family Representative Team Member

“How can I know what other families are feeling?”

At first it might be overwhelming to be expected to represent other families. You may be thinking: “*Everyone’s situation is unique!*” The first thing to keep in mind is that representing (or advocating) for a group of families is not that different from advocating for yourself or a loved one. Your goal is to help improve health care for a broad group of children, including your child.

Before you talk, pause, and consider other families. **Ask yourself, “What would other families think about my thoughts?”** Share if you believe it is important to the improvement effort.

When you share your perspective, try to share why—for example:

“I have a very inflexible job, which seems to be more common these days, so I think offering same-day tests is important to many families.”

“I’m guessing you have issues with patients and families not returning to get tests for many other reasons too—such as transportation issues, and competing priorities.”

Telling Your Story



If you are asked to tell your story, ask why? If you share it, consider the main ideas that are relevant to the team’s quality improvement goals. Be brief and focus on key lessons. Connect them to experiences of other families.

Use your “new eyes”



The team you are joining consists of co-workers who work together frequently and may have been working together for years. Whatever their history together might be, a key value you bring is that you see things in new ways and can help your teammates see them in a new way too.

Gather input from other families⁸

You may find it helpful to talk with other families, or gather information from relevant advocacy or support groups, such as Family Voices of Wisconsin or Parent to Parent of Wisconsin.

You and your team can find ways to include the views of other families. If you want to gather information from other families, get help in doing this systematically by using a focus group or survey.

Being a Health Care Team Member

Just as family representative team members have to consider the experiences of other families, so do health care team members. Not every doctor has the same opinion. Not every medical assistant thinks there is only one right way to do things.

Another way that health care team members need to be representatives is as representatives of the clinic. Health care team members are the hosts of team meetings. Be a good host and make family representative team members feel welcome.



Creating a Welcoming Environment

When you invite family representative team members to join you, make sure it is a positive experience for everyone. Think of how you would like to be treated. What would put you most at ease in a new place?

Make participation easy:

Find out what your family representative team members need to participate, and provide it whenever possible (e.g., a gift card for their participation, free and convenient parking, on-site child care or child care reimbursement, food and/or drinks). Identify a health care team member to serve as a “buddy” to support the family representative team member (e.g., help with acronyms, check in).

Consider a critical mass:



Having more than one family representative team member on a team can put them at ease and encourage talking and assure that at least one is present for all meetings.

Adapt your meetings to welcome a new member:



- Meet at a convenient time.
- Take time to get to know each other.
- Provide background materials.¹⁰
- Use common shared language (avoid jargon and acronyms).¹⁰
- Use check-ins throughout the meeting to make sure everyone is following the discussion.

“Take time to get to know each other: Tell stories and share information that breaks the ice, and help people develop real connections with each other.”

- Essential Allies: Families as Advisors. Institute for Patient and Family-Centered Care

Learn together!

Concerns and Actions:

Family Representative Team Member Concerns

Potential Family Representative Team Member Concerns	Possible Actions by Health Care Team
Concerns about damaging their relationships with health care providers if their comments are negative	<ul style="list-style-type: none"> • Share that providers are equally nervous about sharing their imperfections. • Ensure ground rules: (1) explain that feedback will not negatively impact individual care and (2) encourage respectful listening. • Thank family representative team members for their candor when they share suggestions for improvement.
Concerns that their opinion may not be valued or respected	<ul style="list-style-type: none"> • Share goals and objectives with family representative team members individually and at meetings. • Explain that the primary goal is the inclusion of family representative team members in the process but not all family (or provider or other team member) recommendations will necessarily be incorporated into final decisions. • Demonstrate commitment by incorporating a family recommendation early in the project. • Hold regular, frequent meetings, especially at the beginning of the project, to build trust in the process.
Lack of knowledge about health care systems and the medical world; belief that they do not have enough medical knowledge to participate constructively	<ul style="list-style-type: none"> • Explain that the expertise you seek from them is grounded in their experiences as family members and/or patients. • Provide educational materials, such as articles and presentations, on relevant information for the project. • Conduct all meetings using nonmedical terminology or jargon. • All input is valued, especially when family representative team members' fresh perspective reveals something valuable.
Logistics (time, location, money) limiting their availability to participate in meetings	<ul style="list-style-type: none"> • Ask family representative team members what they need. • Select a meeting time and location to meet the needs of family representative team members. • Provide support, such as transportation, child care and translator services, if necessary and possible.
Concerns about being active participants and contributors	<ul style="list-style-type: none"> • Invite family representative team members' input from the start. • Assign family representative team members reasonable "homework" and responsibilities to actively engage them.



Health Care Team Member Concerns

Potential Health Care Team Member Concerns	Possible Actions by Health Care Team
Concerns about revealing problems and mistakes in the system with their family representative team members	<ul style="list-style-type: none"> • Review literature and examples from other organizations that have engaged patients—many report this fear was allayed once they began engaging. • Obtain confidentiality statements from family representatives. • If necessary, limit the scope of the project. • Remember that family representative team members may already be aware of the concerns.
Concerns that family representative team members will vent unrelated complaints	<ul style="list-style-type: none"> • Describe expectations to family representative team members. • Use strong meeting facilitation skills to keep meetings on track. • Validate feelings and concerns. • Offer family representative team members another opportunity or venue to share their concerns.
Concerns that a small number of family representative team members will not be representative of all families and patients, including their own	<ul style="list-style-type: none"> • Recognize the limitations of <u>all</u> representatives on the team. (Does the doctor speak for all doctors?) • Highlight the lack of any family or patient perspective that would occur without their involvement. • Propose to expand the number of family representative team members if initial project is beneficial, and/or use various forms of engagement to confirm that their input is being used.
Inexperience with family engagement models	<ul style="list-style-type: none"> • Learn—read this toolkit. • Share that “newness” of the venture with everyone and plan to learn together. • Ask for help.
Concerns about negative repercussions (legal or otherwise) on the staff and organization	<ul style="list-style-type: none"> • Share stories from other organizations that demonstrate positive repercussions without negative results. • Identify how partnering with families is part of cultural transformation toward patient-centered care. • Run any concerns by your team lead, or other appropriate person.



