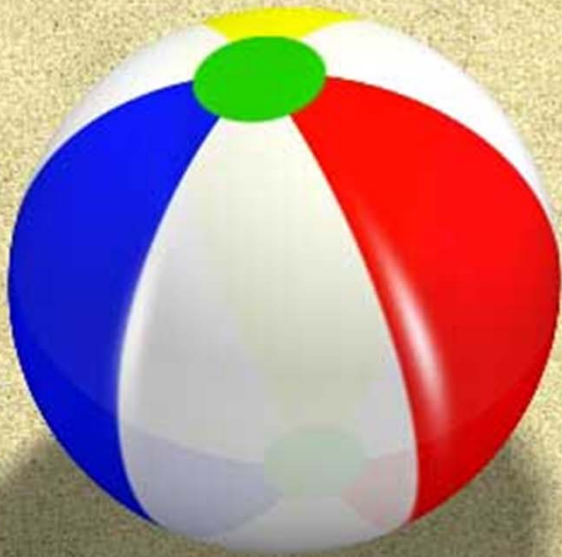


Partnering with Families:  
Is it just a word.....or are we living it?



Liz Drake RN, MN, CNNP, CNS  
CHOC Children's at Mission Hospital

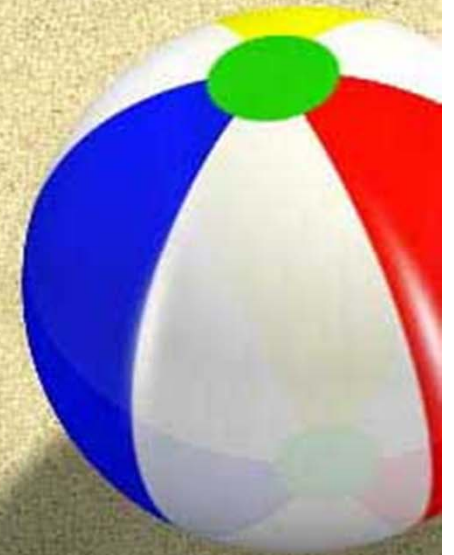




Ever Get Stuck?



Think a little differently





# *“New Awareness”*

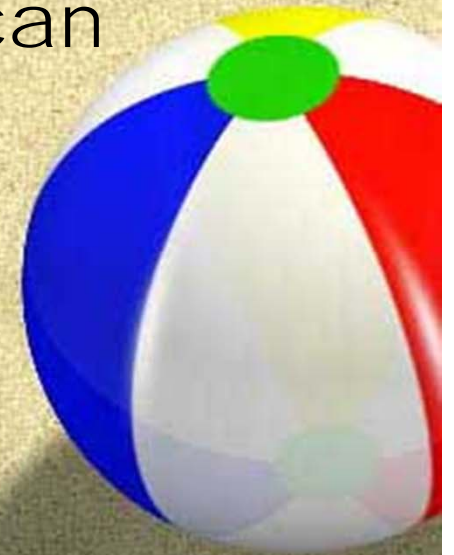
- The day a parent meets us is a day they never planned nor ever expected
- Living life in the NICU is not normal
- The way we care for a family is what helps heal not our knowledge of medicine
- They may forget what you said....they will never forget how you made them feel





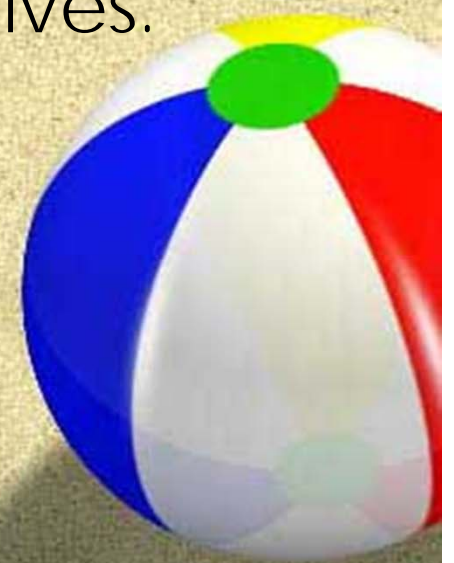
# Objectives

1. Identify 2 behaviors that create a barrier to building a trusting relationship with families
2. Describe/discuss how the collaborative practice of the healthcare team can impact a families experience.





