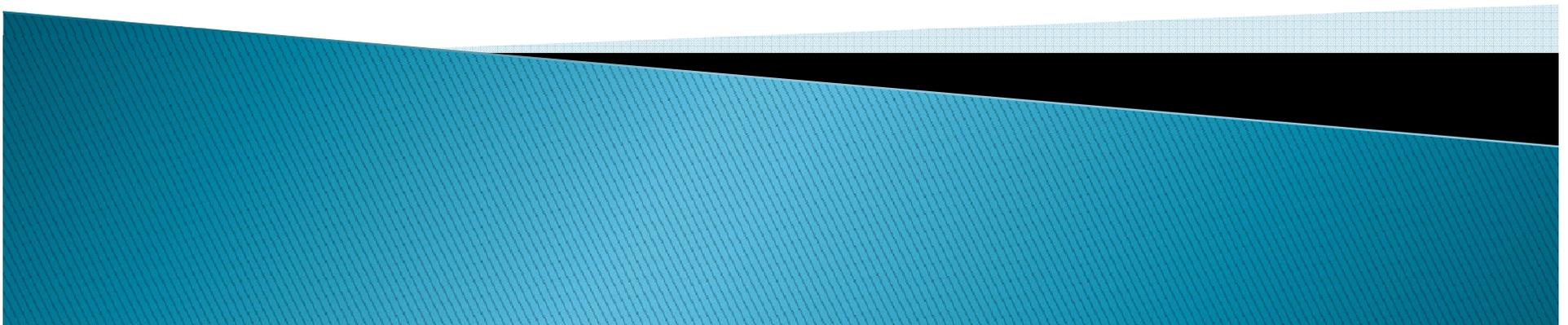


# Partnerships are Key

in Measuring and Improving  
Quality in Child Health

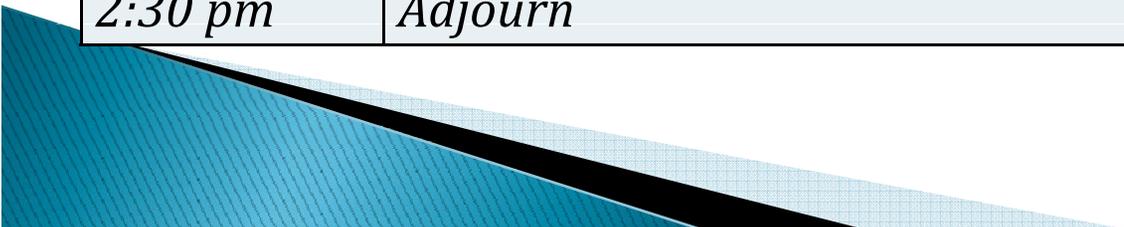
*Moderator: Nora Wells*

*Faculty: Tara Bristol, Beth Dworetzky,  
Pat Heinrich, Dawn Wardyga*



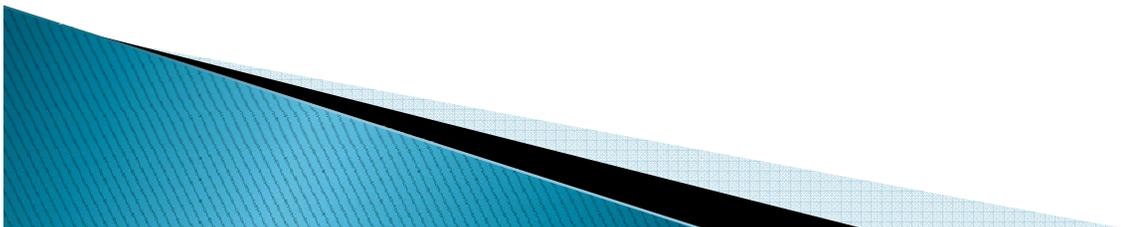
# Agenda

<i>1:15 pm</i>	<i>Welcome and Introduction</i>	<i>Nora Wells</i>
<i>1:20 pm</i>	<i>Quality - How will I know it when I see it?</i>	<i>Pat Heinrich</i>
<i>1:35 pm</i>	<i>Parent Partners on Perinatal Projects</i>	<i>Tara Bristol</i>
<i>1:50 pm</i>	<i>MA Partnerships to Improve Children's Health</i>	<i>Beth Dworetzky</i>
<i>2:05 pm</i>	<i>The Rhode Island Experience - doing the right thing and making it cost effective</i>	<i>Dawn Wardyga</i>
<i>2:20 pm</i>	<i>Summary &amp; Close</i>	<i>Nora Wells</i>
<i>2:30 pm</i>	<i>Adjourn</i>	



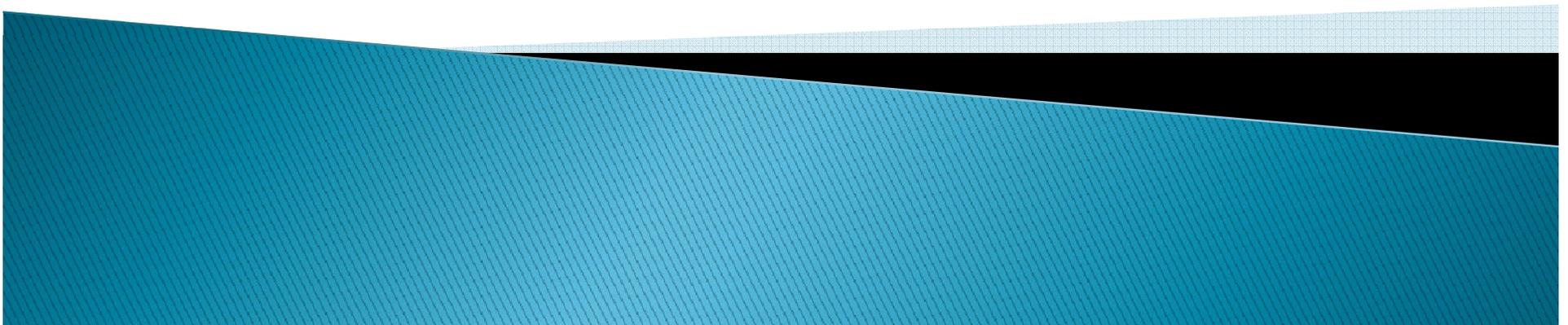
# Objectives

- ▶ Identify key national and state initiatives that provide opportunities for families and professionals to work together around quality improvement
- ▶ Identify current successes, gaps and challenges in successfully engaging families in efforts to improve quality
- ▶ Identify specific strategies that may be replicated in states for quality improvement activities



# **Quality - How Will I Know It When I See It?**

*Pat Heinrich, RN, MSN*

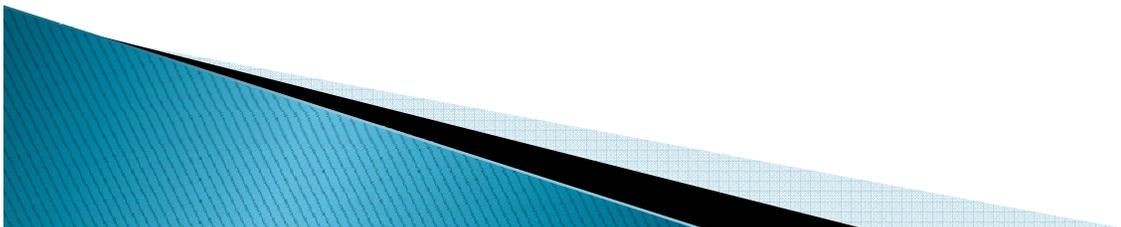


# NICHQ's Mission

To improve children's health by improving the systems responsible for the delivery of children's healthcare.

Specifically, NICHQ:

- builds sustainable system improvement capabilities;
- accelerates adoption of best practices; and
- advocates for high quality children's healthcare.





**Neonatal  
Outcomes  
Improvement  
Project**

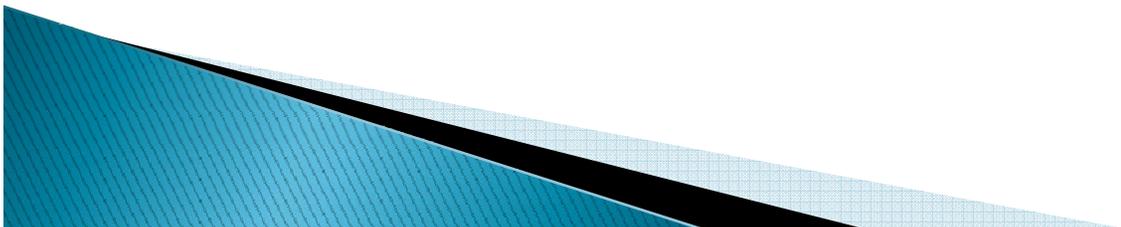
**NICHQ**

**National Initiative for Children's Healthcare Quality**

# What is Quality?

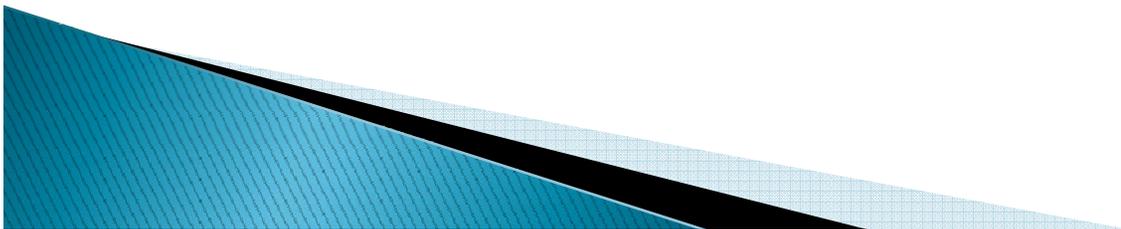
“I don't know,  
but I know when I see it!”

