



# Powerful Partnerships

A Handbook for Families and Providers  
Working Together to Improve Care

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This guide was created by the National Initiative for Children's Healthcare Quality (NICHQ).

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*NICHQ wishes to thank the authors for the considerable time, thought, and effort they contributed to this important project. Thanks also to all the families and healthcare professionals who have worked with NICHQ on improvement projects for many years. Their insights and ideas have helped to improve care, and their commitment to improvement is inspirational.*

**About NICHQ**

The mission of the National Initiative for Children's Healthcare Quality (NICHQ) is to improve children's health by improving the systems responsible for the delivery of children's healthcare.

We seek to catalyze a national commitment to improve healthcare for children, as well as to achieve better outcomes in practices that care for children by developing, testing, and deploying new methods of care.

NICHQ brings experts in improvement together with organizations and individuals who care about and for children. Together, these teams build sustainable system improvement capabilities and accelerate the adoption of best practices.

For more information about NICHQ, please visit [www.nichq.org](http://www.nichq.org)



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## Introduction

This guide is intended to help both family members and healthcare professionals who are working together to improve care for children with special healthcare needs. Joining together in multi-disciplinary teams, family members and providers are increasingly working as equal partners to improve care. Collaborating as equals may be new for family members and providers. This guide includes information and guidance on how to get the most out of this potentially powerful partnership.



### Improving a Flawed System

The United States is home to many of the world's top medical institutions and experts. Day after day, they provide leading-edge care and make important progress in medical research.

But anyone who has ever given or received care—particularly care for a chronic condition—knows that the system of care has many flaws. Test results go missing, and tests are unnecessarily repeated. Medications get inexplicably changed when patients move from one care setting to another. Some patients don't get the care and tests they need. Some get care and tests they don't need. Some errors and omissions are annoying or upsetting, while others are harmful or even deadly.

What can improvement teams do? Here is an example of the sort of problem that interdisciplinary teams of healthcare professionals and parents are successfully tackling:

*Screening newborns for hearing loss is a widely known best practice, and is mandated in many states. Happily, the national screening rate has increased from an estimated 46% of newborns in 1999 to an estimated 98% in 2009.<sup>1</sup> That's the good news. Unfortunately, between 40% to 60% of infants who don't pass the screening test are "lost to follow-up,"<sup>2</sup> meaning that the system of care does not have adequate processes to track whether or not these infants get the early diagnostic tests and intervention they need after discharge from the hospital.*

Improving follow-up for these babies involves birth hospitals, primary care physicians, audiologists, early interventionists and families working together. When each party brings to the table his or her perspective, experiences, and ideas, meaningful and sustainable change is possible.

### The Importance of Working Together

Everyone benefits when healthcare professionals and families work together to improve care. Patients and families are empowered to help improve the system; providers and staff gain new perspectives and build new skills; and healthcare organizations that support the creative solutions that result from these partnerships improve the quality of the services and programs they offer.

<sup>1</sup> 1999 data: DSHPSHWA Survey; 2009 data: CDC EHDI Survey

<sup>2</sup> National Center for Hearing Assessment and Management; [infanthearing.org](http://infanthearing.org)

## Section One:

### A Framework for Improvement

**I**mproving the quality of healthcare requires teamwork. “Trying harder” just doesn’t produce lasting or consistent change. Neither does an edict from the boss. Rather, effective and lasting change — the kind that leads to sustained improvements — comes from the collaborative efforts of those who use and know the system and the processes best: providers and patients and their families.

#### Learning Collaboratives

Many family leaders and healthcare professionals are working together to systematically improve the quality of care through a widely-used framework called a Learning Collaborative. This is a time-limited effort (usually six to eighteen months) during which improvement teams from multiple organizations work together with faculty to learn about and create improved processes in a specific topic area. Teams share expertise and data with each other as they try new ideas. In this way, “everyone learns, everyone teaches.” This improvement method, developed by the Institute for Healthcare Improvement (IHI) and formally known as the Breakthrough Series, has been successfully used to improve processes of care in hundreds of healthcare organizations.

Each team in the Collaborative learns how to test or adapt changes and measure improvement before implementing changes throughout the organization. Learning is accelerated as the Collaborative teams work together and share their experiences through monthly reports, Learning Sessions, Web-based conference calls and email.

The three components of the Learning Collaborative are:

1. Pre-Work Activities
2. Learning Sessions
3. Action Periods

#### **Pre-Work**

Collaborative teams will be involved in “Pre-Work” from the time of their recruitment until the first Learning Session. During this time, the Collaborative team has several important tasks to accomplish in order to prepare for its first Learning Session, including: creating an aim statement, using some practice assessment tools, collecting some baseline data, developing a storyboard, and participating in pre-work calls. Pre-work packets, with more detailed information about this phase, are typically sent out one to three months prior to the first Learning Session.

#### **Learning Sessions**

Learning Sessions (LS) are the major events of the Learning Collaborative. They bring people together to learn, sometimes face-to-face, or more frequently through Web-based video technology.

Through plenary addresses, small group discussions and team meetings, attendees have the opportunity to:

- Learn from faculty and colleagues
- Receive coaching from faculty members
- Gather new information on the subject matter and on process improvement
- Share information and create detailed improvement plans

The Collaborative typically includes three Learning Sessions facilitated by expert faculty. Key Collaborative team members attend each of the Learning Sessions.

### Action Periods

The time between Learning Sessions is called an Action Period (AP). During Action Periods, Collaborative teams work within their organizations toward major, breakthrough improvements by implementing small tests of change. Although each participant focuses on his/her own organization, each remains in continuous contact with other Collaborative participants and faculty.

Monthly conference calls, regular emails, and use of a private online workspace help participants maintain continuous contact during the Action Period. Each organization submits monthly reports on its improvement efforts.

Action Period activities involve participation of all members of the teams, not just those who attend the Learning Sessions. Figure 1 depicts a Collaborative graphically.