Hospitalization is about an “experience” and “feelings” for a family. Satisfaction with the experience goes beyond feelings of a transaction. It’s not like buying a car or staying in a hotel. Those experiences do not have the power to alter the course of our lives.

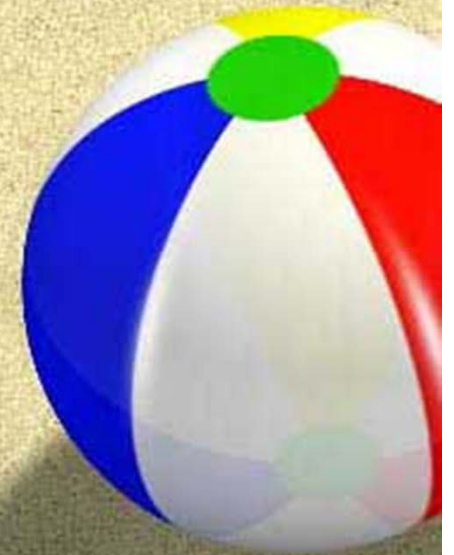




# What is a Family?

Two or more persons related by birth, marriage or adoption who reside in the same household

US Census Bureau





Families are big, small, extended, nuclear, and multigenerational, with one parent, two parents, and grandparents. We live under one roof or many. A family can be as temporary as a few weeks, as permanent as forever. We become part of a family by birth, adoption, marriage or from a desire for mutual support....A family is a culture unto itself with different values and a unique way of realizing it's dream.....

Task Force on Young Children & Families

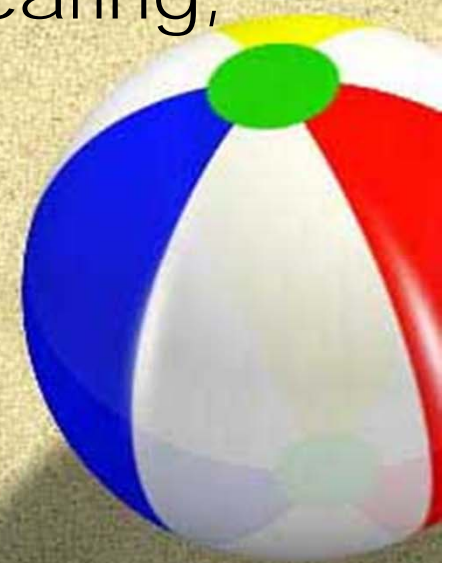




A family is a group of people who make an irrational commitment to each others well being to the point of making each other crazy.

Happiness is having a large, loving, caring, close knit family

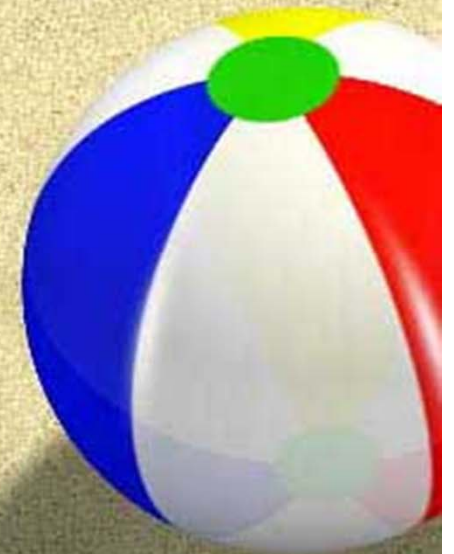
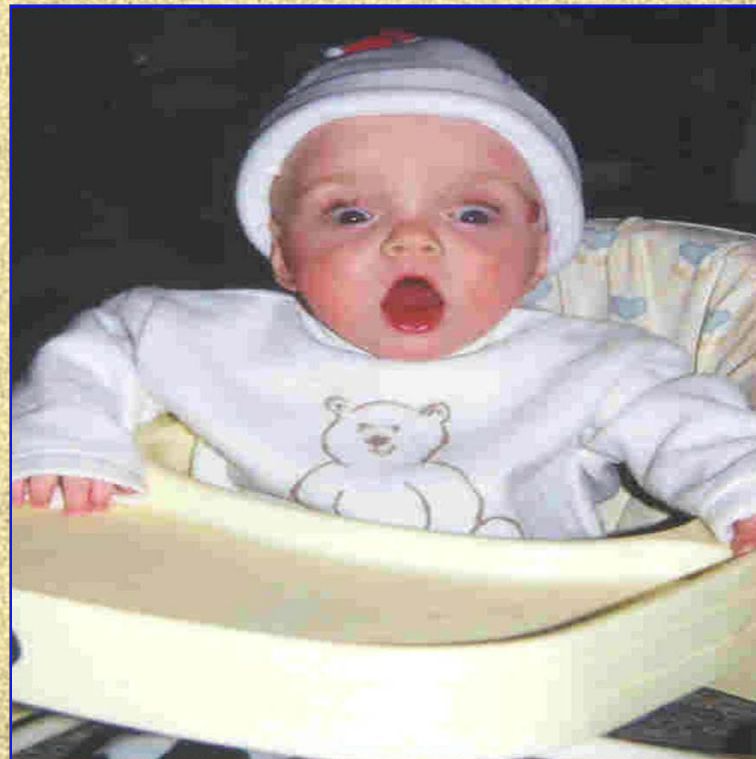
.....in another state