*Anonymous*

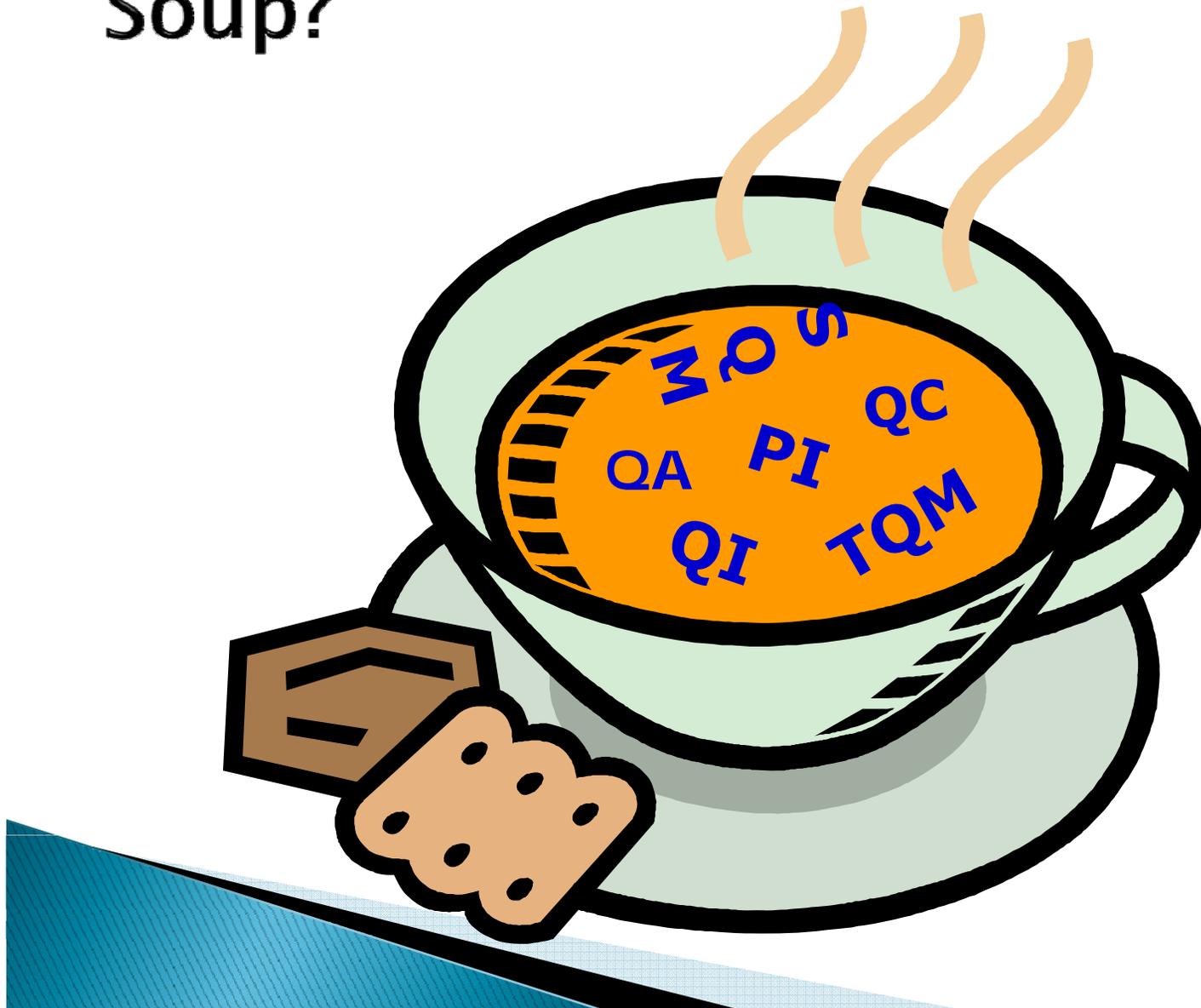


# Institute of Medicine Definition of Quality (2001)

”The degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge.”

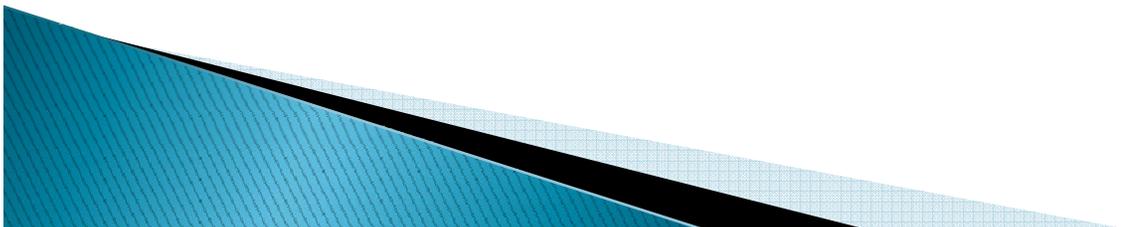


# Quality Improvement or Alphabet Soup?



# Similarities in Approach

1. Organizational commitment to quality
2. Focus on the customer
3. Fix systems (processes)
4. Foster teamwork and group problem solving
5. Base improvement decisions on data
6. Continuously improve (as long as you live)
7. No quick fixes

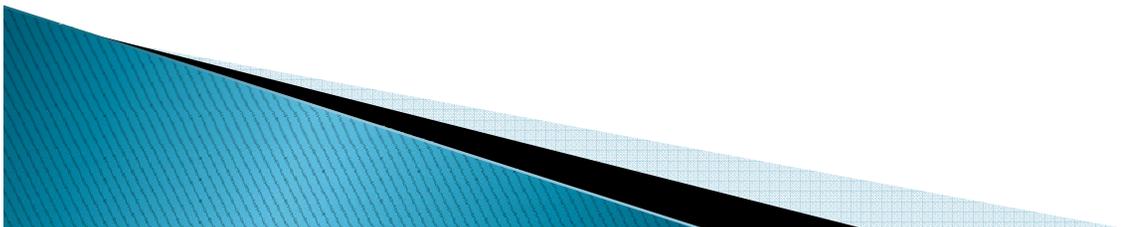


# Evolution of Quality (in healthcare)

1820-1910	1910-1950	1950-1990	1990-Present
<p>Florence Nightingale Uses Statistical Analysis and Plots the Incidence of Preventable Deaths in the Military (1820-1910)</p>	<p>American College of Surgeons/ Donebedian (1918)</p> <p>First Quality Manual Published (18 pages!) (1926)</p> <p>Deming and Juran become prominent figures in the field of quality management in industry (1945)</p>	<p>JCAHO (1951)</p> <p>JCAHO Medical Audit &amp; Performance Evaluation (1972)</p> <p>JCAHO Agenda for Change Announced—Use of Clinical Indicators (1986)</p> <p>Agency for Healthcare Research and Quality (AHRQ) Created (1989)</p>	<p>Institute for Healthcare Improvement Founded (1991)</p> <p>A Variety of Methodologies for Improvement Emerged</p> <p>NICHQ Founded &amp; IOM publishes "To Err is Human" (1999)</p> <p>IOM publishes Crossing the Quality Chasm (2001)</p> <p>IHI launches Improvement Campaigns (2004)</p>

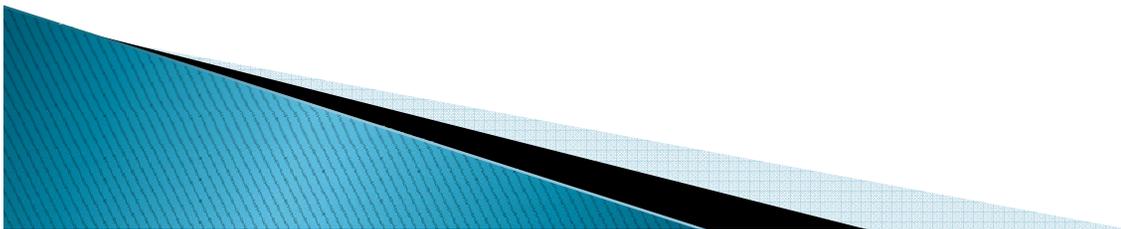
# Dr. Edward Deming

***“We should work on  
our process,  
not the outcome of  
our processes”***

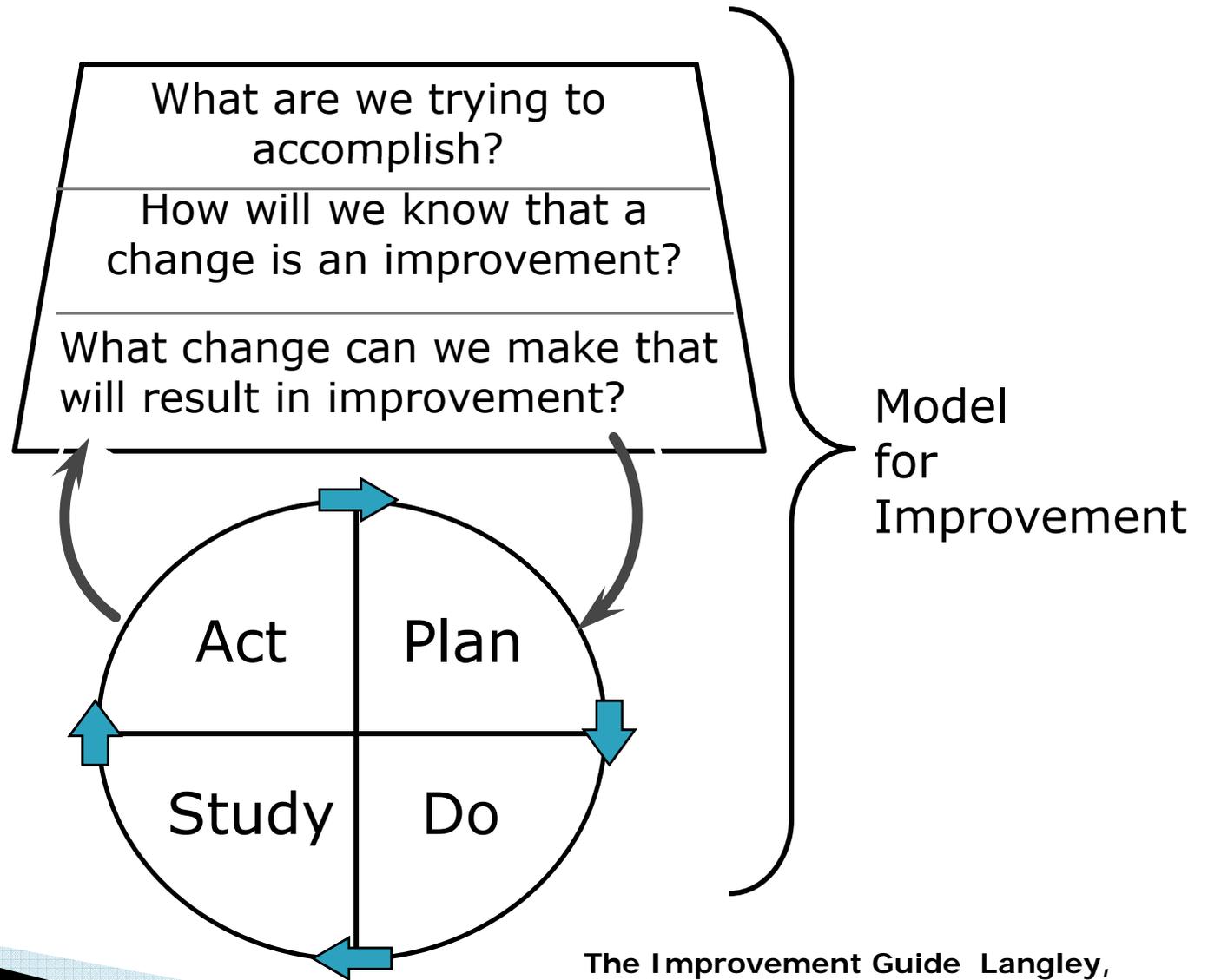


# The Model for Improvement (MFI)

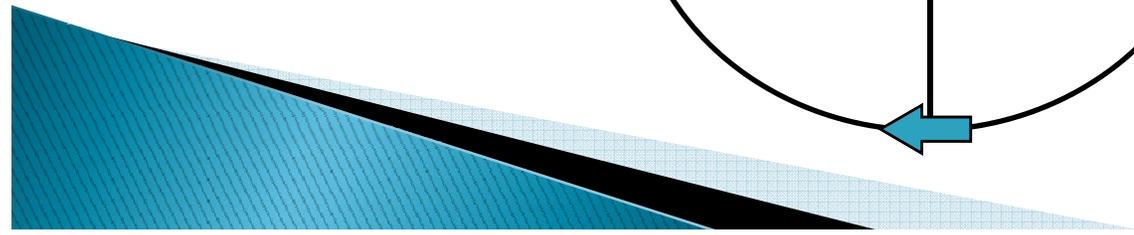
*is a method to help increase  
the odds that the changes we  
make are an improvement.*