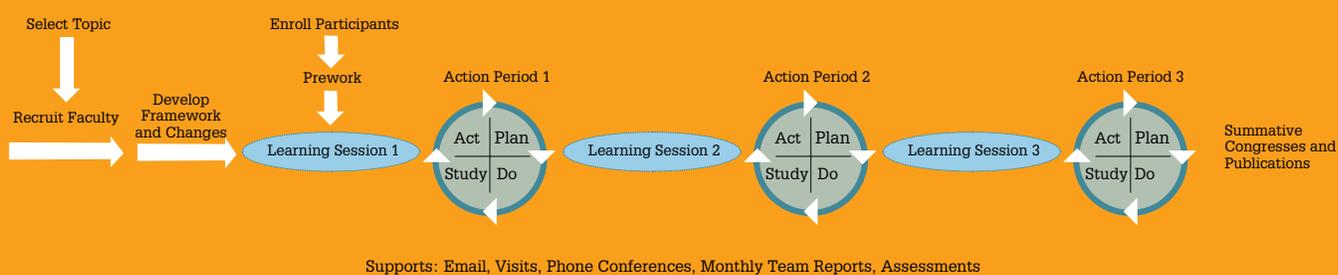


Figure 1. How a Collaborative works. (Associates in Process Improvement, Institute for Healthcare Improvement; ©Jossey Bass)

### The Model for Improvement

During Action Periods, teams use the Model for Improvement to test and track the impact of process changes. Developed by Associates in Process Improvement<sup>3</sup>, the Model for Improvement identifies four key elements of successful process improvement: 1) specific and measurable aims; 2) measures of improvement that are tracked over time; 3) key changes that will result in the desired improvement; and 4) a series of testing cycles during which teams learn how to apply key change ideas to their organizations.

The Model for Improvement has two primary components: a set of questions, and a series of testing cycles. An IHI white paper on the Breakthrough Series methodology describes the Model for Improvement this way:

**The Model for Improvement requires Collaborative teams to ask three questions:**

#### 1. What are we trying to accomplish? (Aim)

Here, participants determine which specific outcomes they are trying to change through their work.

#### 2. How will we know that a change is an improvement? (Measures)

Here, team members identify appropriate measures to track their success.

#### 3. What changes can we make that will result in improvement? (Changes)

Here, teams identify key changes that they will actually test.

<sup>3</sup>The Improvement Guide: A Practical Approach to Enhancing Organizational Performance, Gerald J. Langley, Ronald Moen, Kevin M. Nolan, Thomas W. Nolan, Clifford L. Norman, Lloyd P. Provost

Key changes are then implemented in a cyclical fashion: teams thoroughly plan to test the change, taking into account cultural and organizational characteristics; they do the work to make the change in their standard procedures, tracking their progress using quantitative measures; they closely study the results of their work for insight on how to do better; and they act to make the successful changes permanent or to adjust the changes that need more work. This process continues serially over time and refinement is added with each cycle; these are known as “Plan-Do-Study-Act” (PDSA) cycles of learning.<sup>4</sup> Figure 2 shows how the serial PDSA cycles work.



Figure 2: Plan-Do-Study-Act Cycle.  
(Associates in Process Improvement)



## Planning for Spread

Ultimately, the goal of the Learning Collaborative is not only to improve care at the organizations represented by the participating teams, but also to spread the improvements to new practice sites, departments, and/or organizations on a state or regional level. To some degree, spread will happen naturally through word of mouth as Collaborative teams share their experiences with colleagues and partnering organizations.

Nevertheless, Collaborative teams should develop a strategy for spread from the beginning, so that proven ideas can be adapted and adopted throughout their organizations and beyond.

In addition to a sensible spread strategy, there are two elements that must be present for spread to be effective: The organization’s leaders must support the effort (and make that support well known) and the goals of the improvement work must align with the strategic objectives of the organization. Spread is not possible without both these factors in place.

<sup>4</sup>The Breakthrough Series: IHI’s Collaborative Model for Achieving Breakthrough Improvement. IHI Innovation Series white paper. Boston: Institute for Healthcare Improvement; 2003.

## Section Two:

### A Guide For Families

**F**amilies and healthcare professionals bring complementary expertise to the quality improvement process. As a family member, you gain a unique perspective through your healthcare journey with your child. You see things providers may not see, or you see them differently. Your insights on how the healthcare system works — or doesn't — are invaluable contributions to the improvement process.

Over the past 10 years working on NICHQ projects, families and youth have increasingly and successfully collaborated with healthcare professionals, contributing to the identification and analysis of problems, testing tools and resources, and providing guidance on improvement work from the patient's perspective. Healthcare providers have learned that family partners bring important and unique contributions to improvement work.

#### What Parents Say About Working With Providers

*“This was one of the most empowering projects I'd ever worked on because . . . my voice was an equal one. I felt like I was really helping to make changes in areas that had been big problems for me and my child.”*

*“I learned so much about physicians' constraints and have a better understanding of and compassion for their frustrations.”*

*“As a parent leader, I feel like I am really improving the lives of kids with epilepsy.”*

*“For a lot of doctors and staff that I worked with on my team, this was the first time they ever had a parent involved, and it was a really new dynamic and it took a while to figure out how that was all going to work together.”*

*“For the first time I felt that my voice as a parent was really going to be heard by the professionals. I appreciated that they really included me from the get-go.”*

Dear Families,

As parents of children with special healthcare needs, you play many roles. When you join with providers to improve care, you become an activist, advocate, challenger, change-agent, collaborator, community developer, educator, facilitator, framer, innovator, life-long learner, listener, mediator, negotiator, participant, team member, role model, supporter, visionary.

We have walked in your shoes. We know the challenges and the joys of parenting children with special healthcare needs, and we know the anxiety and the anticipation of taking part in collaborative efforts to improve care.

Our participation as parents contributes to the dialogue and helps to improve the systems in which our children receive care. The opportunity to create a better journey for the next family in need of care keeps us engaged in this important work.

Whether this is your first foray into parent involvement or your 50th, each time you work on a project you expand your expertise, enlarge your circle of colleagues, and create opportunities to continue this important work.

On behalf of all the families and children who will get better care because of you, thank you.

Janet DesGeorges and Elizabeth Aquino  
National Parent Chairs  
NICHQ Collaborative on Improving the System of Care for Children and Youth with Epilepsy and the Newborn Hearing Screening Program

## Epiphanies From The Front Line: One Parent's Lessons From Partnering with Providers

By Elizabeth Aquino

The role of Parent Co-Chair for NICHQ's epilepsy collaborative fell into my lap on a long drive from Los Angeles to San Diego about seven years ago. I was driving my then nine-year-old daughter to our twice-monthly visit to a famous osteopath whose work with severely disabled children, including my own, was profoundly healing. Sophie had been diagnosed with infantile spasms of unknown origin when she was three months old, and despite constant interventions of various antiepileptic drugs and the ketogenic diet, her seizures were not controlled, not even remotely. We had been to the "best" neurologists in New York City and Los Angeles, but no one could really help her. The story is an old one, told over and over by most families of the chronically ill, particularly those whose children have refractory epilepsy: ridiculous waits to see doctors, crucial and life-altering information communicated in often harsh and demeaning ways and sometimes not at all; complex drug regimens with vicious side effects that, when discussed, are blown off with insensitive remarks by doctors who are rushed with no time to even make eye contact, much less speak to one's child.

