

# Implementing Potentially Better Practices for Improving Family-Centered Care in Neonatal Intensive Care Units: Successes and Challenges

Kimberly A. Cisneros Moore, RNC, BSN\*; Kara Coker, RN, MSN‡; Allison B. DuBuisson, MSS; Betsy Swett, RNC||; and William H. Edwards, MD¶

**ABSTRACT.** *Objective.* Multidisciplinary teams from 11 medical center neonatal intensive care units collaborated in a quality improvement project with a focus on family-centered care.

*Methods.* Through a process of self-analysis, literature review, benchmarking site visits, and expert consultation, 10 potentially better practice (PBP) areas were defined. Improvement activities in 4 of the 10 areas are given as examples of successes and challenges that individual centers encountered. The 4 areas are vision and philosophy, unit culture, family participation in care, and families as advisors.

*Results.* Centers were at different places for all of the PBPs at the beginning and throughout the collaboration. Seven centers developed or revised their vision or philosophy of care statements about family-centered care. Incorporating the vision and philosophy of care into performance appraisals, hiring of new personnel, and changing unit culture to a more family-centered practice were more challenging than developing the statements. Full parent participation in care requires unrestricted access to the neonatal intensive care unit. The shift from considering parents to be "visitors" to being partners in caring for their child was more difficult for centers with restricted visitation policies. All centers developed, expanded, or started plans for establishing family advisory councils. The experience of 2 centers is described.

*Conclusions.* Family-centered care is more of a journey than a destination. Collaborating centers in this project found themselves at different places in that journey. Through perseverance in implementing the PBPs, all have moved further along the path. *Pediatrics* 2003;111:e450–e460. URL: <http://www.pediatrics.org/cgi/content/full/111/4/e450>; family-centered care, parental involvement, parent advisory council, collaborative quality improvement, multidisciplinary, neonatal intensive care, NIC/Q 2000.

ABBREVIATIONS. NICU, neonatal intensive care unit; NIC/Q 2000, Neonatal Intensive Care Unit Quality Improvement Collaborative Year 2000; PBPs, potentially better practices.

From the \*Children's Hospital at Providence Alaska Medical Center, Anchorage, Alaska; †DeVos Children's Hospital, Grand Rapids, Michigan; ‡Women's Hospital of Greensboro, Greensboro, North Carolina; ||Woman's Hospital, Baton Rouge, Louisiana; and ¶Children's Hospital at Dartmouth, Lebanon, New Hampshire.

Received for publication Aug 13, 2002; accepted Oct 24, 2002.

Address correspondence to William H. Edwards, MD, Children's Hospital at Dartmouth, One Medical Center Dr, Lebanon, NH 03756-0001. E-mail: [william.h.edwards@hitchcock.org](mailto:william.h.edwards@hitchcock.org)  
PEDIATRICS (ISSN 0031 4005). Copyright © 2003 by the American Academy of Pediatrics.

## KEY POINTS OF ARTICLE

- Family-centered care is less a destination than a journey.
- Neonatal intensive care units (NICUs) that are seeking to provide family-centered care may begin at very different places and proceed along different paths.

## APPLYING LESSONS LEARNED TO PRACTICE

- Family-centered care vision and philosophy of care statements are meaningful only when they are incorporated into the culture and daily practice of the NICU.
- Families can be effective partners both in caring for their own child and in providing advice to improve care in NICUs.

Eleven centers that participated in the Vermont Oxford Network Neonatal Intensive Care Unit Quality Improvement Collaborative Year 2000 (NIC/Q 2000) chose to focus on family-centered care as a strategy to improve the care of infants in NICUs and their families. The project was supported by collaboration with the Institute for Family-Centered Care. Through a process of self-analysis, literature review, benchmarking site visits, and expert consultation, potentially better practices (PBPs) were defined.<sup>1</sup> In this article, some of the successes and challenges encountered by the centers as they implemented these practices are described. Examples are taken from 4 of the 10 PBP content areas: vision and philosophy, unit culture, family participation in care, and families as advisors.