# Method for Change



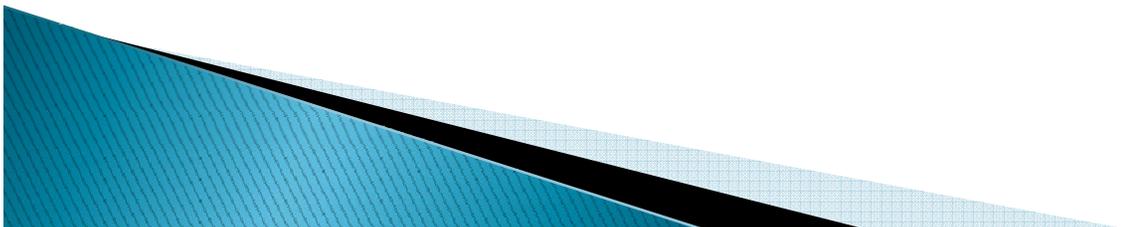
The Improvement Guide Langley, Nolan, Nolan, Norman, Provost 1996



# Question 1: What are we trying to accomplish?

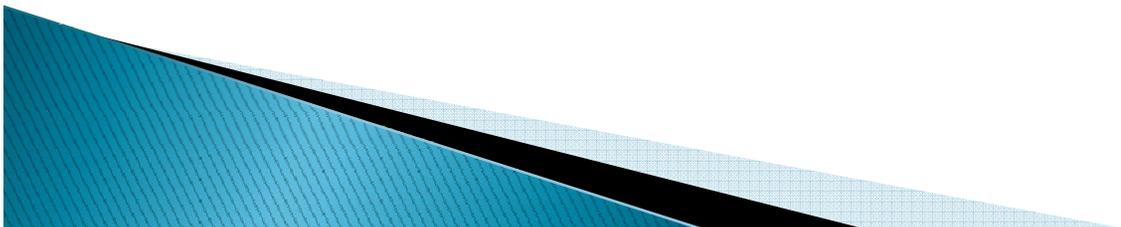
## The Aim Statement

- ▶ Answers and clarifies “What are we trying to accomplish?”
- ▶ Creates a shared language and shared methods
- ▶ Facilitates organizational conversations and understanding
- ▶ Supports accountability for team leaders



# SMAART Aims (Objectives)

- ▶ Specific: Understandable, unambiguous
- ▶ Measurable: Numeric goals
- ▶ Actionable: Who, what, where, when
- ▶ Achievable (but a stretch)
- ▶ Relevant to stakeholders and organization
  - Strategic, Compelling, Important
- ▶ Timely: with a specific timeframe



## Question 2: How will we know that a change is an improvement?

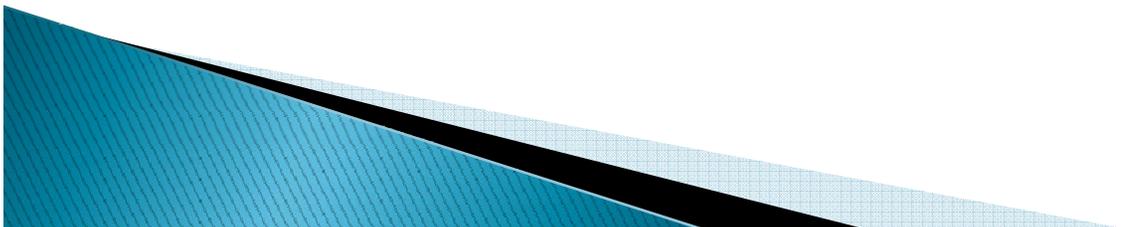
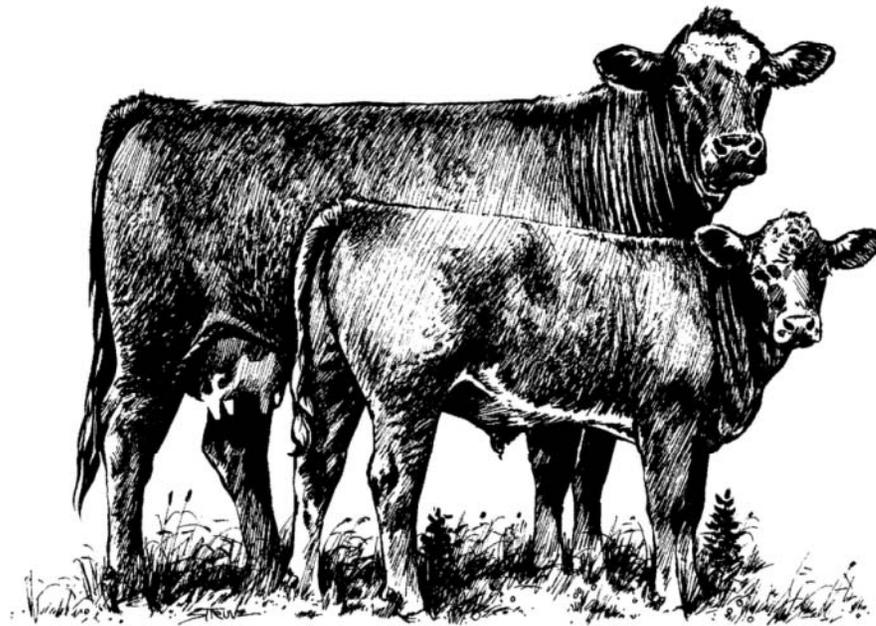
- ▶ Measures
- ▶ Sample Data



# Data is important but.....

“You can’t fatten a cow by weighing it”

- Palestinian Proverb

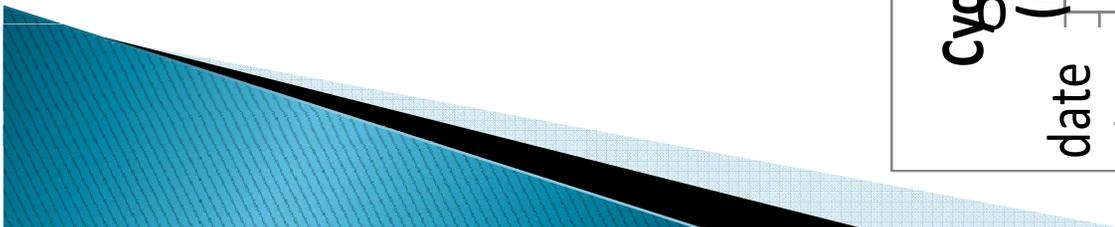
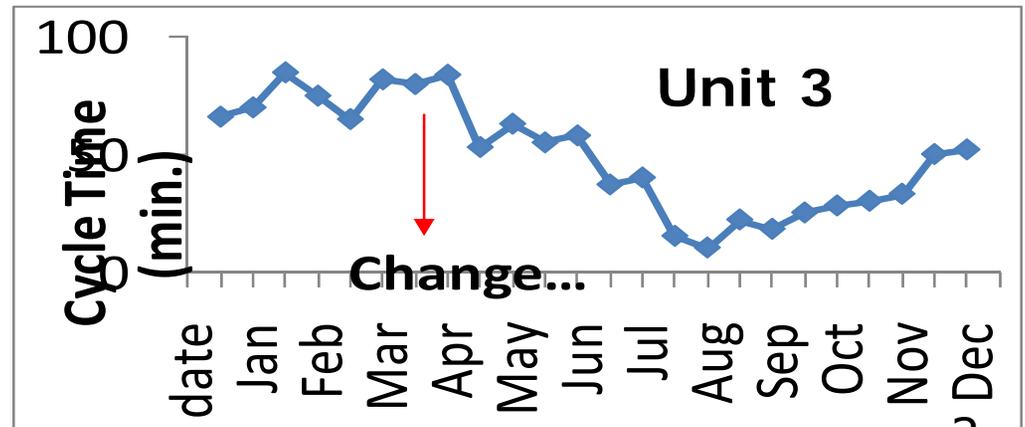
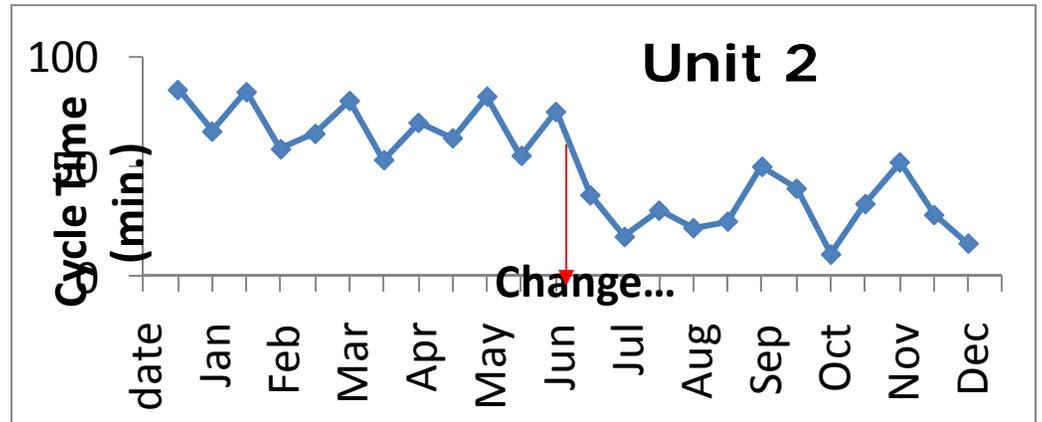
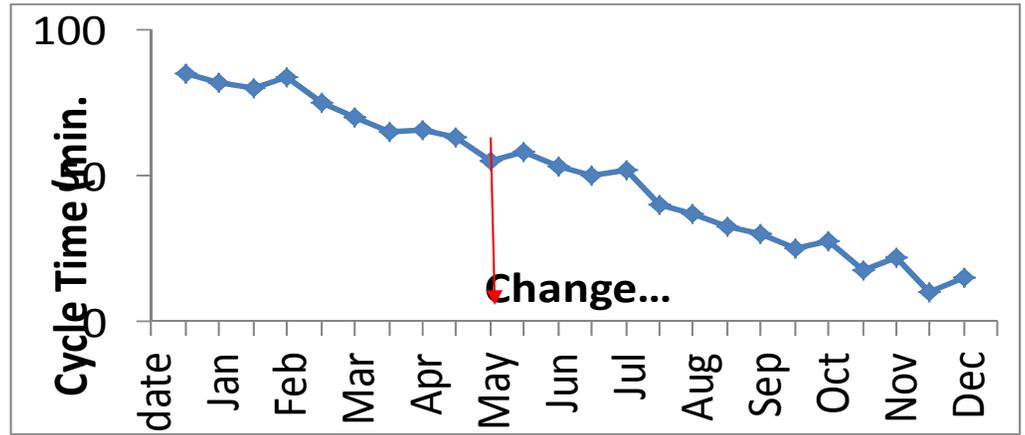
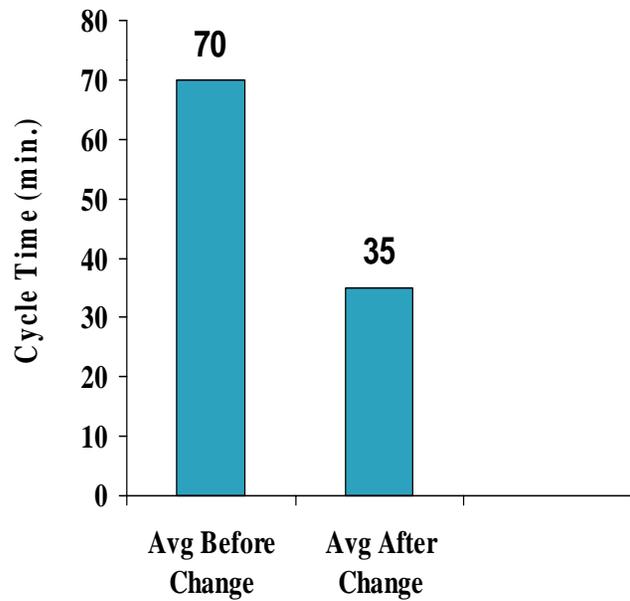