To say that I was hardened and embittered by the world of neurology that I had been thrown into for the past decade would be an understatement, and on that two-hour drive to San Diego, I had the opportunity to express all of my frustrations with the system as a faculty member from NICHQ interviewed me about my experiences for an upcoming "expert meeting." At the time, I was already the founder of a non-profit organization, along with two other families of children with seizure disorders. We had founded PACE (People Against Childhood Epilepsy) in response to the overwhelming diagnoses of our children, the appalling lack of information, coordination of care and, of course, effective treatment for their seizures. The interview eventually led to my being asked to serve on the faculty of the first epilepsy collaborative as Parent Co-Chair, my job to ensure that parents had an equal seat at the table of improvement work and that our voices would be heard and taken into account. I ended up working for the next three collaboratives in that role.

### ***For The First Time I Felt Truly Empowered***

What happened to me over those years working as a parent partner in collaborative work was nothing short of life-altering. I was exposed to countless people who worked in the field of neurology and epilepsy as administrators, nurses, doctors, government employees, family members and patients. As we grappled with the immense problems of a broken system, my voice – and other parents' voices – were heard and responded to in a way that seemed revolutionary. While there were always struggles to get people on board with the whole notion of having "equal parent partners," we found that those teams that "got it" were most successful in implementing real change and often had parents driving that change.

As a parent, it was the first time that I felt truly empowered by and effective in sharing my experiences caring for a child with epilepsy.

Allowed to speak openly about my frustrations, to have them acknowledged and then to work side by side with professionals, I felt as if a weight had literally been lifted from my shoulders and my eyes and ears opened. I quickly learned of the constraints of the system – the incredible shortage of neurologists, the lack of access to quality care for many patients and the frustrated efforts of those working in staid and rigid organizations to make effective change. The epiphany was *Oh! These people really do care about my daughter and other children like her. They are working as hard as they can in a system that is resistant to change.*

I wouldn't say that I *softened* toward the world of neurology as I continued to work on the collaboratives, but I found that my relationship to it became much more reciprocal. I spoke, sometimes quietly and hopefully and other times loudly and angrily. I told stories, over and over, of my experiences and those of other families. I emphasized the necessity of communication and education from the get-go, when a child is diagnosed with epilepsy. I was heard, as were the other parents working on the teams. In turn, I listened to doctors and nurses describe their own desires to help and to heal, their frustrations with families who refused to comply with cultural and linguistic differences and with insurance companies and their arcane systems of billing and reimbursement. While my pet peeve might be the lack of eye contact from a doctor toward my daughter or his talking over her head as if she weren't in the room, I learned that large numbers of patients don't show up for appointments or cancel at the last minute, throwing schedules into chaos.

### ***No Longer an Adversary***

While I was able to make an impact on collaborative participants by demonstrating how important it was to pass along all the information one could, I was, in turn, impacted by one doctor's story of the information she had to carry in the trunk of her car as she visited her migrant worker patients in remote, rural areas.

I cope with my daughter's condition, her uncontrolled seizures and the often frustrating systems of care with a dark and dogged sense of humor. I used to say, quite seriously, that I'd rather my son grow up wanting to be anything other than a neurologist; in fact, I wasn't sure I'd be able to accept him as a neurologist should he have that aspiration! After my work on the epilepsy collaborative, though, I've grown quite a bit wiser and am probably a far more effective parent of a child with epilepsy. No longer an adversary, I am a partner in the system, my expectations no less, but cognizant that we're all in it together.

## The Role of the National Parent Chair(s)

NICHQ has pioneered the use of a parent chairperson to share the leadership of the learning collaborative with clinical experts. The National Parent Chairperson serves on the faculty to facilitate and support family partners on each team. This person, who is typically a parent with a personal interest in the clinical topic, works to ensure meaningful parent participation at all levels. This parent leader is also responsible for defining and implementing special projects at the national level.

Specifically, the National Parent Chair works to create opportunities for the family partners to:

- Spend time together as a group at the Learning Sessions
- Hold phone conferences on a regular basis to share their experiences on their individual teams
- Give input to be communicated to national faculty
- Work together on special projects
- Ensure that areas that parents have defined as critically important are addressed during the Collaborative.

The National Parent Chair is also available to consult with family partners on an individual level to brainstorm, problem-solve, and to ensure that parents on teams are actively engaged.

The Chairperson's scope of work additionally includes:

- Weekly project team/faculty meetings, monthly calls with Collaborative teams, and periodic debriefings
- Posting and responding to questions on the listserv
- Assisting in leadership of the faculty planning group
- Playing an active role in connecting parent/family team members during and between the Learning Sessions
- Guiding the development of Collaborative content from the family perspective
- Presenting at learning sessions
- Reviewing reports, continually assessing the progress of teams, and recommending interventions
- Playing an active role in teaching and mentoring faculty, Collaborative participants, and organizations about the clinical perspective and achieving family aims
- Disseminating Learning Collaborative knowledge



## Examples of Parent Contributions in Collaboratives

Parents can be the driving force behind all sorts of good ideas that improve care and the experience of care. As a parent member of a Collaborative team, your perspective is valuable and important, and your ideas could lead to the development of effective resources and tools. Be sure to speak up if you have ideas or questions. Here are just a few examples of tools developed by parents working in Collaboratives aimed at improving the process of screening newborns for hearing loss and improving care for children with epilepsy.

### **Parent-Led Initiatives in Newborn Hearing Screening**

#### **The Parent Roadmap**

[www.nichq.org/resources/newborn\\_hearing\\_screening\\_toolkit.html](http://www.nichq.org/resources/newborn_hearing_screening_toolkit.html)

The newborn hearing screening process can be lengthy and sometimes confusing for families, particularly since most are experiencing it for the first time. Family leaders recognized that parents needed greater clarity about where they are in that process, which typically takes place over a six-month period or longer. With input from family members in Collaboratives throughout the country, family leaders created a Parent Roadmap that graphically displays the steps involved in screening, as well as a timeline.

#### **Decision Guide to Communication Choices**

[www.cdc.gov/ncbddd/ehdi/documents/Edmaterials/Decision-Guide.pdf](http://www.cdc.gov/ncbddd/ehdi/documents/Edmaterials/Decision-Guide.pdf)

After working with the Ottawa Personal Decision Guide in a Collaborative (a tool designed to help users make health-related decisions), a group of parents worked together to adapt it for families facing choices about communication methods for children who are deaf or hard of hearing. The Guide is now available through the Centers for Disease Control and Prevention.