Resources

Health Care Terms and Acronym List

Everyone uses shorthand to convey complex information. Here are a few terms and acronyms that may be used at meetings. Make sure that jargon is explained by all to all. If you do not know the jargon that is being used, ask! You are probably not the only person in the room who is not clear, and your participation will be enhanced if you fully understand the context of what is going on.

There are resources at the bottom of the page for additional definitions.

CYSHCN	<p>Children and Youth with Special Health Care Needs</p> <p>The Children and Youth with Special Health Care Needs Program collaborates with national, state, and community-based partners to link children to appropriate services, close service gaps, reduce duplication, and develop policies to better serve families.</p>
SPoC	<p>Shared Plan of Care</p> <p>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.</p>
QI	<p>Quality Improvement</p> <p>The framework we use to systematically improve the ways care is delivered to patients. Processes have characteristics that can be measured, analyzed, improved, and controlled.</p>
PDSA	<p>Plan, Do, Study, Act</p> <p>Shorthand for testing a change—by planning it, trying it, observing the results, and acting on what is learned. This is the scientific method, used for action-oriented learning.</p>
EHR/EMR	<p>Electronic Health Record/ or Electronic Medical Records</p> <p>EHRs are real-time, patient-centered records that make medical and health information available instantly and securely to authorized users using a secure computer network.</p>
HIPAA	<p>Health Insurance Portability and Accountability Act</p> <p>U.S. legislation that provides data privacy and security provisions for safeguarding medical information.</p>
PHI	<p>Protected Health Information</p> <p>The HIPAA Privacy Rule provides federal protections for personal health information held by covered entities and gives patients an array of rights with respect to that information.</p>
Medical Home	<p>A trusting partnership between you, your child, and your pediatric health care team. Both families and health care teams have responsibilities.</p>
Care Coordination	<p>The deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services.</p>

The Centers for Medicare & Medicaid Services Acronym List and Glossary found at:

- www.cms.gov/apps/acronyms/
- www.cms.gov/apps/glossary/

Kaiser Health News: www.kaiserhealthnews.org/glossary.aspx

Wikipedia: en.wikipedia.org/wiki/Acronyms_in_healthcare



Shared Plan of Care Quality Improvement Project Team Agreement

Sample

COMMITMENT AND CONFIDENTIALITY AGREEMENT

Commitment:

- I am committed to helping the **Shared Plan of Care** Quality Improvement project team in its efforts at constant improvement.
- I will ask questions when I need clarity or help to improve my ability to participate.
- I will strive to provide valuable input.
- I will attempt to resolve any problems with my team and, if unsuccessful, attempt to resolve any such problems with the team lead.
- I will make my best effort to fulfill my commitment to the SPoC QI project team by completing all assignments that I accept.

Confidentiality:

- As a Team Member, I understand the importance of respecting the privacy and confidentiality of patients and families.
- I will hold as absolutely confidential all information that I may obtain concerning patients, families, medical staff, and the SPoC QI project team business practices. I will not share such information outside my team or my work as a team member.
- I will only seek to obtain confidential information from patients, medical staff, or others that is highly relevant to my work as a team member.

Limitations and Completion of Service:

- I understand that I am free to end my participation on the team at any time. If I choose to do so, I will provide my team with as much notice as possible.
- I understand that the SPoC QI project team may terminate my status for just cause, such as:
a) failure to comply with the SPoC QI project team confidentiality and commitment agreement;
b) inability to participate; c) unsatisfactory attitude, work or appearance; or d) any other circumstances which, in the judgment of the team lead would make my continued participation as a team member contrary to the best interests of the SPoC QI project team.

Name (please print) _____

Signature: _____ Date: _____

Notes and Parking Lot

*"What you do makes a difference,
and you have to decide what kind of difference you want to make."* – Jane Goodall



Parking lot: A place to record important points and feedback to share at a different time



Credits:

This booklet was written by Sarah Davis, JD, MPA, of the Center for Patient Partnerships, UW-Madison and the Wisconsin Children and Youth with Special Health Care Needs team. It is based on content in other material created by Ms. Davis (#1&2), extensive input from the Wisconsin Children and Youth with Special Health Care Needs program (#3), Barbara Katz from [Family Voices of Wisconsin](#), Robin Mathea from [Parent to Parent of Wisconsin](#), staff from the [Wisconsin Medical Home Initiative](#) and many national resources on family engagement for quality improvement. It is licensed under a [Creative Commons Attribution-NonCommercial-ShareAlike 4.0 International License](#).

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Citation:

Davis, S. Wisconsin Children and Youth with Special Health Care Needs team, Team Engagement for Quality Improvement Welcome Booklet, Center for Patient Partnerships, Wisconsin Department of Health Services; 2019.