## VISION AND PHILOSOPHY

- Vision and philosophy of care statements articulate the unit's commitment to family-centered care.
- Family-centered vision and philosophy is consistently applied to unit policies, practices, and programs.

A vision and/or a philosophy of care statement that incorporates the principles of family-centered care provides a foundation for a NICU's policies, decisions, goals, and new directions. Without a vision and core belief system, the culture has no clear direction. This can result in inconsistent family-centered care practices and decision making. The importance of an expressed vision or philosophy of care was evident at all benchmark site visits as well as in

published reports.<sup>1,2</sup> The 11 centers in the family-centered care focus group started the project at different places for this practice. Some had already developed statements, others developed or revised them during the project, and some were still working on them at project end. The individual vision and philosophy statements from 7 centers are included in Appendix A.

Yakima Valley Memorial Hospital developed its vision statement as part of this quality improvement project. After discussion and brainstorming, a multidisciplinary committee that included families proposed several potential statements. Keeping the vision statement short and concise was a priority. The statements were widely presented for input and discussion by nursery staff, physicians, and families, and a single choice was made by consensus. The proposed statement was then communicated to nursery personnel for input by a variety of mechanisms. A banner of the proposed statement was displayed in the NICU and conference room. Newsletters and bulletin boards were dedicated to development of the statement. Over 2 weeks, written and verbal feedback was sought and comments were transcribed onto a board for communications about current issues. All feedback was reviewed, and the statement was revised into its current version: "Memorial and families: Partners in care." It is especially appropriate that the idea for this vision statement originated with a comment from a mother who described the neonatal care team as being "partners in caring for her infant."

After creating the vision statement, the Yakima Valley Memorial improvement team took steps to make it a part of their culture. They incorporated the vision statement on paperwork used for the unit, including meeting agendas and minutes and stationery letterheads. They mailed information about the vision to all nursery staff and placed signs with the vision statement in various places throughout the unit. When a planned survey was conducted of all nursery personnel, 80% both knew the unit had a vision statement and were able to state it.

The philosophy of care statement devised by the NICU at Fairview University Medical Center reflects the key principles of family-centered care: "We recognize the family is the most important and constant factor in each infant's life. Our goal is to establish a collaborative partnership between parents and the health care team to promote communication, respect diversity, and empower families."

The Fairview team used the process of developing their philosophy of care statement and incorporating it into the NICU's policies and parent information to stimulate ideas for promoting family-centered care. One outcome measure for this improvement project was that 86% of nursery staff were able to give examples of ways they could promote family-centered care.

The Children's Hospital at Providence Alaska Medical Center had created a vision statement before this project. Although it existed on paper, it was not a living document in the NICU. The Developmental Care Council, the Family Advisory Board, and the

Parent and Community Coordinator (a paid parent position) together analyzed and rewrote the vision statement, drawing from insights gained during the benchmarking visits and the development of the 10 PBPs. A professionally designed poster of the new vision and mission statements was prominently placed at the main entrance to the NICU. The family-centered vision and mission statements are now important components for hiring new personnel. Potential employees are asked to "define family-centered care" during the interview process. Including family-centered care as a key competence in staff performance appraisals led to counseling some staff to relocate to other positions within the hospital. The commitment to a family-centered care philosophy has not been easy.

#### UNIT CULTURE

- Vision and philosophy of care statements are developed collaboratively by representatives of all disciplines working on the unit and by family representatives.
- Committees that develop programs and practices have members who represent all disciplines working on the unit, and family representatives.
- Accountability for patient and family outcomes is shared by all unit staff.

The process of developing a vision or philosophy of care statement can be a positive affirmation of the core beliefs of a NICU. Once developed, the challenge is to compare systematically current reality with the ideal and make improvements until the vision and philosophy accurately reflect the NICU's culture. This PBP concept naturally follows and overlaps with vision and philosophy.