# Three Faces of Performance Improvement

Aspect	Improvement	Accountability	Clinical Research
<b>Aim:</b>	Improvement of care	Comparison, choice, reassurance, spur for change	New knowledge
<b>Methods:</b>			
Test observability	Test observable	No test, evaluate current performance	Test blinded
Bias	Accept consistent bias	Measure and adjust to reduce bias	Design to eliminate bias
Sample size	“Just enough” data, small sequential samples	Obtain 100% of available, relevant, data	“Just in case” data
Flexibility of hypothesis	Hypothesis flexible, changes as learning takes place	No hypothesis	Fixed hypothesis
Testing strategy	Sequential tests	No tests	One large test
Confidentiality of data	Data used only by those involved in the improvement	Data available for public consumption	Research subjects' id protected

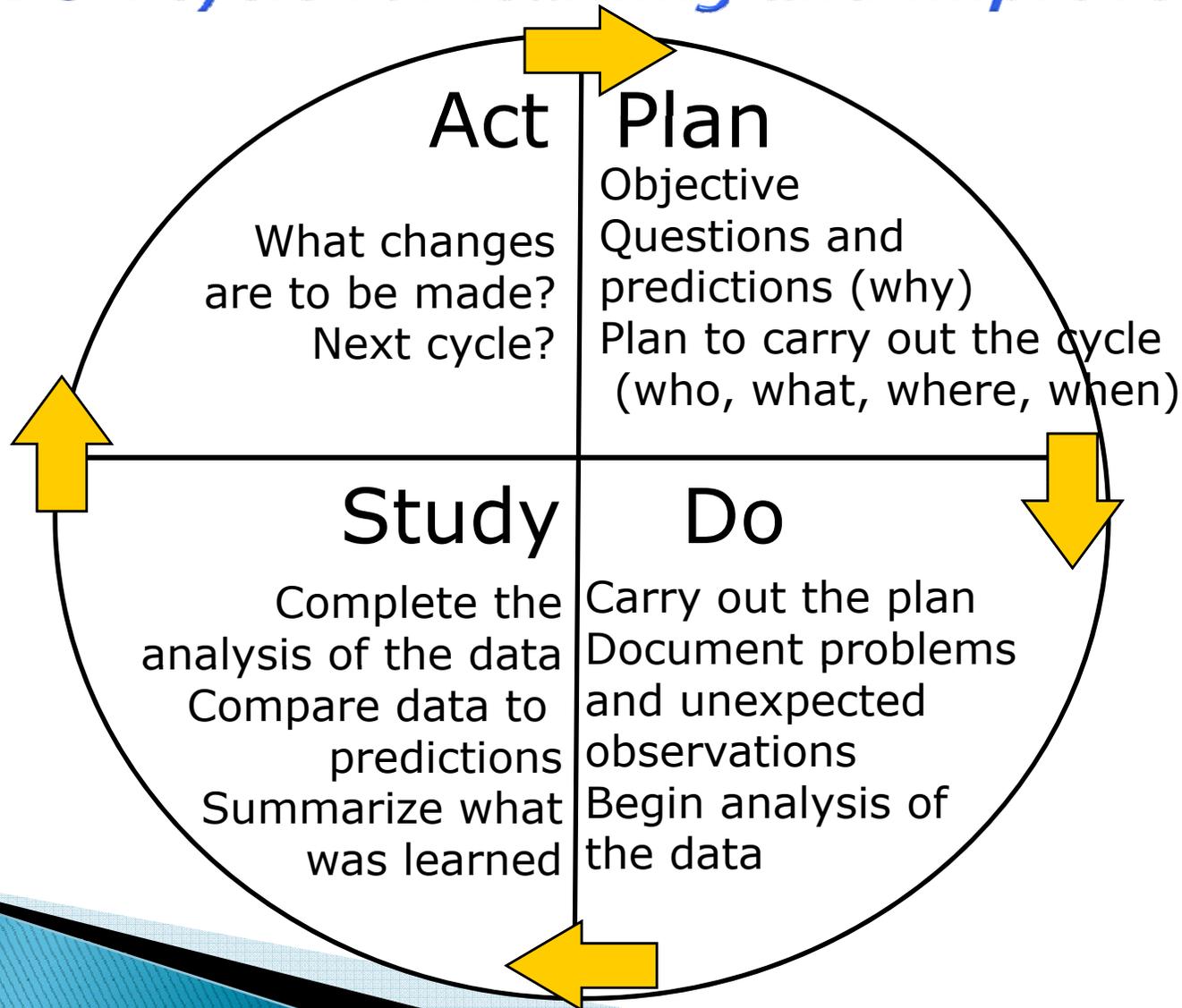
“The Three Faces of Performance Measurement: Improvement, Accountability and Research.” Solberg, Leif I., Mosser, Gordon and McDonald, Susan *Journal on Quality Improvement*. March 1997, Vol.23, No. 3