# Family Perception of Healthcare

The health system is a nightmare to navigate





- Caregivers do not provide enough information
  - *Parents overall rating of quality correlated most strongly with being provided information and partnership in care*
- Patient/families are not involved in decisions about their healthcare
  - *The U.S. ranked last in patient involvement in coordination and decision making of their healthcare*
- Hospital Caregivers were not emotionally supportive
- Attitudes such as compassion, caring, and being a good listener were felt to be more important than knowledge
  - *"No one cares how much you know, until they know how much you care."*
- Hospital Caregivers are not always good communicators.
  - *"The decision to litigate was often associated with a perceived lack of communication, lack of caring, and/or lack of collaboration in the delivery of health care".*

The Commonwealth Fund Report 2004 & 2010





# Crossing the Quality Chasm A Climate of Change.....

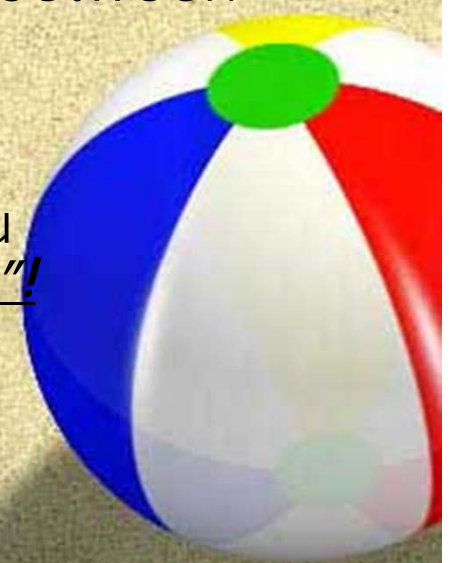
*The Institute of Medicine* called for a profound change in the healthcare system, to ensure patient safety and to improve health outcomes.

- Performance Measures for the HealthCare System
- New guidelines for patient-clinician relationships
- **“What patients should expect from their healthcare,”**  
are concepts that are integral to  
Family Centered Care





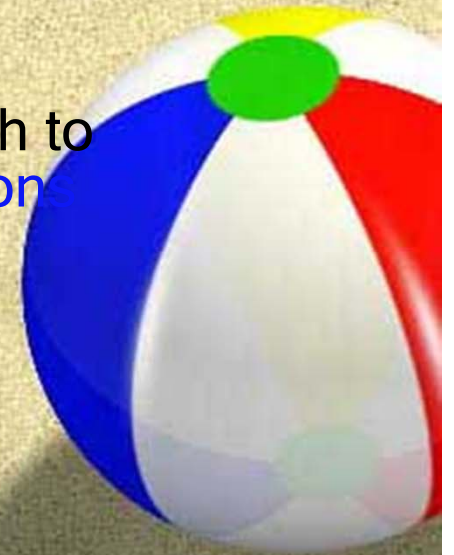
- Decision making is based on the best available scientific knowledge.
- Your care will not vary illogically from provider to provider or from place to place.
- Care is customized according to patient/family needs and values. Choices and preferences will be sought and honored.
- Cooperation among clinicians and the patient/family is a priority. Those who provide care will cooperate and coordinate their work fully with the patient/family. The walls between profession and institution will crumble.
- Education is shared and information flows freely. You can know what you wish to know, when you wish to know it ***“Nothing about you without you”!***