Presbyterian St. Luke's Medical Center in Denver, Colorado, confronted a substantial barrier to implementing family-centered care. Two different units providing neonatal care within the center each had separate staffing and different goals. Communication between the 2 units was poor, and project leaders sensed a general apathy about implementing family-centered care in both. They formed a multidisciplinary committee called INFO (Implementing Neonatal and Family Outcomes) drawn from the standing committees of both units. The purpose of INFO was to find ways to bring family-centered care principles back to the standing committees. Collaboration between the 2 units was further enhanced by establishing daily meetings between the 2 units and setting up e-mail accounts for every staff member. Signs of a positive effect have been an increase in staff involvement in committees and projects and a renewed enthusiasm for providing primary care nursing.

At the Children's Hospital at Dartmouth, it was recognized that ongoing family input into all aspects of unit operations, policies, and practices was a natural evolution of the concept of considering families as true collaborators in care. The way in which the parent advisory council was included in the administrative structure of the unit is a strong statement of the belief in partnership. The parent council has been

Table 1. PDSA Cycles: DeVos Children's Hospital

**Aim:** Promote family visitation to allow siblings to visit when most convenient for parents and the patients.

**Measure:** The Parent Satisfaction Survey question "The visitation policy met my families needs" will show an improvement from prior surveys.

**Cycle #1:**

**Plan:** Home Sweet Home committee will evaluate current sibling visitation practice and compare current practice to information gained at site visits for the family-centered care focus group.

**Do:**

- Do a literature search of visitation practices in NICU's
- Share current visitation policy, information from site visits, and results of a literature search to nursing staff at the policy retreat, and in the interdisciplinary team meeting.
- Present same information to the Infection Control Department

**Study:** Staff agreed the sibling visitation policy needed to change. The policy should be more convenient to families but also be respectful to patient conditions. Infection Control has concerns regarding introduction of communicable diseases and wants more time to review the literature.

**Act:** New sibling visitation policy created. Continue to work with Infection Control to address their concerns.

**Cycle #2**

**Plan:** Write a new sibling visitation policy based on input from staff, information from benchmark centers, and literature.

**Do:**

- Inservice staff to new policy
- Post-new policy on the First Board
- Inform families of the change by posting signs in the parent scrub room and letters at the bedside.

**Study:** Initial reaction from staff was mixed. Many staff members noted less stress when visitation times are not concentrated to two designated time periods during the week. Other staff expressed more stress with families able to visit at there convenience and the interruption in work flow. Staff expressed frustration with poorly supervised toddlers, experiencing an incidence when a sibling was noted to be pulling on critical tubing. Families' feedback will be assessed on the parent Satisfaction Survey (see posted graph Figure 1)

Legend to Table 1. Impact of changes in visitation policies on parents' satisfaction at DeVos Children's Hospital.

**Act:** Adjustments were made in the policy based on feedback. Siblings under 3 years of age will visit only once a week for a brief period.

### Cycle #3

**Plan:** A sibling health screening form acceptable for neonatal services and infection control will be developed.

**Do:** Health screen created based on prior literature search, information from benchmark centers and other centers in the We Are Family Focus group. Present draft health screen to interdisciplinary practice council and infection control.  
Unit secretaries identified to administer health screen.  
Educate staff of process and implement health screening  
Letter to families and a poster in the parent scrub room to inform families of the new sibling health screening.

**Study:** Initially the process was stressful for secretaries. Secretaries did not feel qualified to administer a health screen.

**Act:** Work with the secretaries to refine the screening process. Add the managers and Charge Nurses as a resource for the secretary when he/she has a concern regarding the health of the child.

### Cycle #4

**Plan:** Discontinue announcing families and visitors over the intercom

**Do:** Obtain a sign-in log book with dividers for each room for families and visitors to enter their name, and time of arrival and time of departure.  
Post welcoming signs for families and visitors guiding them to the main desk.  
Keep the doors to the patient care rooms closed to help identify when people are entering the nurseries.