#### **The Parent Survey on Experience of Care**

[www.nichq.org/resources/newborn\\_hearing\\_screening\\_toolkit.html](http://www.nichq.org/resources/newborn_hearing_screening_toolkit.html)

Assessing the experience of care from the parents' perspective provides important information that contributes to improvement efforts. For example, when screening results are faxed from specialists back to primary care physicians, are those physicians then sharing the results with parents during well-baby visits? The National Parent Chair for Newborn Hearing Screening developed this survey, with support from NICHQ.



### **Parent-Led Initiatives in Epilepsy Care Care Notebooks**

[cshcn.org/planning-record-keeping/care-notebook](http://cshcn.org/planning-record-keeping/care-notebook)

A Care Notebook is a powerful parent-designed tool/template for organizing comprehensive information about a child's chronic health condition. The notebook enables parents to easily keep and organize a child's medical history; track changes in medication or treatments; store provider contact information; prepare for appointments; and share information with providers and others caring for the child.

### **Medication Card Templates**

[www.nichq.org/pdf/MedListFINALDarkerzig.pdf](http://www.nichq.org/pdf/MedListFINALDarkerzig.pdf)

Parents developed wallet-sized medication card templates to help facilitate accurate and consistent communication among families, primary care providers and specialists. The card, which folds to the size of a credit card, is convenient, easily updatable, and accessible.

### **“All About Me” Page**

[www.nichq.org/resources/ISC\\_toolkit\\_landingpage.html](http://www.nichq.org/resources/ISC_toolkit_landingpage.html)

Physicians and other providers sometimes focus so intensely on a clinical situation that it can feel like they've forgotten there is also a child before them. The “All About Me” page, designed by parents for inclusion in the Care Notebook, is a communication tool for personalizing a clinical encounter, reminding the provider that the child is “more than a diagnosis.”



### **Pictorial Information Sheet**

[www.uscuedd.org/downloads/products\\_publications/parent\\_resources/epilepsy/Seizure\\_Description\\_Sheet\\_Farsi\\_English.pdf](http://www.uscuedd.org/downloads/products_publications/parent_resources/epilepsy/Seizure_Description_Sheet_Farsi_English.pdf)

Parents led the development of this tool to help non-English speakers communicate about seizure disorders. It enables parents to describe details about their child's seizures using pictures.

### **PCP Training Tool**

Pediatric neurologists are in short supply nationally, and there are regions where they are quite scarce or non-existent. When a neurologist is not readily available, patients and families bring all their questions to their primary care physician. Family leaders created a comprehensive list of possible questions to help prepare primary care physicians for these conversations.

### **Support Groups**

One parent leader initiated and led a support group for parents whose children have epilepsy.

### **Seizure Action Plans For Schools**

One parent partner helped to develop and deliver a plan for school nurses to use when a child has a seizure at school. The parent led a small PDSA cycle that was later expanded.

### **Care Plans**

Parents helped to create care plans that are now in use by both primary care and specialty care providers.

### **Professional Advisor**

One hospital recognized the value that parent partners bring to improvement work, and offered a parent a paid position on the hospital's parent advisory board.

# Tips

to help you maximise your effectiveness as a partner parent

## Communicate Effectively

- Recognize that most professionals are happy to have you at the table and are ready to work with you.
- See beyond your own personal experiences and represent the needs of other families who have made different decisions than you, or have other life experiences.
- Share information about your experiences and your insights in ways that others can learn from.
- Be succinct and make sure that the story you are telling is relevant to the topic/conversation at hand.
- Keep an open mind, and respect the perspectives of others.
- Work in partnership with others.
- Don't 'demand' respect from professionals, 'command' it by being prepared for meetings, coming on time, and giving input and suggestions that can make a difference.
- Listen, listen, and listen.

## Articulate Your Needs

- Ask for more orientation to your state system, if you need it.
- Contact the National Parent Chair for help.
- If meetings are at an inconvenient time for you, offer other times that are better and/or participate via phone/video conferencing.
- If you need reimbursement for childcare and mileage, talk to your team leader.
- Clearly identify the person on the team who can assist you with reimbursement and other issues.
- If an acronym is used and you don't know what it means, ask. If you can't ask right then, write it down and ask later, or ask the person next to you.

## Define Your Role

- Can you write a job description for yourself? Talk to the team right at the start so everyone is clear on what is being asked of you.
- Try to put your particular strengths and skills to work. Are you a good writer? Then offer to help with any written materials being developed (brochures, etc.) Do you have good people skills? Maybe there is an outreach/education effort you can join.
- Good follow-through will gain you respect. If you say you are going to do something, take it seriously and meet the deadline. If you can't, let the team know when it will be done.

## Stay Actively and Confidently Engaged

- Take the lead on one of the PDSAs your team is working on.
- Participate in discussions actively and with confidence. The other members of the team expect you to be an equal partner.
- Try not to call yourself "just a parent" – you are a Parent Partner!
- If you think a PDSA is getting bogged down or don't believe it pertains to real patients' needs, speak up. It is the parent's voice that often drives change.
- If direction from your team is vague, ask for specifics.
- Always remember that you are an equal partner on the team and that your voice is necessary for change.

## Resources for parent partners and leaders

- The Institute for Family-Centered Care has published several books useful to parent leaders and those who support parent leadership: [www.familycenteredcare.org](http://www.familycenteredcare.org)  
Recommended reading: *Essential Allies: Families as Advisors* (1995)
- Hopeful Parents is a family blog for parents of children with special healthcare needs, an excellent resource for support and encouragement: [www.hopefulparents.org](http://www.hopefulparents.org)
- Patient Decision Aids is a useful site that shows samples of different tools families can use: [decisionaid.ohri.ca](http://decisionaid.ohri.ca)

In addition, of course, the Internet provides access to a vast range of information on organizations and resources related to specific pediatric conditions. Be sure the information is from a reliable source.

# Frequently Asked Questions

The following questions are commonly asked by parent partners working on Collaboratives.  
You may find your own questions answered here.

1. [I don't feel the team is really using me in a meaningful way, and/or I seem to keep hitting obstacles to getting a project done. What can I do?](#)

Many professionals have not worked with parents before at this level. Sometimes the members of your team aren't sure how to use you, or need a bit of time to see your expertise emerge. If there doesn't seem to be a natural fit, be proactive and suggest some areas where you can contribute meaningfully. Talk it over with the National Parent Chair or other parent partners in the Collaborative to get more suggestions. Your Parent Chair is there to ensure that you are an active participant on your team and to gently guide the other team members on how to work most effectively with their parent partners.