# What is Family Centered Care?

- The priorities and choices of patients and their families **drive** the delivery of healthcare
- Family Centered Healthcare is an approach to healthcare delivery that re-defines the **relationship** between an among families and health providers
- Information **sharing** and **collaboration** between patients, families and staff are cornerstones of FCC
- Family Centered Care is a philosophy an approach to health care that shapes **staffs day to day interaction**
- It's a **partnership** and **collaboration**

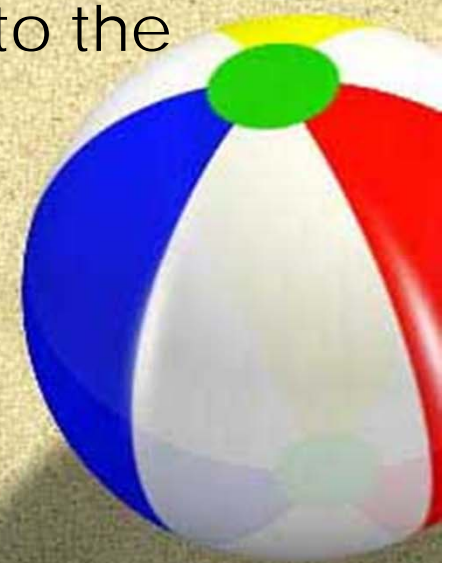




# Core Concepts of Family Centered Care

## Dignity & Respect

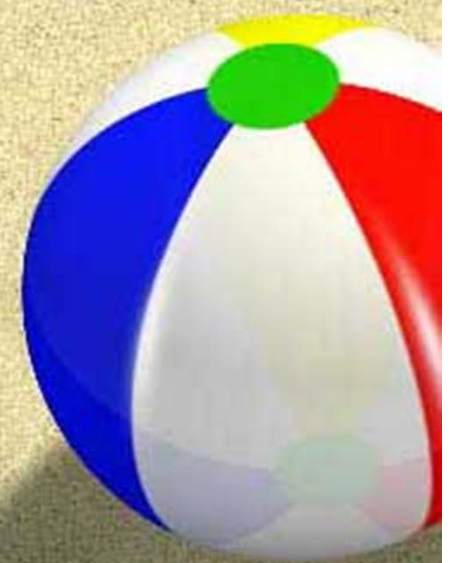
Health care practitioners **listen** to and **honor** patients and family perspectives and choices. Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care.





## Information Sharing

Practitioners **communicate** & **share** complete & unbiased information with patients and families in ways that are affirming and useful. Patient and families receive timely, complete and accurate information in order to effectively participate in care and decision making

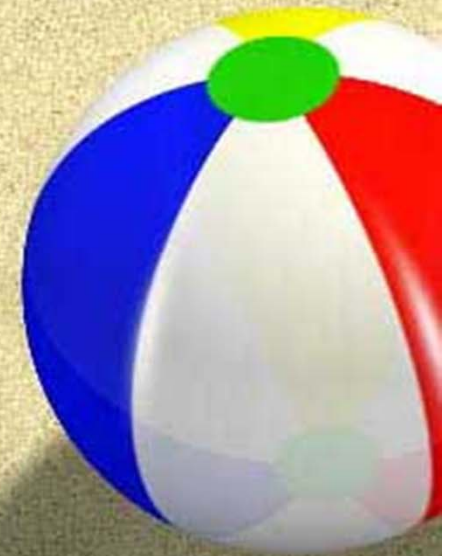




Two words, information and communication are often used interchangeably but they signify quite different things. **Information is giving out; communication is getting through.**

Sidney Harris

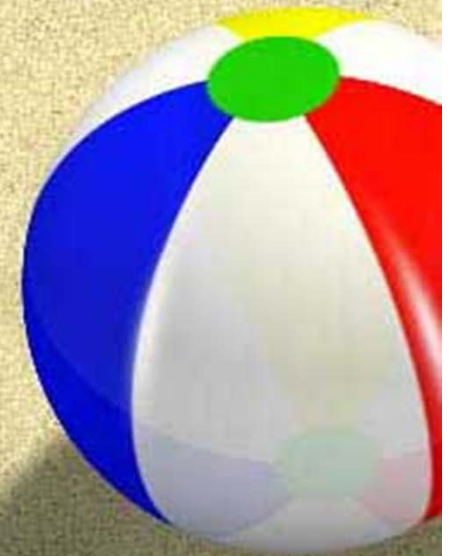
FCC is a **direct** and **intentional effort** to unequivocally communicate to patients and families.