**Study:** Parents with infants in the unit were initially confused by the change. No family complained about the change. Maintaining closed doors was a hassle and did not seem to add a benefit to identifying when a parent or visitor arrived. Staff fears of parents walking in during a procedure were unfounded. Discussions with staff about comfort level of doing procedures such as an IV insertion with parents present enabled staff to feel more comfortable. Decreased noise levels were appreciated by eliminating the announcement.

**Act:** Evaluate Parent Satisfaction Survey. Discontinue closing doors unless the unit noise level became a problem.

Table 1. *Continued.*

incorporated and voted into the by-laws as an equal partner in the intensive care nursery shared governance model. The chair of the parent council is a voting member of the coordinating council, composed of the chairs of each of the shared governance councils and the unit nursing and medical directors.

#### FAMILIES' PARTICIPATION IN CARE

- Families are viewed as integral members of the care team and as primary caregivers to their infants (not as visitors).
- Families are seen as the primary decision makers for their infants.



- Families are asked how they would like to participate in their infants' care and are given the education, resources, and support to participate to the level they desire.
- Families have the opportunity to discuss and record observations of their infant.
- The unit welcomes families 24 hours a day, including during rounds and change of shift.

The differences among the centers collaborating on improving family-centered care were nowhere more evident than in policies and practices about family participation in care. Some centers encouraged parents' participation in rounds and nursing shift changes, whereas others had rules excluding parents. This PBP required each center to reevaluate its visitation policies. When family-centered care is practiced, parents and family are collaborators, or partners, in care and not "visitors." Many centers rewrote guidelines to distinguish parent and family participation in care from visitation guidelines for extended family and friends. Making changes in visitation guidelines was difficult for some centers. DeVos Children's Hospital's experience illustrates the barriers and challenges in changing visitation policies.

At DeVos Children's Hospital, an interdisciplinary committee called the "Home Sweet Home" committee was created to improve the nursery environment so that families were better supported to participate in care. The committee was presented with information from several sources: preliminary work by the NIC/Q 2000 collaborative focus group on family-centered care, including benchmarking site visit results, information from the Institute for Family-Centered Care, and information from the DeVos parent satisfaction survey. The committee identified and prioritized several ideas for improvement. Reevaluation of the current visitation policy with emphasis on sibling visitation was selected as the first priority. Changes to the visitation policy were made in stages over 1 year to receive staff input and address their concerns. These stages were conducted as improvement cycles using the improvement method of plan-do-study-act (Table 1). The overall aim was to promote family visitation by allowing siblings to visit when most convenient for parents.

The existing visitation policy allowed parents to "visit" any time except change of shift. Grandparents could also visit at any time with a parent. Siblings and other family members could visit only when accompanied by a parent on Thursday night from 7:30 to 9:30 or Sunday afternoon from 2:00 to 4:00. The neonatal unit was closed to all visitors except parents during respiratory syncytial virus season, which typically began in the fall and ended in late spring. The committee believed that these rules were too restrictive and set a goal of creating an environment where families would always feel welcome. Initial reactions to liberalization of visitation guidelines were mixed. Concerns were expressed that infection rates would increase, infants would become overstimulated from increased noise, and the increased number of people visiting would interrupt workflow.

The first improvement cycle included gathering information on the rationale and safety of the proposed change and presenting it to nursery staff and to the infection control department. The infection control department was particularly skeptical because of concern for potentially introducing into the unit communicable diseases such as chicken pox and respiratory syncytial virus.

The second improvement cycle involved drafting new visitation guidelines, training personnel, and initiating a pilot trial. Some staff initially believed that having families with children on the unit more frequently would adversely affect their workflow. After initial issues were addressed, most staff expressed feeling less stress with more open sibling visitation. Expanded sibling visitation reduced crowding that had been a problem during the previous sibling visitation hours. Problems encountered with lack of supervision of toddler-age siblings and an incident involving a toddler pulling on critical tubing led to a decision to continue to restrict visitation by siblings below age 3 to 1 brief visit per week.