# Display of Data for QI

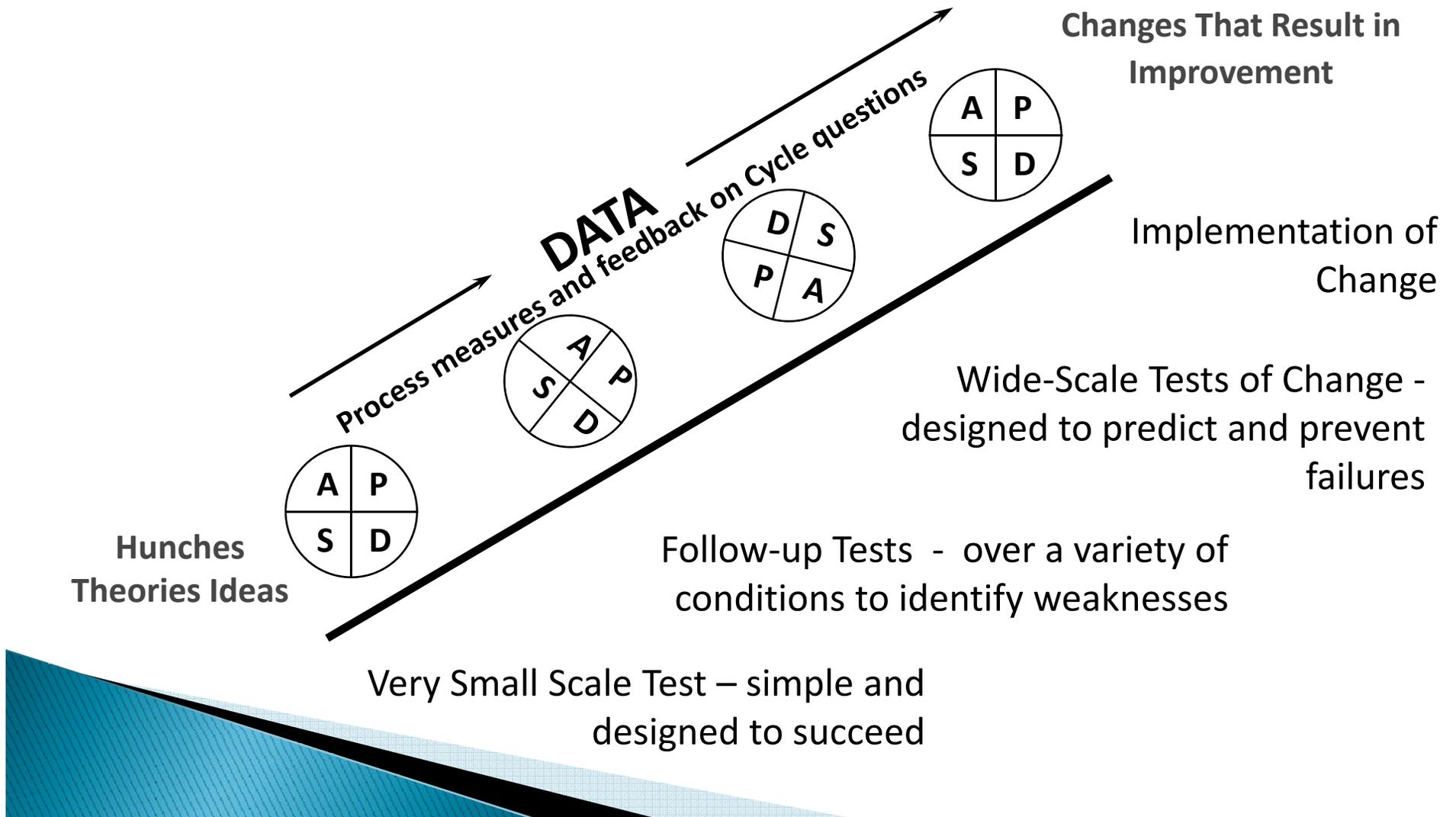


**Question #3** What changes can we make that will result in an improvement?

*The PDSA cycle for learning and improvement*

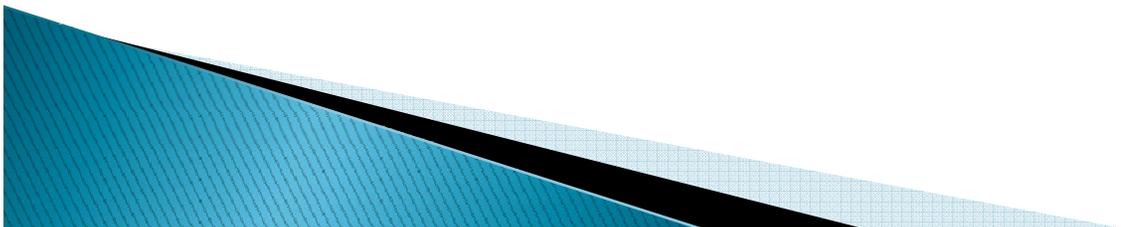


# Repeated use of PDSA cycle



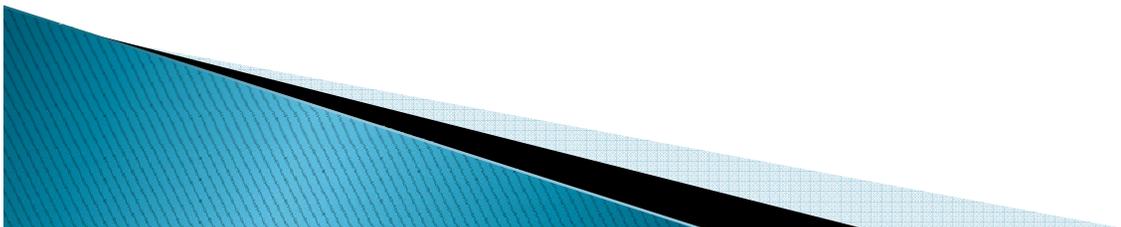
# Using PDSA Cycles to test *better* ideas

- ▶ Plan multiple cycles for a test of a change
- ▶ Initially, scale down size of test (# of patients, clinicians, locations)
- ▶ Test with volunteers
- ▶ Do NOT try to get buy-in or consensus for test cycles
- ▶ Be innovative to make test feasible
- ▶ Collect useful data during each test
- ▶ In latter cycles, test over range of conditions



# Tips for success

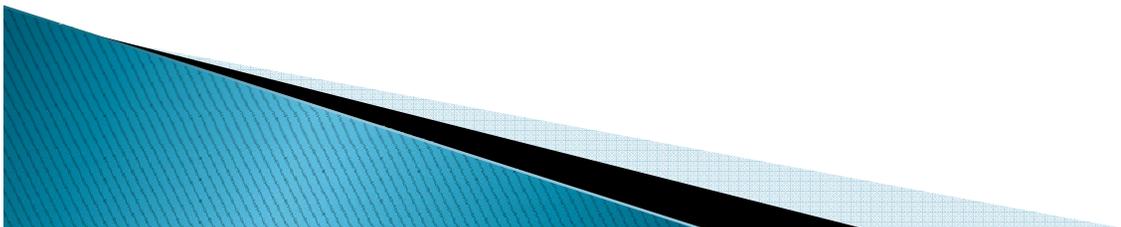
- ▶ Improvement occurs in small steps
- ▶ Repeated attempts needed to implement new ideas
- ▶ Assess regularly to improve plan
- ▶ Failed changes = learning opportunities
- ▶ Plan communication
- ▶ Engage leadership support



For more information:  
[www.NICHQ.org](http://www.NICHQ.org)

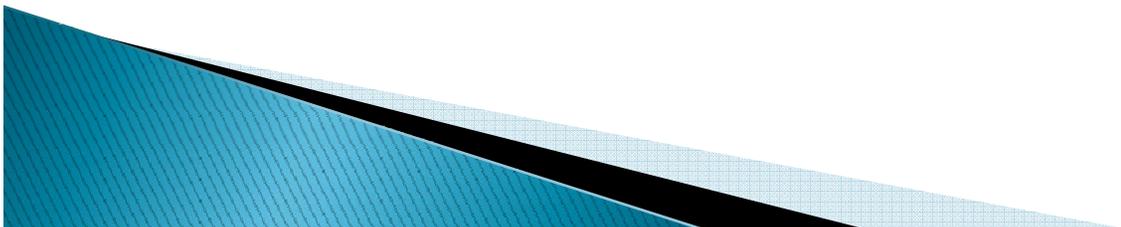


National Initiative for Children's Healthcare Quality



# References

- ▶ Langley, K. Nolan, T. Nolan, C. Norman, L. Provost. *The Improvement Guide: A Practical Approach to Enhancing Organizational Performance*. G. Jossey-Bass Publishers., San Francisco, 2009. Second Edition.





# Parent Partners on Perinatal Projects

Tara Bristol, MA

March of Dimes NICU Family Support Specialist  
North Carolina Children's Hospital

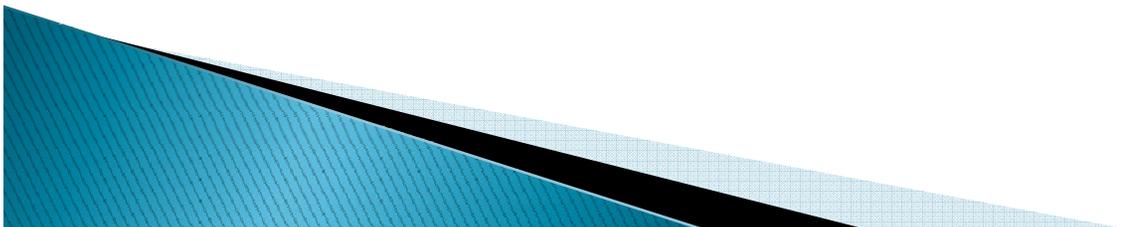


UNC  
North Carolina  
CHILDREN'S  
HOSPITAL



PQCNC





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## "Gabby"

On the importance of the Catheter Associated Blood Stream Infections (CABSI) initiative...



### Materials

- [About PQCNC](#)
- [Institutions](#)
- [Members](#)
- [Conferences](#)
- [Initiatives](#)
- [Resources](#)
- [Family Focus Group](#)
- [Of Interest](#)
- [Blogs](#)
- [Friends of PQCNC](#)

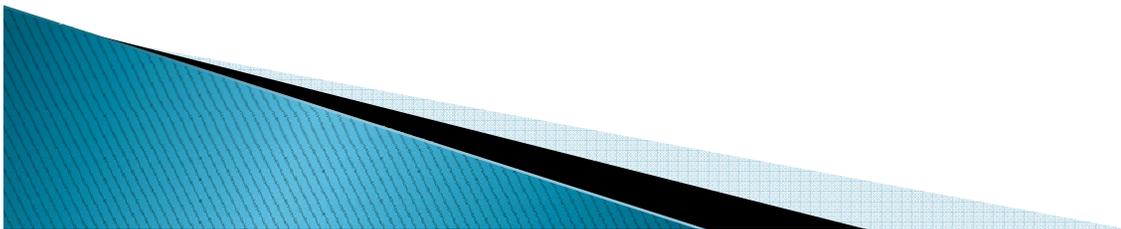
### Members

# Duke ICN Infection Committee



“... ask the nurse or doctor; ‘Did you remember to wash your hands?’ ...”

*From the Duke RAIN Family Letter*



# Wash Hands



**After use!**



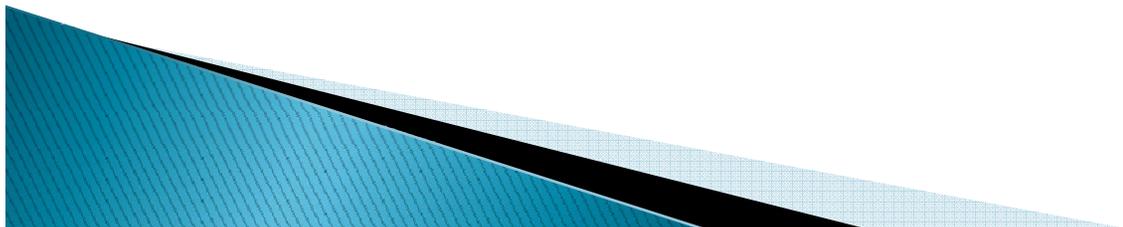
100 Days and counting!  
Zero BSI is achievable!