# Parents Perspectives on Communication in the NICU

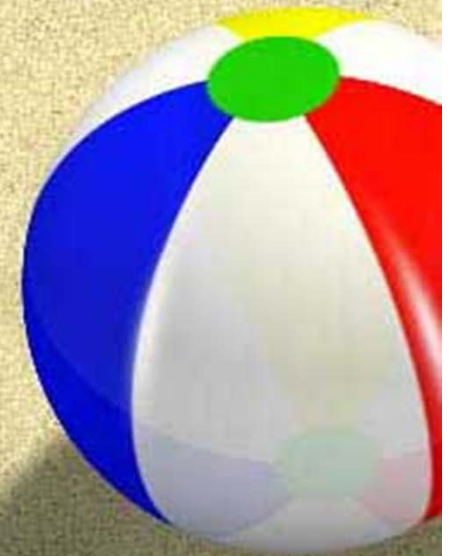
- Communication needs to be used to “explain things”
- Need to hear “feeling” words
- Staff use “assessing” or “telling” words
- Staff use policy/procedures as a means to communicate





## Participation

Parents and families are encouraged and supported in participating in care and in decision making at the level they choose.

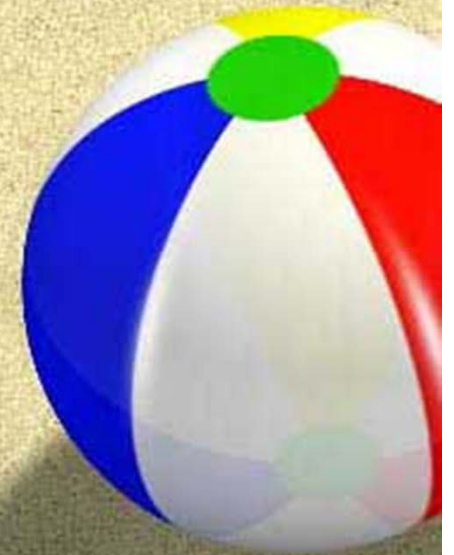




## Collaboration

No one interest group is always right. It means taking what you think and what I think and what someone else thinks and coming up with something that works for everyone.

Essential Allies: Families as Advisors





# Understanding Parents Trust

Parents have intense need to trust infant's care providers. It only develops when parents feel:

- Staff are providing expert care
  - *staff are competent unless proven otherwise*
- Staff recognize the importance of the parents role in the child's care and that the role is preserved
- Information exchange is honest/anticipatory
- Continuity of care

Meyer E, Snelling I, Myren-Manbeck L (1998). Pediatric intensive care: The parents' experience. *AACN Clinical Issues*:9 64-74.

Thompson VL, Hupcey JE, Clark MB (2003). The development of trust in parents of hospitalized children *Journal of Specialists of Pediatric Nursing*, 8:4 137-147





# Development of Trust

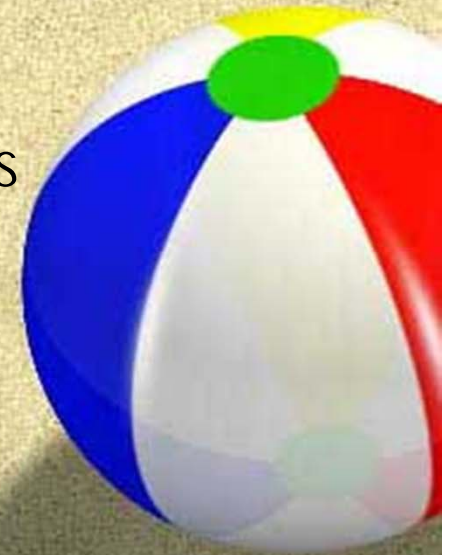
Trust is the dependence on another person based on the congruence between the **expected** and **actual** behaviors of the trusted person

Trust is a dynamic process that can change throughout the hospital experience

Result of multiple interactions between parents and staff

Trust is established when the parent develops confidence in our ability to provide the needed care.