The third improvement cycle was designed to address concerns about the potential infection risk with a more open visiting policy. The committee reviewed literature and asked other NICUs with more liberal policies how they managed infection risks.<sup>3</sup> A simple questionnaire was developed to screen for recent fever, runny nose, flu- and cold-like symptoms, and exposure to chickenpox. The unit secretary was assigned to help families answer the questionnaire and maintain documentation of the screening. When a child was cleared for entering the unit, he or she received a fun sticker of his or her choice, which served to identify that the sibling had been screened. The secretary documented the initial screening in a notebook. At each subsequent visit, the secretary and family would repeat the questions and the date would be recorded. The process was stressful for the secretaries initially. They did not feel qualified to screen families about health. Assigning the clinical managers and charge nurses to serve as resources for the secretaries solved their concerns. Since changing to a more liberal sibling visitation policy, acquired infection as a result of transmission by siblings has not yet been suspected.

The fourth improvement cycle was designed to decrease noise and distraction in the patient care areas by discontinuing the practice of announcing the arrival of parents over an intercom. Staff were concerned that a family member might walk into the patient care area during a procedure or resuscitation. A system of calling out to the desk to inform the secretaries when such an event was happening was initially developed but over time became unnecessary. In the rare instance when a family member may walk in during a procedure or resuscitation, a staff member will assume the responsibility of explaining what is happening and supporting the parent if necessary. Not only has the elimination of added noise from the intercom been an improvement, nurses no longer have to stop what they are doing to answer the telephone when a parent arrives.

Reponses by parents to the question on the parent

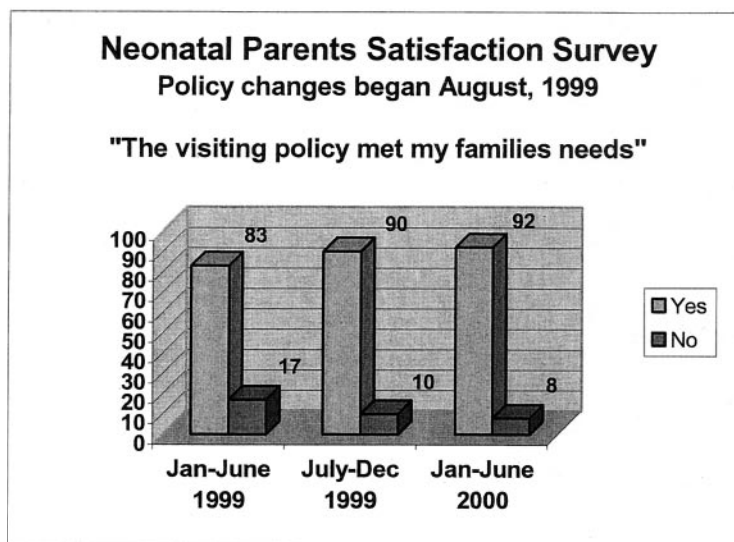


Fig 1. Neonatal parent satisfaction survey.

satisfaction survey of whether the visiting policy met their needs showed improvement (Fig 1). Before initiation of the project, 83% of parents indicated that the policy met their needs compared with 92% after the cycles were completed. Introducing change in small increments was believed to be key to success. Although visitation policies at DeVos are more restrictive than in some of the other centers, progress was made and staff accepted the changes.

#### FAMILIES AS ADVISORS

- Families serve on family advisory boards.
- Families are included as members of family-centered steering committees.
- Families provide family-to-family support within the unit.
- Opportunities exist for families to serve on other hospital committees and task forces.
- Paid positions are established for former family members to serve as family consultants or family liaisons.
- Families serve as faculty and trainers in orientation and other education and training activities.