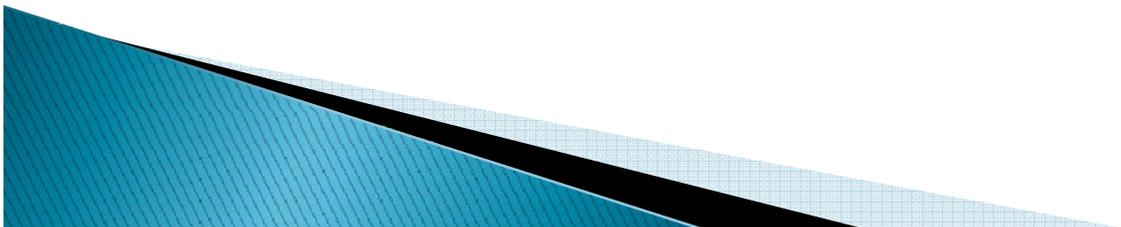
# Rally Against Infection **RAIN**

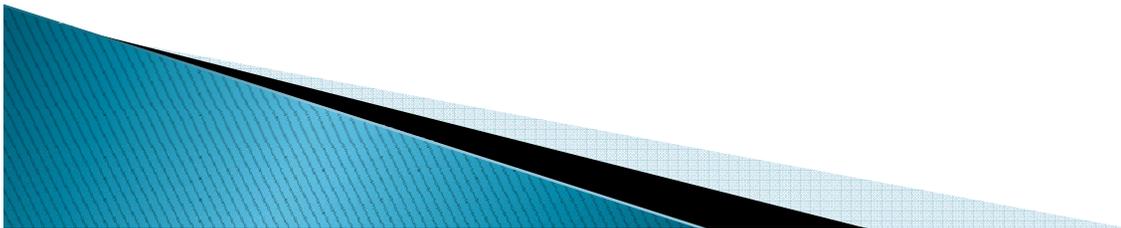


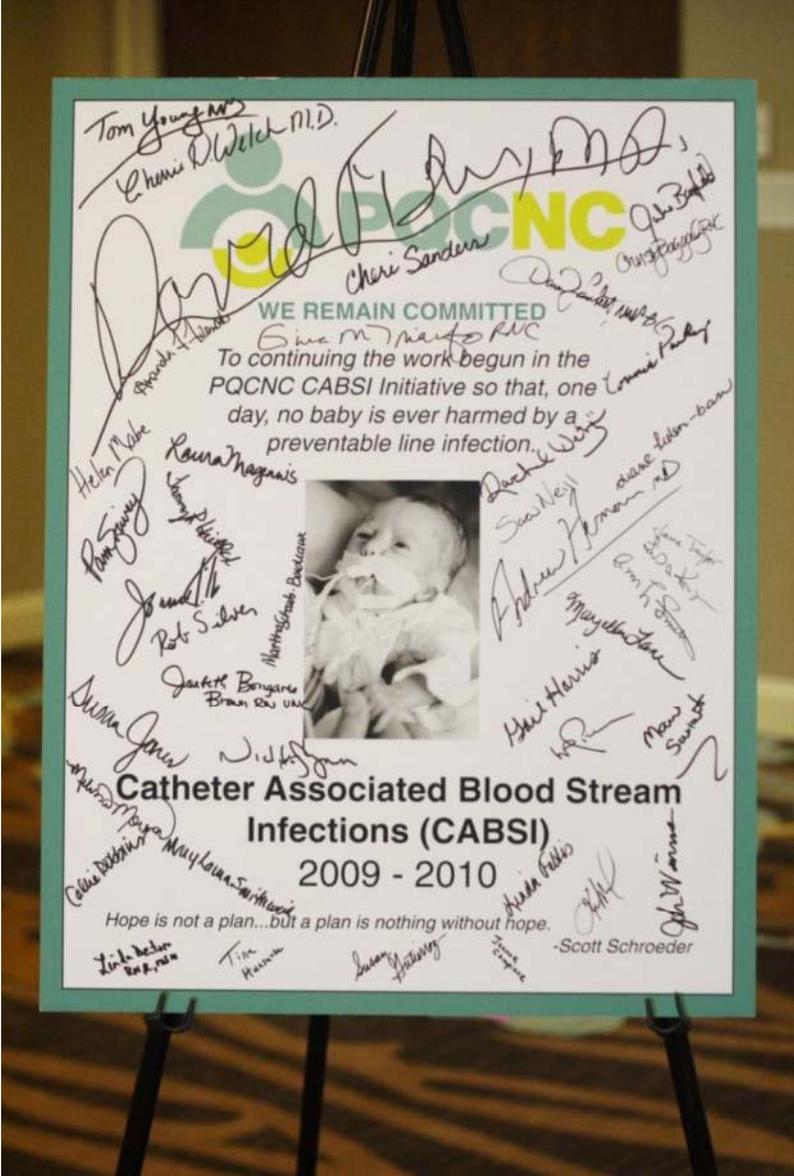
Can we do it?  
Yes we can!!!



## Avery & Raegan at One-Month-Old







Tom Young MD  
Cheri DeWet M.D.

Cheri Sanders  
Dan...  
Chris...  
Chris...

WE REMAIN COMMITTED  
To continuing the work begun in the  
PQCNC CABSI Initiative so that, one  
day, no baby is ever harmed by a  
preventable line infection.

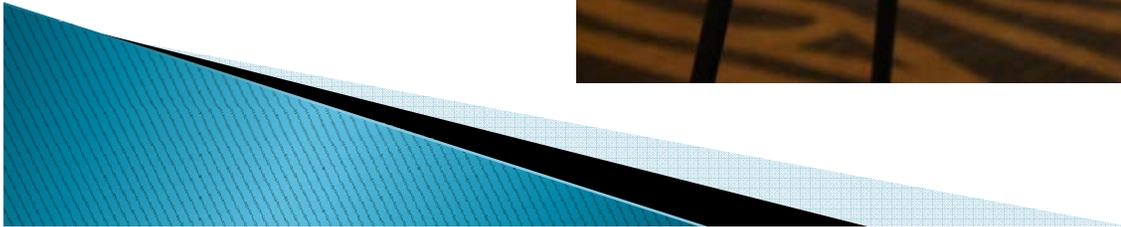


Helon...  
Raura...  
J...  
R...  
J...  
B...

De...  
S...  
A...  
M...  
H...  
M...

**Catheter Associated Blood Stream Infections (CABSI)**  
2009 - 2010

Hope is not a plan...but a plan is nothing without hope.  
-Scott Schroeder

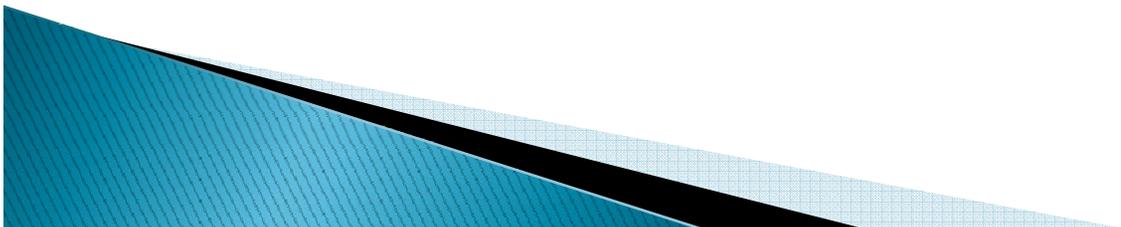


# MA Partnerships to Improve Quality of Children's Health

*Beth Dworetzky*

# MA Partnerships to Improve Quality of Children's Health

- ▶ System Level
- ▶ Medical Home/Hospital Initiative
- ▶ Statewide Initiative
- ▶ Tools



# System Level Partnership – CBHI

- ▶ Problems Identified by MA F2F HIC
  - Data re: Access to service – the trouble with TPL
  - Data re: Regulations/Protocol to address transition from DCF
- ▶ Response from CBHI

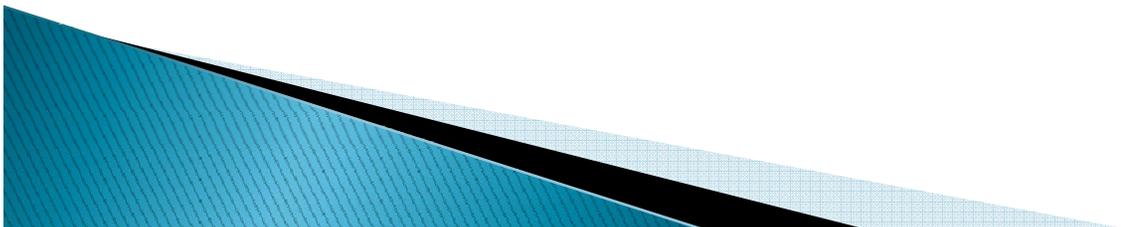
*Thank you SO much for passing this along...I just checked the written protocols we have with DCF and we DON'T address this issue. We will be revising the protocols this Summer, so we will work with DCF to add appropriate language on this. I will also talk to staff at DCF about this...but, as you know, given the very large number of DCF staff, this will take time to change...the flow of the EXISTING information on CBHI is still working it's way through the layers of appropriate DCF staff.*

*I'm thinking we should also work on this from the parent end...informing/educating parents involved with DCF to apply for MassHealth...do you have any thoughts about that...?*



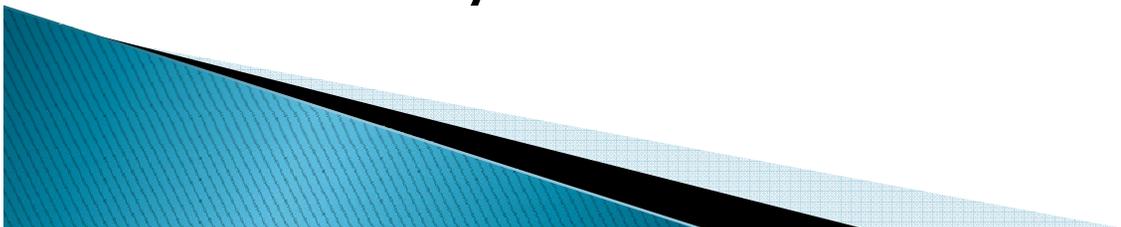
# System Level Partnership – CBHI

- ▶ Partnership Activities
  - Worked together to create protocol
  - Written into MassHealth Regulations
  - Provider/family workshops & individualized TA
- ▶ Outcome – Improved Quality of Children’s Health
  - Families could more easily navigate service
  - Continuity of care
  - Community based services vs. in patient
- ▶ Measure of Success
  - Decreased number of calls



# Medical Home/Hospital Initiative – Collaborative Care Model for Headaches

- ▶ Problems identified by Medical Home
  - No standard of care for headaches: when imaging needed, when to prescribe meds,
  - Little/no communication bet. Neurology & Med. Home
- ▶ Problems identified by Neurology
- ▶ Limited appts for non-urgent headache care
- ▶ Access to neurology & imaging
- ▶ Follow up w/neurology for stable headaches  
→ costly



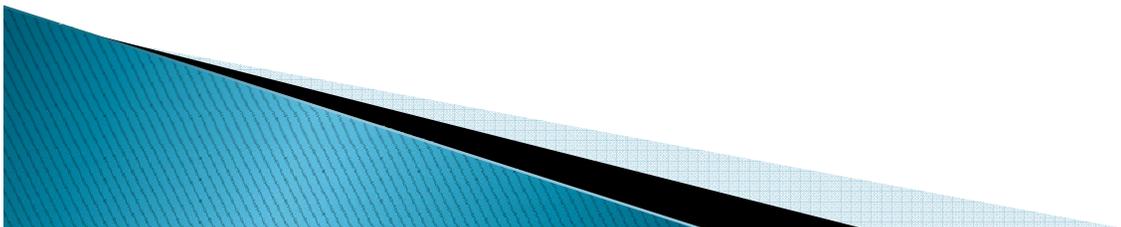
# Medical Home/Hospital Initiative – Collaborative Care Model for Headaches

- ▶ Partners in Quality Initiative
  - Medical Home
  - Children’s Hospital Neurology Dept
  - Health Insurer
  - Mass Family Voices
- ▶ Protocol/Materials
  - Feedback about proposed model of care
  - Worked together to develop family care maps for Neurology and Medical Home
  - Headache diary
  - Surveys to measure family experience w/care
- ▶ Outcomes
  - Empower families/patients to be active participants in care
  - Reduce unnecessary imaging
  - Improve coordination of care
  - Decrease costs



