I have no conflicts to disclose.

Objective:

After attending this presentation/discussion, the conference participant will identify six activities in the NICU that indicate the NICU is applying family-centered care principles.
## NICU Family Support Goals

<table>
<thead>
<tr>
<th>Program Goal</th>
<th>Evaluation Activities</th>
<th>Purpose</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) Promote family-centered NICU care.</td>
<td>Measuring NICU family-centered care principles, beginning in 2015</td>
<td>Evaluate NICU family-centered care practices and NICU ECC status and compare effect.</td>
</tr>
<tr>
<td>2) Provide information and comfort to NICU families during the hospitalization of their newborn, during the transition home, and in the event of a newborn death.</td>
<td>Parent Education Core Curriculum Evaluation, 2014-2015 and beyond</td>
<td>Identify best practices around implementation of each standardized Core Curriculum parent education class to guide future implementation and assure quality.</td>
</tr>
<tr>
<td>3) Contribute to NICU staff professional development.</td>
<td>Hospital Partners Survey, 2014-2015 and beyond</td>
<td>Identify areas of priority focus for hospital partners and areas of perceived impact of NFS on their hospitals. Assess benefits of having a NFS program and the degree of alignment of program goals and offerings with hospital needs and expectations. Provide information to ensure quality of the program, identify gaps, and facilitate change as needed.</td>
</tr>
</tbody>
</table>

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## Promote Family-Centered NICU Care

**Family-Centered Care Survey**

Understand and report current family-centered care policies and practices in NICU Family Support network hospital sites across the country.
**Promote Family-Centered NICU Care**

**Family-Centered Care Survey**
Understand and report current family-centered care policies and practices in NICU Family Support network hospital sites across the country.

**Measuring NICU Family-Centered Care Principles**
Develop set of March of Dimes neonatal family-centered care principles; evaluate NICU family-centered care status and measure progress in improving family-centered care practices.
Core Concepts of Patient- and Family-Centered Care

Dignity and Respect: Healthcare practitioners listen to and honor patient 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: Healthcare practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision making.

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

Collaboration: Patients and families are also included on an institution-wide basis. Healthcare leaders collaborate with patients and families in policy and program development, implementation, and evaluation; in health care facility design; and in professional education, as well as in the delivery of care.

Source: Institute for Patient- and Family-Centered Care
Why new and why now?

- Specific to NICU family-centered care
- Lessons from over 130 NICUs
- Experiences of NICU leadership
- Preparing to measure progress
- Improving the quality of FCC

March of Dimes

Family-Centered Care Principles

Vision: Improve the quality of family-centered care in NICUs by establishing, promoting and measuring March of Dimes principles of family-centered care.

Domains:
- Environment
- Families
- Staff
Environment
• The NICU consistently demonstrates a culture of respect for all families.
• The NICU environment is accessible and welcoming to families and has designated and appropriate spaces for family engagement and participation.

Families
• The NICU embraces and involves families as a partner in care planning and care giving for their child.
• The NICU collaborates with families in policy development, quality improvement, and professional education.
• The NICU offers parents and extended family members supportive and educational activities and resources.

Staff
• The NICU incorporates family-centered care principles and practices into professional development for all NICU staff.
• The NICU ensures staff competency on cultural sensitivity, health equity, and needs of diverse populations.

Domain: Environment
Principle #1
The NICU environment is accessible and welcoming to families and has designated and appropriate spaces for family engagement and participation.

Rationale
Key learnings from NICU leadership, NFS Network, NICU families:
• Physical environment is the manifestation of the NICU’s family-centered care focus
• Parent’s first experience of the environment is a lasting one
• What is important, regardless of layout, is how the NICU uses environment to embrace families

Examples of the literature:
• The ethics of space in clinical practice
• An office or bedroom? Challenges for FCC in the pediatric intensive care unit
• Clinician perceptions of a changing hospital environment
• Individual rooms in the NICU – an evolving concept
Domain: Environment
Principle #2
The NICU consistently demonstrates a culture of respect for all families. (focus on equity among race/ethnicity, health status, age, religion, sexual orientation, education)

Rationale
Key learnings from NICU leadership, NFS Network, NICU families:
- Strong general support among and within NICUs, but varies widely by NICU and individual
- Respect for all people is core to partnering with parents, but can be challenging
- Importance of focusing on families who are commonly marginalized
- March of Dimes puts high value on serving women/families in greatest need

Rationale
Examples of the literature:
- The differential effects of maternal age, race/ethnicity and insurance on neonatal intensive care unit admission rates
- Minority ethnic families and family-centered care
- Normative cultural values and the experiences of Mexican-American mothers who have had infants in the NICU
- Maternal-infant separation at birth among substance using pregnant women
- The potential of shared decision making to reduce health disparities
- Parent perspectives from a neonatal intensive care unit: A missing piece of the culturally congruent care puzzle
- A delicate subject: The impact of cultural factors on neonatal and perinatal decision making

Domain: Families
Principle #3
The NICU embraces and involves families as a partner in care planning and care giving for their child.