2. [Everyone else on the team actually works in this field, and I'm doing most of this in the spare time I have outside of work and family life. How can I be actively engaged and still balance my 'other' life?](#)

Make it clear from the beginning what time you are able to give to your team and what constraints you might have. Because of the nature of the work, most of the team members understand that life with a special needs child is not always predictable. Things come up! You will probably find that most of the team members are grateful for your input and even in awe of whatever you are able to contribute.

3. [Is this a volunteer position or do I get paid?](#)

This varies according to situations and budgets. Some parent partners are paid to participate because they already hold a position such as parent representative. Some parent partners are paid a stipend or are paid through their position in a state/agency/organization. Many others are volunteers. This is a decision that each team will make. Paying parents can increase the time and attention they devote to the work, as well as the group's willingness to hold them accountable. Some parents prefer to perform this service on a voluntary basis.

4. When I start telling stories about my child, the team's eyes start to glaze over. What's up with that?

As tempting as it is to relate stories of your own situation, try to think about how your story fits into the broader context of your work. Can you make your story relevant to all children with special healthcare needs? If there is a particularly powerful instance in your own life that you can use as a parallel to the work being discussed, be honest about that but don't use your team time as a place to vent your frustrations. Where you CAN do this is with your fellow parents!

5. I can't always make the meetings, as they often occur during the day, or I live too far away. How can I stay involved?

Ask your team coordinator whether you might be able to join meetings by phone. If you're unable to make a meeting or a conference call, ask for minutes of the meeting and carefully read them. If your work schedule creates a problem, talk with your employer. In past Collaboratives, when parent partners explained to their employers what they were up to, they often got a surprising amount of understanding and schedules or lunch breaks were rearranged to accommodate them.

6. I feel like I don't really understand all the technical jargon that is thrown around. And it bores me. What can I do about it?

If you don't understand or know a term, ask what it means. This is not only important for you, it is a useful reminder to healthcare professionals who communicate with parents all the time, whether in the Collaborative or in the exam room. Keep your eye on the big picture which is quality improvement for kids with special healthcare needs – sometimes it seems arduous to get there, but it does happen!

## Section Three:

### A Guide for Healthcare Professionals

**P**atients and their families are essential allies and key stakeholders in efforts to improve care. In fact, no one has more invested than they do in maintaining what is good about the delivery of care and improving the areas that need improvement. While this is often acknowledged, providers still find themselves doing things to and for the patient, rather than with them.

This is especially the case when it comes to quality initiatives, particularly those of a clinical nature. Understandably, healthcare professionals consider themselves the experts when it comes to clinical issues. What they sometimes don't realize, however, is that patients and families are able to identify issues and problems they may not see. Inviting patients and families to bring to the table their perspective, their experience, and their passion has the potential to accelerate change and partnership.

#### How Healthcare Professionals Benefit From Partnering With Parents

Working in partnership with parents can benefit healthcare professionals and organizations in the following ways:

- Improves the planning process
- Helps you carry out your mission
- Increases your knowledge and skills
- Helps you do a better job
- Brings fresh perspective to problems
- Provides an ally to advocate for better services for children and families
- Increases your empathy and understanding for families
- Brings about better consumer satisfaction

Dear Health Care Professionals,

Making improvements in healthcare requires resources, support, time, and knowledge. The knowledge needed to improve the system comes from many disciplines, requires many views, and we believe should include, if not be driven by, the needs and experience of those we serve.

The National Initiative for Children's Healthcare Quality (NICHQ) has been working in partnership with parents and families since its inception. These remarkable partners have diligently and thoughtfully shared their time and experience to assist NICHQ and many others in their efforts to improve our healthcare system.

Many have noticed this partnership and asked NICHQ for ideas on how and where and when to develop such a relationship. It is our hope that this guide will offer useful guidance on how you and your organization might move towards partnering with those you serve.

Tara Bristol, Parent Partner  
Ginna Crowe, RN, MS  
Pat Heinrich, RN, MSN

## Understanding the Patient Experience

Patients and families have a very unique perspective on the healthcare system. Many enter into it with little knowledge of how it works or what to expect and often feel helpless to control care for themselves or their loved one.

Medical professionals, on the other hand, work within the system every day. Everything about it is familiar, even comfortable. This is why two skills are immediately important when providers partner with parents to improve care: careful and respectful listening and the ability to empathize without feeling defensive. These are key ingredients for accelerating improvement efforts.



Really listening to a patient or family member as they share a story can be a powerful experience, especially if it is shared in person. Stories can also be shared via video or through pictures and writing. It is often through hearing about how patients and families experience care—the triumphs or losses, the confusion, the things or people that help, and those that don't—that providers are moved to action.

The following pages offer an example of how patient stories can bring about change. Read about the indelible experiences of one family as they navigated a frightening and confusing passage through the health care system, and how those experiences ultimately led to positive change.

There are a number of other ways that providers can gain insight and perspective into the patient experience of care:

- Conduct surveys among families three, six and twelve months post-discharge to gather feedback on their experiences and to identify any barriers they are encountering to follow-up care. Examples of evidence-based patient/family surveys can be found here: [https://www.caahps.ahrq.gov/content/products/Prod\\_Intro.asp](https://www.caahps.ahrq.gov/content/products/Prod_Intro.asp)
- Provide a story template that families can complete online to help providers and QI leaders better understand their perspective and needs
- Form parent panels to meet with new nurses. Parents can share their NICU experiences with new staff to help them understand what the experience is like from the parents' perspective.
- Create an evaluation form for parents to complete on discharge, asking for feedback on staff performance in such areas as respect, terminology, open communication, and listening

## Tara's Story: Thrust Into the World I Was Trying to Change *By Tara Bristol*

During my pregnancy and at the time I gave birth to my son, I was working for the Center for Children's Healthcare Improvement at the University of North Carolina. My training and experience focused on improving the health care system, and I was used to working with physicians, nurses, educators, and quality experts on projects to improve care.

I had no idea that I was about to be thrust into the world that I was working so hard to change.

At week 27 in my pregnancy, I was concerned about some swelling that wouldn't subside, so I made an appointment to see my provider. I expected a quick once-over before going back to work. Blood pressure: good. Baby's heart rate: good. Protein in the urine: not so good.

The nurse midwife who saw me consulted with an OB, who said I needed to go to Labor and Delivery at the hospital right away. I began to cry, and called my husband who quickly joined me.

At L&D, I was put into a triage room. My blood pressure reading was twice what it had been earlier. While gathering her supplies to leave the room, without even making eye contact, the nurse said, "You're going to be here for a while."