Thompson VL, Hupcey JE, Clark MB (2003) The development of trust in parents of hospitalized children  
*Journal of Specialists of Pediatric Nursing*, 8:4 137-147





# Degrees of Trust

- General Trust: occurs when child's hospitalization goes smoothly and parents are pleased with the care their child receives.
- Global Trust: occurs when expectations for care are exceeded. Hospitalization goes better than expected and parents feel staff go out of their way to care for their child.
  - *parents may not feel they have expectations until disappointed that something they "expected" to happen didn't*
  - parents look for "good" in us staff find it.
- Distrust: Expectations for care are not met. Parents look for the "bad" and find it.

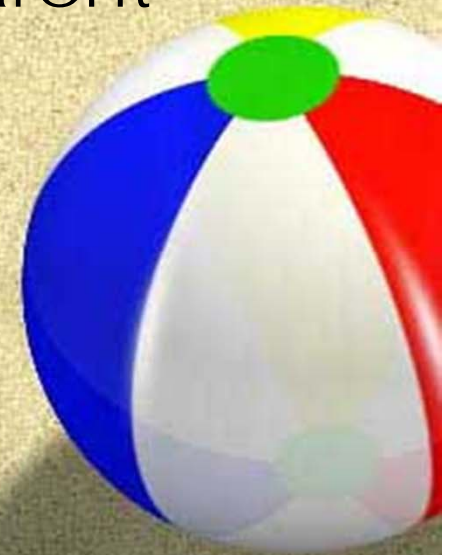




# Behaviors that Build Trust

Behaviors that build parents trust

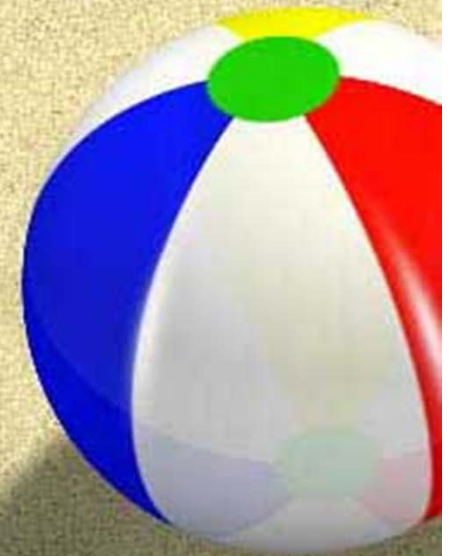
- Responding to child as a person
- Anticipating needs of child and parent
- Getting to know parent/family





# Behaviors When Parents Do Not Trust

- Refuse treatments
- Withdraw from mutual relationship with us
- Watching and questioning the care provided
- Rude
- Demanding
- Overly vigilant





# Nurses Trust for Parent

Family behaviors that build nurses trust of the parent/family

- Parent being truthful
- Asking the nurse for advice and guidance
- Not questioning the nurses' actions
- Parent agreeing to go home and allowing the nurse to care for the child

Hupcey JE (1998). Establishing the nurse-family relationship in the intensive care unit. *Western Journal of Nursing Research* :20, 180-194





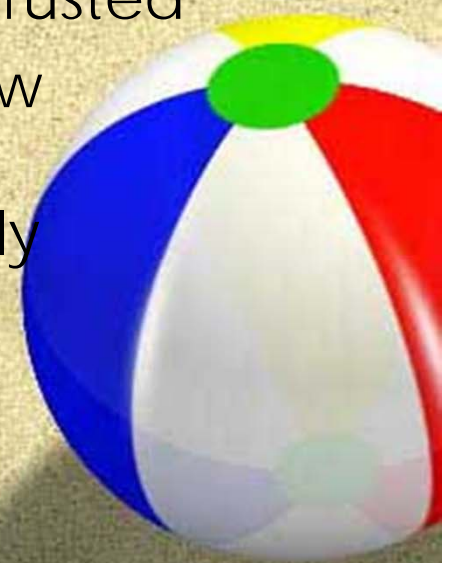
# Ranking of Importance of Needs: Nurse vs. Parents

## Nurses Assessment of parent needs

- The need to know how their child's treated medically
- The need to trust
- The need to be trusted
- The need for information
- Nurse cared about child