Rationale
Key learnings from NICU leadership, NFS Network, NICU families:
- “Parents as care-givers” is at the core of family centered care
- Embracing parents in care of their baby is empowering while in the NICU
- Parenting in the NICU is critical preparation for parenting after discharge
- Parent participation in care improves infant outcomes
The NICU embraces and involves families as a partner in care planning and care giving for their child.

**Rationale**

Examples of the literature:

- Parenting in the neonatal intensive care unit
- Effects of implementing family-centered rounds in a neonatal intensive care unit
- Parental involvement in neonatal pain management: an empirical and conceptual update
- Decision-making consensus in the NICU: What does parent-clinician collaboration actually look like?
- Parental influence on clinical management during neonatal intensive care: a survey of US neonatologists
- Partnerships between mothers and professionals in the NICU: caregiving, information exchange, and relationships
- Promoting family-centered care in the NICU through parent-to-parent manager position

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Domain: Families

**Principle #4**

The NICU collaborates with families in policy development, quality improvement, and professional development.

**Rationale**

Key learnings from NICU leadership, NFS Network, NICU families:

- Represents the value that the NICU places on parents: their perspectives and parents as experts on their baby
- Demonstrates the importance of families at the systems level, not only the individual level
- Many parents want to make lasting impact that improves the outcomes for others

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The NICU collaborates with families in policy development, quality improvement, and professional development.

**Rationale**

Examples of the literature:

- The role of parents in improving care (Chapter 4, Toward Improving the Outcome of Pregnancy III: Enhancing Perinatal Health Through Quality, Safety and Performance Measures)
- Implementing family-integrated care in the NICU: engaging veteran parents in program delivery and design
- Parents’ perspectives on safety in neonatal intensive care: a mixed-methods study
- Collaborative quality improvement for neonatal intensive care
- Families as “Faculty”: Parents educating caregivers about family-centered care
Domain: Families
Principle #5
The NICU offers parents and extended family members supportive and educational activities and resources.

Rationale
Key learnings from NICU leadership, NFS Network, NICU families:
• Importance of building support for the parents among the family members
• Programs tailored to grandparents, siblings, and other family members minimizes parent’s need to provide support
• Specific activities for moms, dads, siblings, and grandparents help target messages and support appropriately

Examples of the literature:
• Supporting fathers of premature infants hospitalized in the NICU
• Differences in parents’, nurses’ and physicians’ views of NICU parent support
• Going home: Facilitating discharge of the preterm infant
• In search of social support in the NICU: features, benefits, and antecedents of parents’ tendency to share with others the premature birth of their baby.
• Social support of parents and grandparents in the neonatal intensive care unit
• Support for Siblings of NICU Patients: An Interdisciplinary Approach
• “I’m Special, Too”: Promoting Siblings Adjustment in the Neonatal Intensive Care Unit

Domain: Staff
Principle #6
The NICU incorporates family-centered care principles and practices into professional development for all NICU staff.

Rationale
Key learnings from NICU leadership, NFS Network, NICU families:
• Excellence in FCC hinges on practices and attitudes of all staff
• NICU teams express need for professional development in FCC
• Increasing requests about what/how other NICUs are doing in FCC
• Staff development in FCC is a critical success factor in systems shift
The NICU incorporates family-centered care principles and practices into professional development for all NICU staff.

**Rationale**

**Examples of the literature:**
- Processes in the creation and diffusion of nursing knowledge: an examination of the developing concept of family-centered care
- Family-centered care: do we practice what we preach?
- Predictors of nurses' family-centered care practices in the neonatal intensive care unit
- Patient- and family-centered care and the pediatrician's role
- Application of theory to family-centered care: a role for social workers

Domain: **Staff**

**Principle #7**

The NICU ensures staff competency on cultural sensitivity, health equity, and needs of diverse populations.

**Rationale**

**Key learnings from NICU leadership, NFS Network, NICU families:**
- Removes the disconnect between “wanting” and “doing”
- NICUs express growing need for professional development in this area
- Every NICU is diverse, but in different ways; tailoring to NICU needs is important
- May be difficult to face, to address, to achieve, but important that we succeed

**Examples of the literature:**
- Health care providers perspective of providing culturally competent care in the NICU
- Connection versus disconnection: examining culturally competent care in the neonatal intensive care unit
Integrated through all domains
Principle #8
The NICU employs multiple communication channels
honest, transparent, plain language that ensures
understanding and acknowledges privacy.

Rationale
Key learnings from NICU leadership, NFS Network, NICU
families:
• (By far) the most requested presentation from March of
  Dimes Network members
• All other principles are dependent on success in this area
• Advances in technology in the past decade have changed
  the nature of and need for communications

The NICU employs multiple communication channels
honest, transparent, plain language that ensures
understanding and acknowledges privacy.

Rationale:
Examples of the literature
• Examination of the perception of communication and collaboration in a
  neonatal intensive care unit: a decade on, has it changed?
• Effective nurse parent communication: A study of parents’ perceptions in
  the NICU environment
• Tweets, friends, and links: The use of social media by NICU health care
  providers
• Communication and collaboration technologies
• Human factors: The importance of communication to outcomes in the
  NICU
• Communication with parents in neonatal intensive care
• Strengths and weaknesses of parent–staff communication in the NICU: a
  survey assessment

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References