"How long is a while?" I asked fearfully. "Until this baby is born," she answered, and left the room.

### ***Pain and Panic***

My head was spinning. I was sobbing. My husband tried to comfort me. A nurse entered the room to insert a catheter. She seemed annoyed that I was so upset, and in response to my cry of pain, said, "It really doesn't hurt that much."

My admitting physician—whom I had just met—came by to check on me before leaving for the weekend. I'll always remember her simple act of human kindness: she put her hand on mine, and said, "They will take good care of you."

Through the night, my blood pressure continued to climb. The baby's heart rate continued to fall. There were ultrasounds, heart monitors, residents, nurses, it's all a blur. I sensed that people were panicky. My husband signed some forms. Then, seemingly without warning, they took me away.

I have no idea how many people were in the delivery room, but I knew my husband wasn't there. I felt alone. Someone started to swab my belly with iodine. I heard a voice say there was no time for that, and so the liquid was poured over me. Just then the gas mask covered my face and I was told to breathe.

### ***"They Must Think My Son Is Going To Die"***

I don't know how long I was out. When I woke up, I was in agonizing pain. My husband handed me some photos. I had given birth to our son—and he was alive. He weighed 1lb. 13oz.

I was still sick and on a lot of medication, so I was not allowed to see my son. I asked repeatedly for a breast pump, and was told the lactation consultant had been paged. But she never came. They must think my son is going to die, I thought; that's why they aren't bringing me the breast pump. I pleaded to see my baby. Finally, when I was able to get out of bed and walk a few steps, my nurse brought me in a wheelchair to see him. By then he was nearly three days old.

I would spend 11 days as an inpatient. My son would spend 83 days in the NICU. Leaving the hospital without my baby was excruciating.

Each day, no matter how sick I felt, I went to the hospital to see him. In the beginning, I merely sat by his side, watching doctors and nurses administer life-saving care, while I felt helpless. I had to be taught how to touch my baby—he couldn't be stroked, but a firm touch might comfort him. When our son was two weeks old, I was allowed to hold him for the first time. I cried as I held his tender skin against mine. Finally, I felt like a mom.

### ***People at Their Best and Worst***

I was determined not to let another day go by where I wouldn't hold my baby. Despite the pulmonary hemorrhage, blood transfusions, multiple failed extubation attempts, and fear of brain bleeds, my worst day in the NICU was the day my son's nurse told me she was too busy to help me hold him. I crumbled, and my husband took me home.

Still, we never missed a day. We became sponges, absorbing everything we could about our son's needs and care. We were the first to identify that it was time to change his CPAP cap—because he had passed the weight limit for his old one. We knew when he needed to be suctioned and when an alarm meant real 'distress,' as opposed to a loose lead. We overheard conversations about medical errors. And the day a baby in our pod died, we held ours extra close. We saw people—nurses, doctors, families—at their best, and at their worst.

After 83 days in the NICU, we took our little boy home. I would never want to repeat the experience, but nor do I want to forget it. We learned so much. We learned how to advocate for our son, to seek out resources and support.  
*continued*

*continued*

We learned that it takes everyone—providers, patients and families—working together, for care to be at its best.

About a year later, we attended our NICU's reunion. There was a sign-up sheet for people interested in joining a new "Parent Advisory Board." I signed up. That was five years ago.

### ***Making a Positive Difference for Other Families***

When I went to my first meeting of the Family Advisory Board, the leaders didn't really know what they were doing. They just knew that bringing providers and families together to work on quality was the right thing to do.

So we began a process of looking for resources that would guide us, and we found the Institute for Patient- and Family-Centered Care. Through them, we found models of folks who were doing what we wanted to do, and we were able to learn from their examples.

I chaired the Board that first year, and one of the things we learned was that there is a learning curve for both family members and staff members, because we don't always see things the same way. Everyone on staff thinks they know what patients and families want and need because they work with them day in and day out. But when we toured another hospital's NICU, we reacted differently to some of the things we saw. For example, this unit had a beautiful meditation room for families, and the family members on our Board pointed out that our hospital had no private space for families. Staff thought the small, uninviting, undecorated "consult room" served that purpose. We pushed for funds to renovate the space, and got them. That project built trust among the Board members and opened the door for work that was more clinical in nature.

When the project is very clinical in nature, staff members sometimes struggle to see how parents can help. But I sat in on a lot of meetings that first year and I learned that you can't predict when something will resonate with parents. You can't pick and choose when to involve them because you never know when their perspective is going to bring value to the opportunities for change.

### ***Aha Moments***

After a year, we were able to create a paid staff position in the unit focused on enhancing family-centered care, and I got that job. I wanted staff who weren't part of the Advisory Board to be able to benefit from parents' insights, so every month we invited someone to come and present the work they were doing to the Board and get feedback. They would report back to us about how they had integrated our advice, and that was a huge thing for us.

We also started a program called "A Day In The Life," where providers would talk with the Board about their role in the NICU, what they loved about their work and what they found challenging. After a while staff really looked forward to it; they would say "I want to get parent feedback on this, or that." This was a great tool for partnering on the unit level.

As a group we had a lot of "aha moments." Here are some of the lessons we've learned:

- Don't worry about exposing the system's weaknesses to families. They already know about them. Staff sometimes resist the idea of involving parents in improvement activities because they don't want to "air their dirty laundry" to the very people they are trying to serve. But most parents recognize how hard it is to do everything perfectly, and respect a system and staff who acknowledge and embrace opportunities for change.
- Continuously educate staff about patient- and family-centered care. Patient- and family-centered care is about doing things with families, not to or for them. There is a need for constant education on this point. Staff may think they are providing family-centered care because they give parents a handbook, or design a room for them. But it is really about engaging in the process with them. Whether it is a quality improvement project or some other work, involving families from the very beginning is the best way to get it right.
- Just get started. Quality improvement begins with small tests of change. It is not about changing the whole system or process overnight. If you want to start a Family Advisory Board, don't wait until you think everything is perfectly in place to start. Just start with one family. Ask them how they think things could be improved. And go from there.
- Find a way to create a paid position. Having a staff member focused on improving family-centered care increases organizational commitment, accelerates improvement, and demonstrates to families that meeting their needs is a priority.

After my experience with my son's birth, I knew I wanted to come back and help somehow. This job is the perfect marriage of my background as a project manager and my experiences as a parent. Every parent who comes through this unit can contribute in some way, because no matter how empathic the providers are, they will never understand the experience the way that patients and families do.