Ad hoc family advisory committees have been advocated and incorporated into building programs for new or remodeled NICU facilities for many years.<sup>4</sup> The concept of having standing parent advisory councils or boards is relatively new.<sup>5,6</sup> Parent-to-parent support for various neonatal conditions has developed largely outside the hospital environment. Parent-to-parent groups for supporting families of children with special needs are active in 30 states. Parents' providing family-to-family support within the NICU environment are a recent development.<sup>7</sup> Some children's hospitals and nurseries are now even incorporating paid positions for parents of previous patients to serve more formally as consultants, support for current parents of hospitalized infants and children, and liaisons for families. At all benchmark site visits, there were active examples of families participating in advisory and support roles. Rainbow Babies and Children's Hospital in Cleveland established a Family Advisory Board in 1991,

introducing parent input into all aspects of unit process, including physical design, one-on-one parent support, and parent education materials. The NICU at the University of Massachusetts in Worcester employed a parent as librarian and aid to parents in seeking resource materials in print or on the Internet. Utah Valley Regional Medical Center in Provo has an extensive system of parent-to-parent support offered to the family of every NICU admission, in addition to 3 paid parent positions.

Developing strategies for including families as advisors at various levels has been 1 of the most active areas of improvement for centers in the family-centered care focus group. There have been challenges to engaging families as advisors. It is not easy to negotiate the working relationships among parents who are volunteers, parents who are employees, and hospital staff. Medical and nursing caregivers may be defensive and find it difficult to hear and respond to what parents have to say. The parent volunteers or advisors may feel intimidated at first or overwhelmed by the emotional recall of their own hospital experience. Examples of how family advisory activities have evolved in 2 centers follow.

#### Legacy Emanuel Children's Hospital

From collaboration with the family-centered care focus group, particularly as a result of benchmarking site visits, staff and interested parents from the NICU at Legacy Emanuel Children's Hospital in Portland, Oregon, began planning a parent-to-parent support program. They used 2 existing family-centered care groups to plan and implement the program: a family advisory board and a multidisciplinary family-centered care committee.

The family advisory board members discussed their experiences and ideas for providing direct support from 1 parent to another. They then became the core group of volunteers who underwent hospital volunteer training and took a separate class to re-familiarize themselves with the workings and staff of the NICU. Hospital confidentiality policies were particularly stressed. As "family volunteers," they be-

gan spending blocks of time in the unit, reconnecting with staff and meeting current NICU families. Their schedules appear alongside unit staffing schedules to boost visibility and integration. They wear special buttons to distinguish them from “regular” hospital volunteers. The parents of a newly admitted infant will find a “calling card” at the infant’s bedside, giving information about the program. If the parents express interest, then a family volunteer will be asked (usually by the bedside nurse) to meet with them. The interaction and support are tailored to each family’s interests and needs during their child’s inpatient stay. A family volunteer is on call around the clock to talk with parents by telephone.

The new program, called Precious Beginnings, has a mission “to touch the life of each family in the NICU in a positive and lasting way.” Precious Beginnings has incorporated as a nonprofit organization in the state of Oregon. This has been an important step that allows them to engage in tax-exempt fundraising. In addition to parent-to-parent support activities, participating volunteers publish a family newsletter monthly and hold pizza night twice a month to broaden their network of support to parents.

Benefits from the Legacy Family Advisory Board and Precious Beginnings are

- Increased support presence on the NICU
- Education of families
- A growing network of committed volunteers
- Promoting Legacy Emanuel Children’s Hospital as a champion of family-centered care

Establishing a collaborative and even collegial relationship between parent volunteers and NICU staff has been a goal and will be a key to success. Acceptance of the parent-to-parent program has depended on the enthusiasm and energy of the family volunteers, the grateful responses of NICU parents, and the emerging visibility of the program. The volunteers have found that their strong commitment to making the NICU experience less stressful for parents makes a lasting and favorable impression on staff.

### Children’s Hospital at Dartmouth

Founding and establishing a parent advisory council has been one of the most important changes that has resulted from Children’s Hospital at Dartmouth’s participation in the family-centered care focus group. Founded officially in October 1999, the idea originated with the Parent Care Initiative, an ad hoc multidisciplinary task force that preceded the NIC/Q 2000 project. That task force developed the intensive care unit philosophy statement: “We believe the parent-child relationship is essential. We believe in providing a nurturing environment where the child is part of a family, and the family is part of the care team.”