## Parents Needs as Identified by Parents

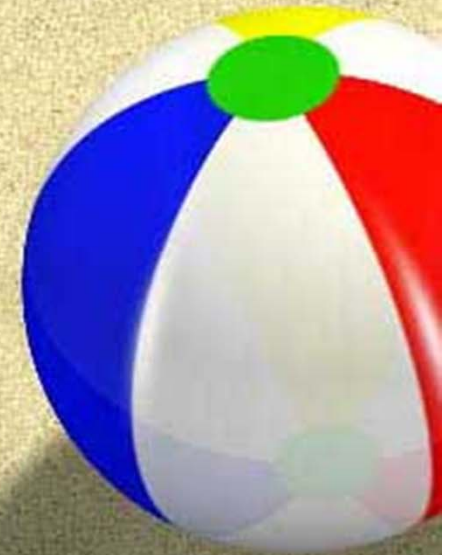
- Nurse cared about child
- The need to trust
- The need for information
- The need to be trusted
- The need to know how their child is treated medically





# What Creates a Good Experience/Relationship

- Caring, attentive, listens
- Concerned, gentle, kind, compassionate
  - *"I really did trust the staff that works there, because they were all very nice, and all very loving and you could tell they genuinely cared about the kids."*
- Make me feel comfortable being here
- Eye contact, greet me by name
- Use humor
- Prompt, followed through, not rushed
- Anticipate possible complications
- Keep track of what's happening
- Positive attitude toward work
- Uses language easily understood





# What Creates a Good Experience/Relationship

## Collaboration

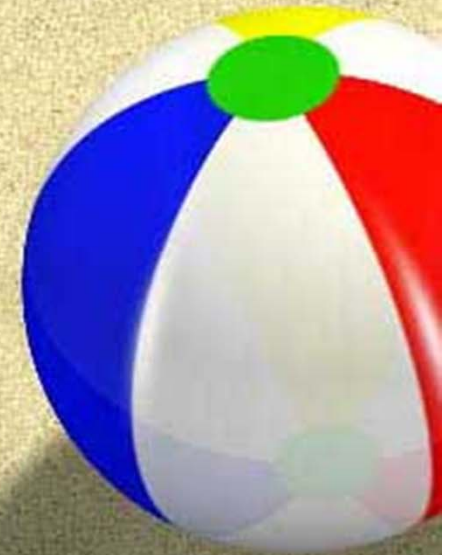
- Establishing rapport is a precondition to engaging in collaborative practice
- Interaction between parents and professionals is most effective when based on reciprocal interchange
- Clear communication is a precursor to collaboration
- Attitudes of health professionals create a climate that either supports or impedes collaboration...professionals are in a position to control the amount of parent participation in their child's care.
- Work as a team
- Consistency between care providers
- Treat other caregivers with respect





# Ask Ourselves?

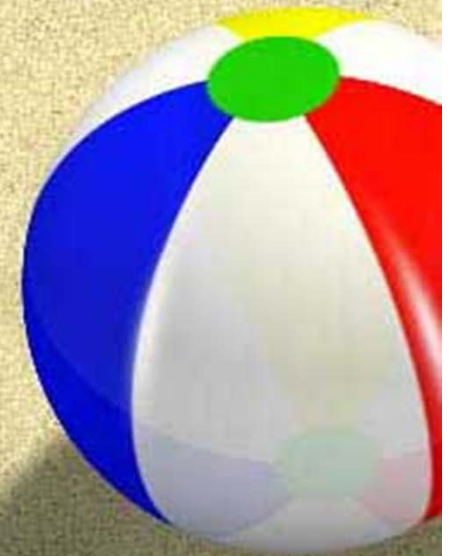
- Do we work as a team?
- Is there consistency within our own practice and across disciplines?
- Do we work together and help each other produce the best possible results?
- Do we treat other caregivers with respect
- Or—something else???