## Involving Patients and Families in Improvement Activities

It is fairly common for parents to be invited to help with improvement activities that focus on non-clinical issues, such as choosing furniture or artwork for a new family space. However, patients and families can also be powerful allies in clinically-focused improvement efforts. Making this leap can feel uncomfortable for healthcare professionals at first, as improvement work includes review of data, detailed discussions regarding care processes, and a start-up period full of unknowns. While there is sometimes a push to not include parents in all meetings, the value of patient and family involvement comes from their unique perspective. Including them in every step is often the best way to determine how and where their perspective is most helpful.

### Recruiting and Selecting Family Partners

Identifying and recruiting parents to serve with healthcare professionals on an improvement team is a process best done one-on-one by providers. Nevertheless, it can be helpful to get the word out to parents about the opportunity to serve. This can be done through newsletter articles, meetings, posters, and word-of-mouth.

It is also a good idea for team leaders to develop a written summary of the team's work to give to parents who are interested. To standardize the recruitment process if multiple providers are involved, create a list of criteria you are looking for in parent partners, and some specific interview questions.

# Tips

for Providers Working with Parents

- Identify **early** a parent leader with expertise in the specific focus area for a Learning Collaborative or other quality improvement activity.
- Look for parent leaders with qualities such as:
  - Parent of a child or young adult
  - Able to go beyond the self component of the *Concentric Circle Model of Parent Leadership* (see page 21)
  - Is passionate about the need for change
  - Understands and can communicate the purpose of the Learning Collaborative
  - Able to travel
  - Able to facilitate meetings
  - Skilled at empowering parents
  - Good writer
  - Attached to other parent resources in the state and possibly across the country
  - Committed to attending faculty and parent calls with appropriate schedule accommodations
  - Insightful with interpersonal dynamics
  - Good public speaker
  - Self-starter
  - Approachable
  - Culturally sensitive and respectful of differences
  - Good listener
  - Good sense of humor
  - Big picture thinker
- Include parent/family partners in all planning meetings from beginning of collaborative and strategize ways for parents to be involved in the system changes of the team.
- Tangible outcomes assist families in getting involved – for example, developing seizure action plans and care notebooks or care plans in the epilepsy Collaborative were initiatives begun and carried out by parent partners.
- Support a parent partner as a leader by giving him/her a role in the agenda – for example, a presentation at one of the collaboratives or leadership on a test of change.
- Follow-up with parents who don't attend team calls or meetings.

The Institute for Patient- and Family-Centered Care offers the following tips on selecting patients and families to serve as advisors. Look for people who are:

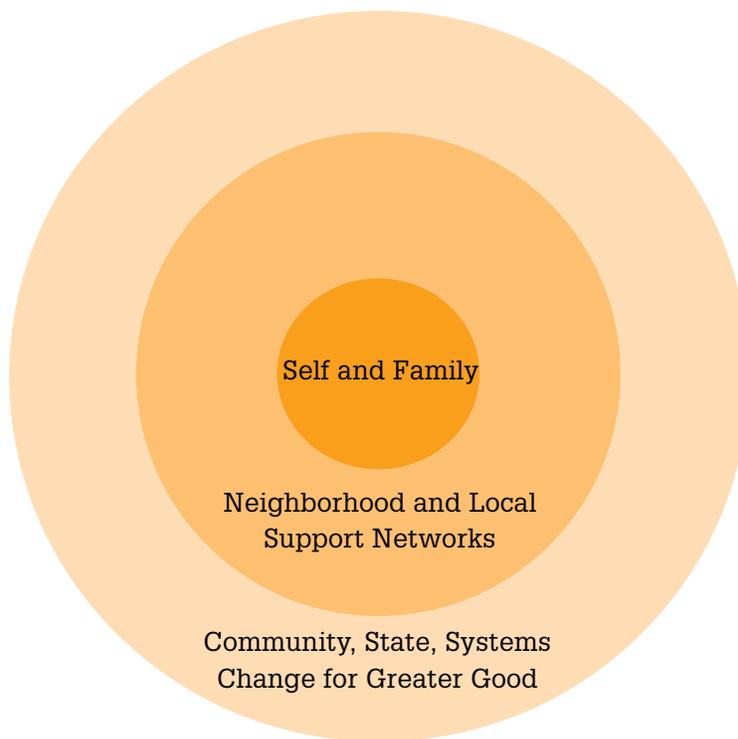
- Interested in the topic being addressed by the committee or task force
- Comfortable speaking in a group with candor
- Able to use their personal experience constructively
- Able to listen and hear differing opinions

Also, the Institute says that having just one patient or family member on a committee is not usually successful. Strive for patients and family members to be one-third to one-half of the committee's membership. Remember that serving as a patient or family advisor is a new role for many people. Some patients and family members will need more support than others. Recognize that individuals can grow and develop in this role.<sup>5</sup>

### The Concentric Circle Model of Parent Leadership

Parent family leaders typically grow during the course of a partnership in their ability to see beyond their own experience and consider the “greater good” for all children. The concentric circle model shown in Figure 3 demonstrates this growth. Parents/family often find themselves in the center of the circle. They manage the care of their children and their family without moving to the next circle, which is leadership in their community. The center is often a place families return to, for example, during a child's surgery or crisis. Family leaders “flow in and out of the center,” but, with increased experience, are able to move from a personal level to the greater good in the outer circle.

**Figure 3. The Concentric Circle of Parent Leadership**



<sup>5</sup>Institute for Patient- and Family-Centered Care. Partnering With Patients And Families To Enhance Safety and Quality: A Mini Toolkit

## Providing Orientation and Education

Successfully launching a committee of any sort requires spending time up front laying a strong foundation for the group's work. This is perhaps even more important when the team includes healthcare professionals and parents. For many or most, working in this sort of partnership will be new. Working together to establish goals, ground rules, roles, expectations, schedules, and policies is an essential part of this important work.

It is also important to provide education and training in the science of improvement. Although improvement theory and methods have become much more common in industry, business, and healthcare, the specific concepts and language of quality improvement are often new for healthcare providers, patients and families alike. In addition, clinical content and language are also unfamiliar to most patients and families.

To establish common knowledge and language — to “level the playing field” — it is worthwhile for teams to participate in quality-related training and education programs together.

There are many excellent resources for this, including:

- The National Initiative for Children's Healthcare Quality (NICHQ): [www.nichq.org](http://www.nichq.org)
- The Institute for Family- and Patient-Centered Care (IFPCC): [www.ipfcc.org](http://www.ipfcc.org)
- The Institute for Healthcare Improvement (IHI): [www.ihl.org](http://www.ihl.org)



## Conclusion

**Patient- and family-centered care involves collaborative relationships between those who give and those who receive care. When these powerful partnerships are extended into the realm of quality improvement, everyone benefits: patients, families, providers, and organizations.**

**When that work is focused on improving the quality of care for the smallest and most vulnerable patients—our children—the rewards are perhaps the most profound of all.**

## Appendix A: Alphabet Soup: Sorting Through the Acronyms

The following list contains some acronyms and terms you may hear as you work on improving care for children with special healthcare needs.