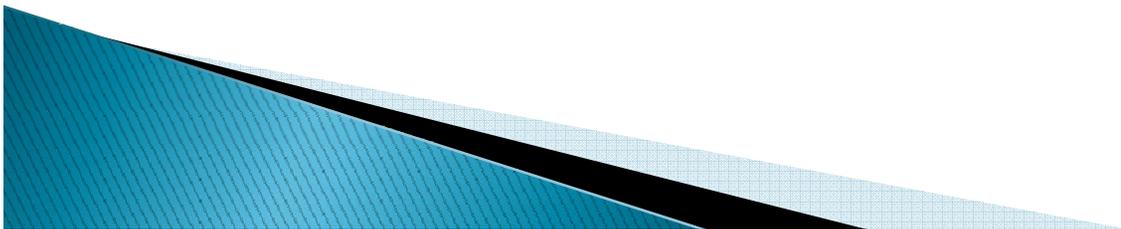
# Statewide Initiative – CHIPRA Quality Demo Grant

- ▶ CMS grant funded through CHIPRA Section 401 (d)
- ▶ MA EOHHS Division of Medical Assistance, with partners
  - MA Health Quality Partners,
  - NICHQ
  - UMass Medical School
  - Children’s Hospital Boston
  - NEACH
  - Mass Family Voices



# Statewide Initiative – CHIPRA QI Grant

- ▶ Improve child health care quality
- ▶ Identify gaps in child health quality
- ▶ Identify new & useful quality measures for consumers
- ▶ Include child health issues in broader state activities
- ▶ Ensure consumer education & transparency



# FCC Assessment Tools

## FAMILY-CENTERED CARE SELF-ASSESSMENT TOOL

Developed by  
**FAMILY VOICES**<sup>®</sup>  
*...keeping families at the center  
of children's health care*

with funding from  
Maternal and Child Health Bureau (MCHB), Health Resources and  
Services Administration, U.S. Department of Health and Human  
Services under Cooperative Agreement #U4QMC00149-09-00

OCTOBER 2008

# Family Tool

## INTRODUCTION

Health care visits for children, youth and their families can be more than getting shots, having ears examined or treating the physical symptoms of an illness. Each visit is an opportunity for families, youth and health care providers to partner to assure quality healthcare for the child and to support the family's needs in raising their child. This enhanced aspect of the family and health care provider relationship is called family-centered care. The foundation of family-centered care is the partnership between families and professionals. Key to this partnership are the following:

- Families and professionals work together in the best interest of the child and the family.
- As the child grows, s/he assumes a partnership role.
- There is mutual respect for the skills and expertise each partner brings to the relationship.
- Trust is fundamental.
- Communication and information sharing are open and objective.
- Participants make decisions together.
- There is a willingness to negotiate.

Within that framework, ten components of family-centered care have been identified. (National Center for Family-Centered Care (1989); Bishop, Woll and Arango (1993)) Family-centered care accomplishes the following:

1. Acknowledges the family as the constant in a child's life.
2. Builds on family strengths.
3. Supports the child in learning about and participating in his/her care and decision-making.
4. Honors cultural diversity and family traditions.
5. Recognizes the importance of community-based services.
6. Promotes an individual and developmental approach.
7. Encourages family-to-family and peer support.
8. Supports youth as they transition to adulthood.
9. Develops policies, practices, and systems that are family-friendly and family-centered in all settings.
10. Celebrates successes.

## PURPOSE OF THE FAMILY-CENTERED CARE SELF-ASSESSMENT TOOL

Family-centered care is a key aspect of quality in healthcare for children, youth and their families. This tool is designed to:

1. Increase outpatient health care settings' and families' awareness about the implementation of family-centered care and,
2. Provide an organized way for healthcare settings to assess current areas of strength and identify areas for growth, plan future efforts and to track progress.

This tool is not designed to provide a score, but is meant as an opportunity for reflection and quality improvement activities related to family-centered care within outpatient healthcare practices. It can also be used by families to assess their own skills and strengths, the care their children and youth receive, and to engage in discussions within health care settings and with policy makers in organizations, health plans and community and state agencies about ways to improve healthcare services and supports. The tool is intended to assess care for all children and youth and also has some questions that are specific to the needs of children and youth with special health care needs and their families. Questions on the tool address the ten components of family-centered care and the key aspects of family/youth/provider partnerships.

**Directions:** Please answer each question by choosing only **one** answer. It may be difficult to rate some items; just answer each question based on your knowledge, experiences and opinions. **There are no right or wrong answers.**

**Note:** In each question the term “provider” refers to the health care professionals and other staff within your health care setting.

## THE FAMILY/PROVIDER PARTNERSHIP

### The Decision-Making Team

FCC Components: 1, 2, 4, 9

#### 1. Does your provider:

- A. Partner with your family to help you define your role in your child's care?  Never  Some of the Time  Most of the Time  Always
- B. Honor your requests for others, (extended family, community elders, faith leaders or traditional healers that are designated by the family) to participate in the process that leads to decisions about care?  Never  Some of the Time  Most of the Time  Always
- C. Help you advocate for services and work to improve systems of care, if you so choose?  Never  Some of the Time  Most of the Time  Always  Does Not Apply
- D. Act to support your family's chosen role in decision-making?  Never  Some of the Time  Most of the Time  Always

#### 2. Do you and your provider:

- A. Work together as partners to make healthcare decisions?  Never  Some of the Time  Most of the Time  Always
- B. Talk about the range of treatment and care choices for your child/youth?  Never  Some of the Time  Most of the Time  Always
- C. Discuss which treatment and care choices would be best for your family and child/youth?  Never  Some of the Time  Most of the Time  Always
- D. Decide together what the desired outcomes are? (e.g., improved health status, better school attendance, less pain, or better involvement with social activities or sports.)  Never  Some of the Time  Most of the Time  Always

#### 3. Do choices of diagnostic and treatment approaches take into account:

- A. Family and child/youth preferences for site of care, type of provider (gender, language spoken, etc.)?  Never  Some of the Time  Most of the Time  Always
- B. Child/youth's ability to tolerate the procedure?  Never  Some of the Time  Most of the Time  Always
- C. How it will affect the family's stress level?  Never  Some of the Time  Most of the Time  Always
- D. Family insurance status and economic situation?  Never  Some of the Time  Most of the Time  Always
- E. Family, child/youth work and school schedules?  Never  Some of the Time  Most of the Time  Always

4. Does your provider make sure you have the information you need to understand the range of treatment and care choices for your child/youth?  Never  Some of the Time  Most of the Time  Always

5. Does your provider make sure all your questions about your child/youth's treatment and care have been answered before you leave the office?  Never  Some of the Time  Most of the Time  Always

6. Do you feel comfortable letting your provider know if/when you disagree with medical advice and recommendations for treatment and care of your child/youth?  Never  Some of the Time  Most of the Time  Always

## CARE SETTING PRACTICES AND POLICIES

### Giving a Diagnosis

FCC Components: 1, 2, 6

#### 1. Does your provider:

- A. Fully inform your family about all test results, positive and negative?  Never  Some of the Time  Most of the Time  Always
- B. Fully inform your family about any diagnosis in a way that you can understand?  Never  Some of the Time  Most of the Time  Always
- C. Help your family name and explain your child's diagnosis to others?  Never  Some of the Time  Most of the Time  Always
- D. Work together with your family so you can explain how your child's diagnosis might affect how she will be able to participate in school, social, community and faith-based activities?  Never  Some of the Time  Most of the Time  Always  Does Not Apply

### Ongoing Care and Support

FCC Components: 1, 2, 3, 4, 6

#### 1. Does your provider:

- A. Help you identify your strengths, skills and knowledge related to your child's health care?  Never  Some of the Time  Most of the Time  Always
- B. Ask you what is working well?  Never  Some of the Time  Most of the Time  Always
- C. Help you identify areas where you may need additional support?  Never  Some of the Time  Most of the Time  Always
- D. Ask you about your child's care based on your knowledge about your child's temperament, behavior and reactions, and other current personal and family needs and priorities?  Never  Some of the Time  Most of the Time  Always
- E. Ask your family and child/youth to share information, such as changes in daily routine or new stresses that may provide insight into the interpretation of test results or diagnostic procedures?  Never  Some of the Time  Most of the Time  Always
- F. Ask your family to initiate consultation appointments or other meetings to discuss changes in your child's care, for example, changes in medications, or other daily procedures?  Never  Some of the Time  Most of the Time  Always
- G. Fully inform your family about diagnostic and treatment options in a way you can understand?  Never  Some of the Time  Most of the Time  Always
- H. Encourage questions about treatment options and the need for any procedures?  Never  Some of the Time  Most of the Time  Always
- I. Offer developmentally appropriate information (for example: stories, workbooks, videos, web-resources, tours) to prepare your child/youth for medical testing and procedures?  Never  Some of the Time  Most of the Time  Always

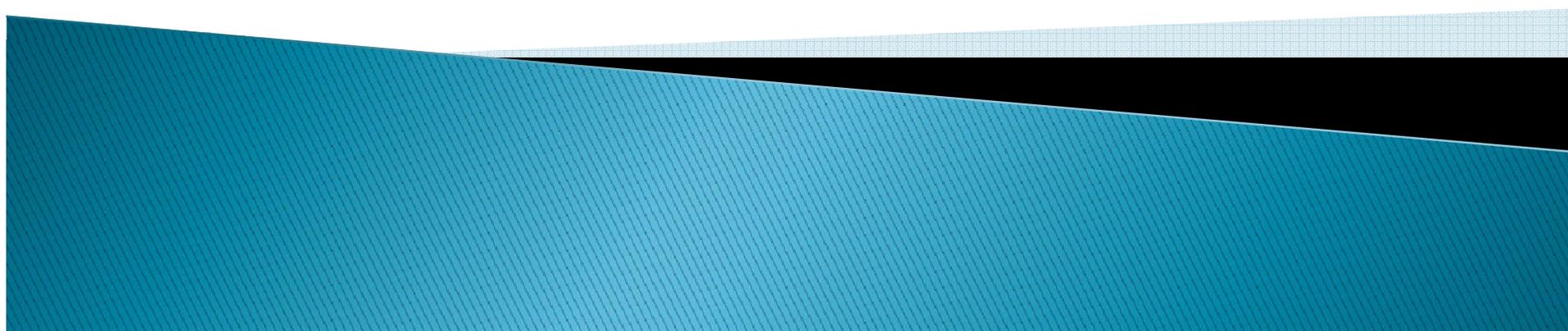
3. Does your provider offer house calls, or other ways that care/treatment can be provided where your child typically spends time?  Never  Some of the Time  Most of the Time  Always