# Something Else: The Soap Opera Culture

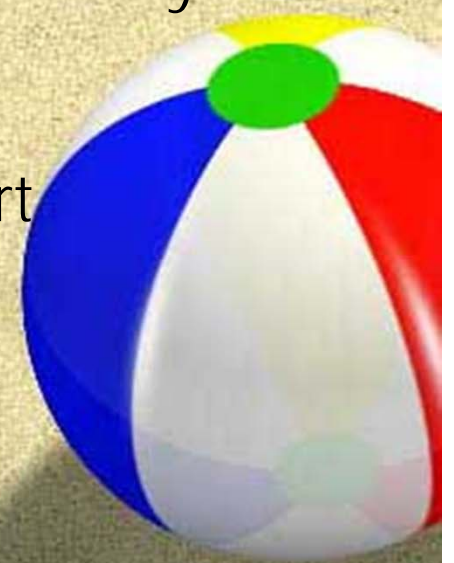
- Nitpicking and backbiting
- Lack of support for one another
- Silo behavior
- Negativity and complaints





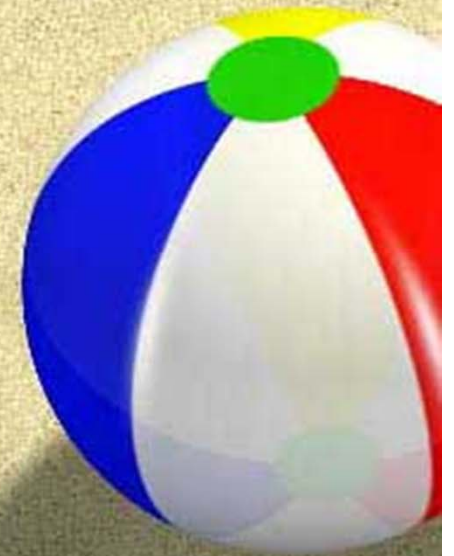
# Barriers to Collaboration

- Unclear roles- Physicians, Nursing, Therapists (OT/PT/Speech/Respiratory, Dieticians, Lactation)
  - Lack of collaborative practice across disciplines (teamwork)
- Inconsistency in Practice
- Using a culture of we vs. them as basis for inability to work as a team
- Communication patterns that don't support collaborative practice





So where do we go  
from here?



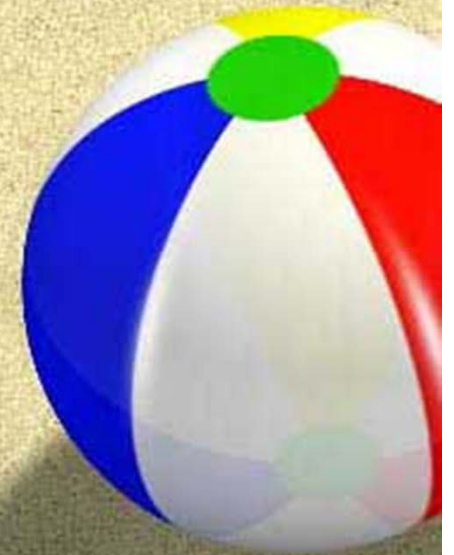


What Does Collaborative Practice  
“Teamwork”  
Look Like?

*“None of Us is as good as all of Us”*

- Implies professionals working collectively
- Non-hierarchical fashion
- Each member’s contribution is valued
- Mutually agreed upon common goals

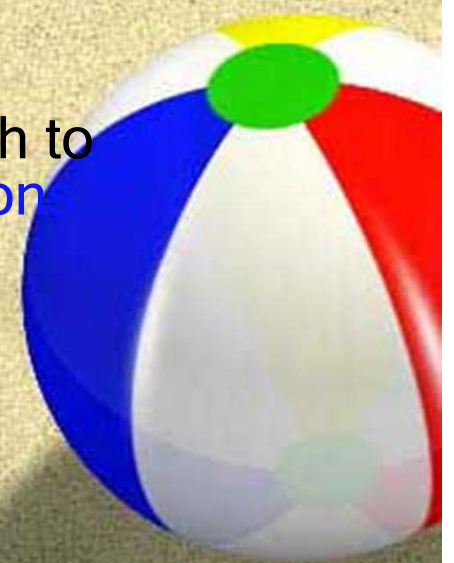
*“Common Focus”....partnering  
and building trust with parents  
for the sake of the infant*





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# Final Thoughts

## *"New Awareness"*

- The day a parent meets us is a day they never planned or ever expected.
- This is not normal
- The way we care for a family is what helps heal not necessarily our knowledge of medicine
- Parents may forget what you said...but they will never forget how you made them feel
- Attitudes of health professionals create a climate that can either support or hinder a trusting partnership
- What we do together with families is greater than what any of us can do separately as professionals