### **AAP**

The **American Academy of Pediatrics (AAP)**. This is an organization of pediatricians, physicians trained to care for infants, children, and adolescents. Its motto is “Dedicated to the Health of All Children.” Most American pediatricians are members of this physician-focused organization. They are strong advocates for children’s health.

### **The Buckley Amendment**

See FERPA

### **CDC**

The US **Centers for Disease Control and Prevention**, part of the US Department of Health and Human Services, works to create the expertise, information, and tools that people and communities need to protect their health – through health promotion, prevention of disease, injury and disability, and preparedness for new health threats.

### **CHIP**

The **Children’s Health Insurance Program**, administered by CMS, is a state and federal partnership that targets uninsured children and pregnant women in families with incomes too high to qualify for most state Medicaid programs, but often too low to afford private coverage. Within Federal guidelines, each State determines the design of its individual CHIP program, including eligibility parameters, benefit packages, payment levels for coverage, and administrative procedures.

### **CMS**

The US **Centers for Medicare and Medicaid Services**, part of the US Department of Health and Human Services, is responsible for administering Medicare, Medicaid, and the Children’s Health Insurance Program.

### **CYSHCN**

**Children and Youth with Special Health Care Needs**. The federal government defines CYSHCN

as those who have or are at risk for chronic physical, developmental, behavioral, or emotional conditions that require health and related services of a type or amount beyond that required by CY generally.

### **EPSDT**

**The Early Periodic Screening, Diagnosis, and Treatment Program** is the child health component of Medicaid. It’s required in every state and is designed to improve the health of low-income children, by financing appropriate and necessary pediatric services. This website (<http://mchb.hrsa.gov/epsdt/overview.html>) provides information about how EPSDT works with public health, families, managed care organizations, pediatricians, and other health providers.

### **FERPA**

The **Family Educational Rights and Privacy Act** of 1974 (FERPA or the Buckley Amendment) is a United States federal law codified at 20 U.S.C. § 1232g, with implementing regulations in title 34, part 99 of the Code of Federal Regulations. The regulations cover violations such as parent volunteers grading another child’s work, school employees divulging information to someone other than the child’s parents about a child’s home life, grades or behaviors, and school work posted on a bulletin board with a grade.

### **FQHC**

A **Federally Qualified Health Center** is a reimbursement designation that refers to several health programs funded under Section 330 of the Public Health Service Act of the United States of America’s Federal Government. The grantees in the Health Center Program include:

- Community Health Centers which serve a variety of underserved populations and areas;
- Migrant Health Centers which serve migrant and seasonal agricultural workers;
- Health Care for the Homeless Programs which reach out to homeless individuals and families and provide primary and preventive care and substance abuse services; and
- Public Housing Primary Care Programs that serve residents of public housing and are located in or adjacent to the communities they serve.

FQHC are community-based organizations that provide

comprehensive primary and preventive health, oral, and mental health/substance abuse services to persons in all stages of the life cycle, regardless of their ability to pay.

### **HIPAA**

The **Health Insurance Portability and Accountability Act** (HIPAA) was enacted by the U.S. Congress in 1996. According to the Centers for Medicare and Medicaid Services (CMS) website, Title I of HIPAA protects health insurance coverage for workers and their families when they change or lose their jobs. Title II of HIPAA, known as the Administrative Simplification (AS) provisions, requires the establishment of national standards for electronic health care transactions and national identifiers for providers, health insurance plans, and employers.

### **HRSA**

The **Health Resources and Services Administration** (HRSA), an agency within the United States Department of Health and Human Services, is the primary Federal agency for improving access to health care services for people who are uninsured, isolated, or medically vulnerable. According to HRSA, the agency “envisions optimal health for all, supported by a health care system that assures access to comprehensive, culturally competent, quality care.”

### **HRTW**

**Healthy and Ready to Work** initiatives focus on ensuring access to quality care as youth with special health care needs become adults, transitioning from child centered to an adult oriented systems of care. The Maternal and Child Health Bureau’s Division of Services for Children with Special Health Care Needs (MCHB/DSCSHN) funds the development and demonstration of model Healthy & Ready to Work (HRTW) state programs focused on children and youth with special health care needs (CYSHCN).

### **IRB**

An **institutional review board** (IRB), also known as an **independent ethics committee** (IEC) or **ethical review board** (ERB) is a committee that has been formally designated to approve, monitor, and review biomedical and behavioral research involving humans with the aim to protect the rights and welfare of the research subjects. IRBs are governed by Food and Drug Administration (FDA) and HHS (specifically OHRP) regulations.

### **MCHB**

The **Maternal and Child Health Bureau** is an agency within HRSA that addresses the health care needs of pregnant women, mothers, infants, children and their families, and children with special healthcare needs. The largest of the programs, the Maternal and Child Health Services Block Grant to the States, creates Federal-state partnerships to develop service systems in our nation’s communities to meet the critical challenges facing maternal and child health. HRSA’s other programs designed to improve the health of the nation’s women and children are the Healthy Start Program, Universal Newborn Hearing Screening, Traumatic Brain Injury, Sickle Cell Service Demonstrations, Family to Family Health Information Centers, and Emergency Medical Services for Children

### **MFI**

The **Model for Improvement**, developed by Associates for Process Improvement, is a methodology for accelerating improvement. It is described in detail in the first section of this handbook.

### **PDSA Cycle**

A **Plan-Do-Study-Act cycle** is a method for testing and implementing changes in real work settings. The PDSA cycle guides the test of a change to determine if the change is an improvement.

### **QI**

**Quality Improvement** initiatives in healthcare can focus on improving access to care, processes of care, the experience of care, health outcomes, and/or the cost of care.

### **State Title V CSHCN Programs - Children with Special Health Care Needs**

Every state and the District of Columbia has a Title V Program for Children with Special Health Care Needs (CSHCN) that is funded, in part, through the Federal Title V Maternal and Child Health Block Grant. These programs began in 1935, when Congress passed the Social Security Act, a law designed to bring some financial and health security into the lives of America’s most vulnerable citizens. The fifth article of that act, known as Title V (five), provided funds to states to develop and operate public health care programs for certain children with special healthcare needs as well as to establish other programs to promote the health of low-income mothers and children.

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National Initiative for  
Children's Healthcare Quality