# **The Rhode Island Experience**

## **Doing the Right Thing and Making it Cost Effective**

**Pediatric Practice Enhancement Project (PPEP)**

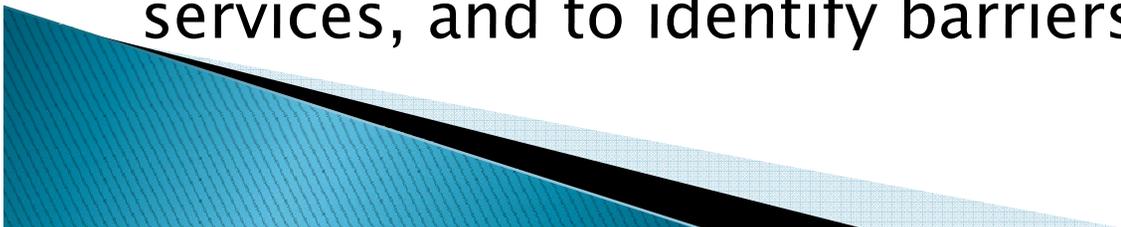
*Dawn Wardyga*



# Mission

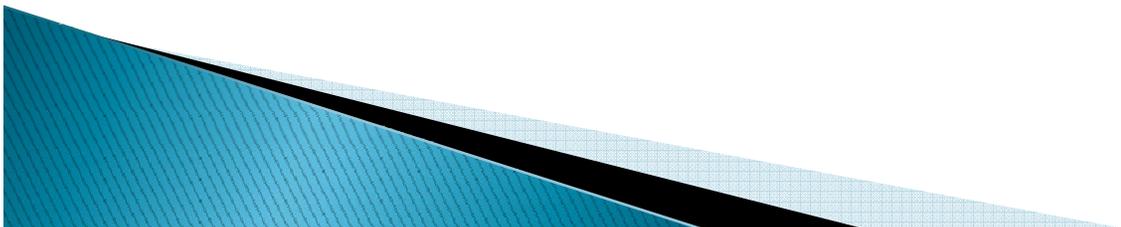
Pediatric Specialty Services works to provide medical home enhancement for children and youth with special healthcare needs including children and youth with Autism Spectrum Disorder.

The Pediatric Practice Enhancement Project (PPEP) ensures a coordinated system of care for children and youth with special needs, and their families, by placing trained Parent Consultants in pediatric primary and specialty care practices to assist families in accessing community resources, to assist physicians and families in accessing specialty services, and to identify barriers to coordinated care.



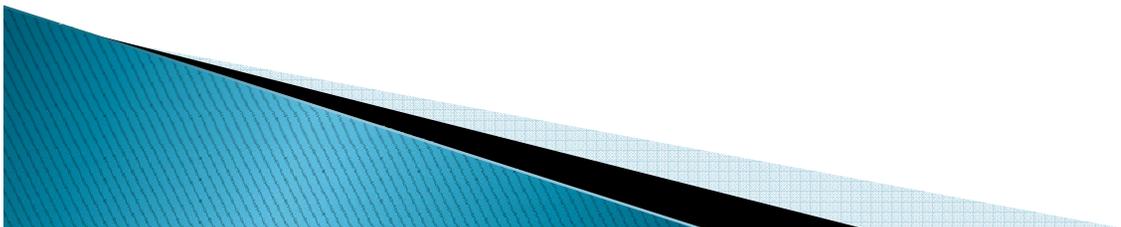
# 2009 Accomplishments and Milestones

- ▶ 24 pediatric and specialty care clinics hosted a Parent Consultant.
- ▶ Annual healthcare costs were lowered by 15% for PPEP participants.
- ▶ PPEP was accepted as a Promising Practice in the field of Maternal and Child Health by the Association of Maternal and Child Health Programs and written up as a case study by the Robert Wood Johnson Foundation.



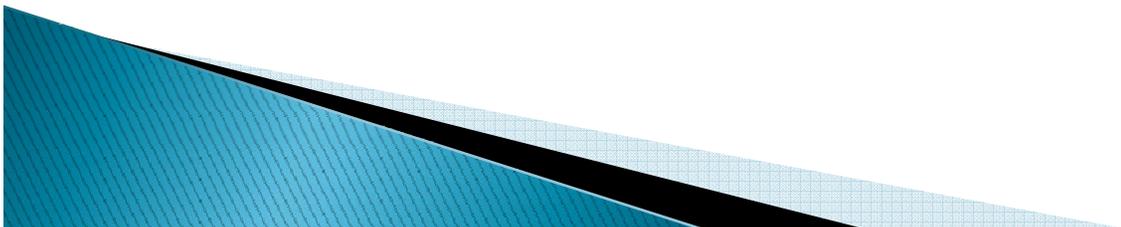
# Medical Homes

- ▶ A medical home is a team approach to providing healthcare that is accessible, family centered, coordinated, comprehensive, continuous, compassionate and culturally appropriate.
- ▶ A medical home begins in a primary healthcare setting that is focused on the families' needs.
- ▶ A partnership develops between each family, the primary healthcare team, and community partners.
- ▶ Together they manage all services.



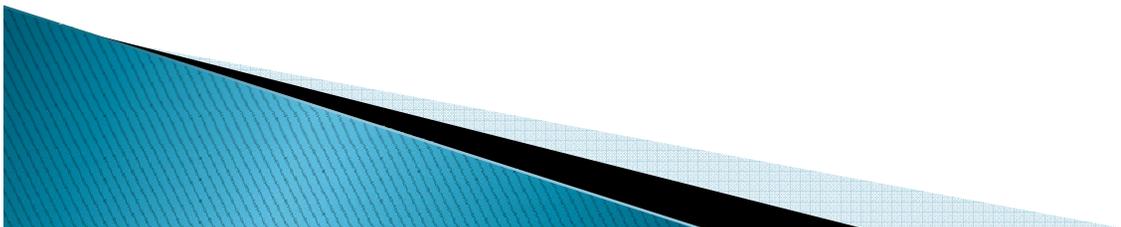
# The goal of the PPEP

- ▶ To maintain the “medical home” model of care by fostering partnerships among families, pediatric practices, and available community resources
- ▶ *Objectives:*
  - Provide coordinated and comprehensive care to children with special healthcare needs.
  - Improve awareness and communication with community resources.
  - Recognize families of children with special healthcare needs as critical decision makers
  - Increase understanding of the healthcare delivery system and access to community resources



# Parent Consultants / Family Resource Specialists

- ▶ The Project places and supports trained family members in clinical settings to link families with community resources, assist physicians and families in accessing specialty services, and identify systems barriers to coordinated care.
- ▶ **Partners**
  - RI Department of Health
  - RI Department of Human Services
  - Family Voices Leadership Team
  - RI Parent Information Network  
(including Family Voices)



# PPEP increases the capacity and quality of care for CSHCN

- ▶ The RI DOH developed PPEP in 2003 to accomplish the Healthy People 2010's Maternal & Child Health objective: to increase the proportion of CSHCN who have access to a medical home.
- ▶ Over 4,200 families served by PPEP to date.
- ▶ PPEP employs Parent Consultants/Family Resource Specialists across pediatric primary and specialty care sites, including private practices, specialty sites, community health centers and hospital-based clinics.



# Sample Evaluation Results

- ▶ **PATIENT PROBLEM RESOLUTION**
    - 81% of the presenting problems were resolved.
    - Many included long-term educational or behavioral health issues.
  - ▶ **COORDINATED CARE**
    - CSHCN had fewer health care encounters than before care coordination occurred.
  - ▶ **LOWER INPATIENT UTILIZATION**
    - Inpatient utilization was 24% lower for PPEP participants compared to pre-PPEP and 34% lower compared to CSHCN in standard care.
  - ▶ **LOWER PATIENT COSTS**
    - Annual healthcare costs were 39% lower for PPEP participants compared to pre-PPEP and 27% lower compared to CSHCN in standard care.
- 

# Information and Resources

<http://www.health.state.ri.us/publications/programreports/2010PediatricEnhancementProject.pdf>

<http://www.amchp.org/AboutAMCHP/BestPractices/InnovationStation/ISDocs/PPEP.pdf>

<http://www.innovations.ahrq.gov/content.aspx?id=2289>

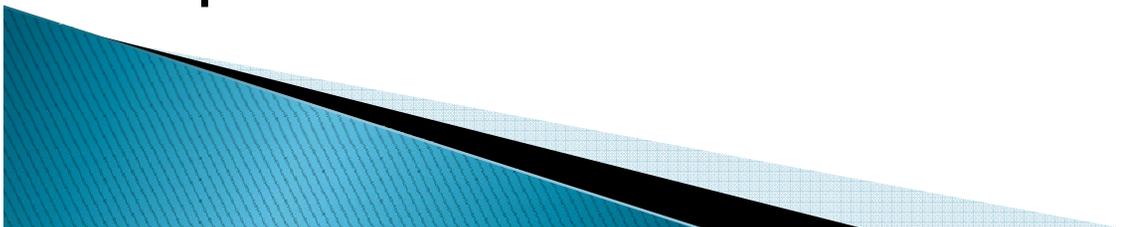
[http://www.commonwealthfund.org/~media/Files/Publications/Case%20Study/2010/Jan/1361\\_SilowCarroll\\_Rhode\\_Island\\_PPEP\\_case\\_study.pdf](http://www.commonwealthfund.org/~media/Files/Publications/Case%20Study/2010/Jan/1361_SilowCarroll_Rhode_Island_PPEP_case_study.pdf)

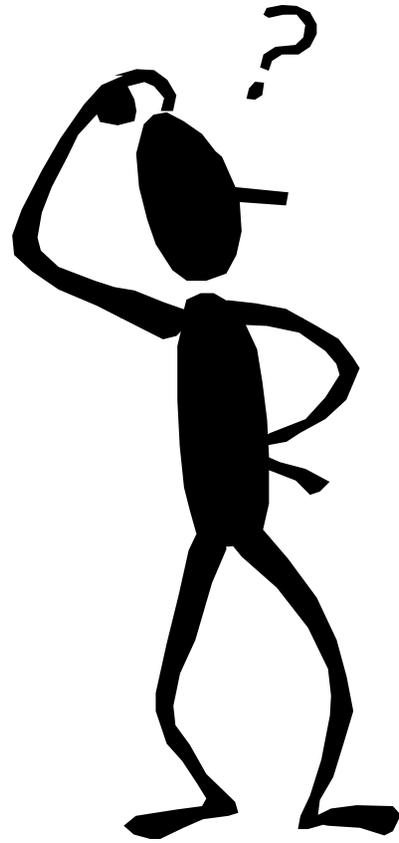
**FOR MORE INFORMATION**

**mailto:Colleen.Polselli@health.ri.gov**

# SUSTAINABILITY

- ▶ Participating sites have chosen to support the PPEP model, utilizing Family Resource Specialists to varying degrees to suit their individual site needs.
- ▶ Ongoing need for “creative funding” to sustain the model
- ▶ “Buy-in” from managed care plans, private practices and other community sites





**Thank you!**

**Efharisto**

**Merci**

**Amesegënallô**

**Gracias**

**Toda**

**Danke**

**Grazie**

**Asante**

**Salamat po**

**Arigato**