Several factors contributed to the successful initiation of the parent advisory council. Multidisciplinary teams including staff nurses and parents participated in the benchmarking site visits. The

enthusiasm generated on return from the visits was a major factor in developing and promoting improvement ideas for family-centered care. A second factor was the commitment to a bidirectional free flow of ideas. Nursery staff members are encouraged to participate in monthly parent advisory council meetings and to present new ideas and initiatives for family input. Conversely, representatives from the parent council frequently serve on ad hoc nursery committees for specific improvement projects. A third factor has been support for the parent council in the form of space to meet at the medical center, food for meetings, and on-site child care. Incorporating the parent advisory council into the shared governance of the unit was described in the section “Unit Culture.”

There have been several challenges to starting the parent advisory council. Some nurses were concerned that parents would be overly critical and make demands for changes without understanding all of the issues that nurses encounter. Open communication and collaboration have largely dispelled this concern. Because the intensive care nursery is a regional referral center, most parents reside a distance away from the medical center. This creates obvious logistic problems in recruitment of council members and participation. Some strategies have been to use speakerphones to connect to the meetings and developing tasks that can be done by communication over electronic mail rather than attendance at meetings. A problem shared by most parent councils is getting representation from parents across the cultural, age, and economic spectrum. Finally, strategies for funding activities have not been fully resolved. Fundraising efforts done by the parent council may conflict with similar activities by Children’s Hospital at Dartmouth. Clearly defining the goals and needs has led to success in designating the proceeds of certain fundraising activities for the parent advisory council.

A brief list of accomplishments by the parent advisory council include

- Creating a combination parent information guide and journal called “Special Beginnings” to be given along with a gift bag to the parents of every admission to the intensive care nursery
- Successfully advocating with nursery staff for a toll-free call-in line for parents
- Supporting and explaining why eliminating exclusion of parents from nursing “change of shift” was important
- Teaching nursery staff about parents’ perspectives during mandatory “Skills Days” and during orientation of new staff
- Participating in interviewing and recruiting nurses and physicians
- Participating in fundraising and promoting Children’s Hospital at Dartmouth
- Expressing parents’ perspective on the issue of parents presence during teaching and patient care rounds and collaborating to address issues of confidentiality
- Sponsoring parent support activities, such as pizza nights and Sunday coffee hour, for intensive care nursery parents



- Contributing articles to the unit's monthly newsletter

Future goals of the parent advisory council include developing a parent-to-parent support program and helping to establish a salaried permanent parent support liaison.

Parent volunteer programs have special challenges, and each hospital has had to answer crucial questions during their evolution. When is a parent "ready" to serve in an advisory role? How can parent councils address issues of diversity and language barriers? What is the best way to "support" a family in the NICU? Welcoming families to serve as advisors requires commitment from the organization and from departmental leaders. Like most new programs, it requires time, money, and enthusiasm, as well as sensitivity to the resistance that may arise from introducing a new "culture" to the workplace.

### DISCUSSION

In 1992, a group of parents met with neonatal professionals to discuss how care providers could collaborate more effectively with parents of sick newborn infants. Subsequent to that meeting, an article summarizing "The Principles for Family-Centered Neonatal Care" was published.<sup>8</sup> These principles have since been reflected in statements from the American Academy of Pediatrics as well as other organizations, supporting the role of families in decision making.<sup>9–11</sup> Although progress has been made to include families in major decisions, intensive care units remain environments where nurses and physicians maintain most of the control.

Families dealing with the stress of sick infants who require critical care often feel lost, out of control, and in unfamiliar surroundings.<sup>12–14</sup> Parents have repeatedly expressed their need to be an integral part of the care of their children. Unfortunately, examples of breakdowns in the relationships between neonatal care providers and parents abound.<sup>15–17</sup> The problems in neonatal intensive care are not unique but are representative of a broader problem. The current health care system often falls short of meeting the needs of the population. Improving the care provided will require a change in the fundamental beliefs and philosophy of care.

The Institute of Medicine proposed changes needed to improve the quality of health care in the United States for the 21st century.<sup>18</sup> The proposed rules address patient and provider relationships.

Recommendations include customizing care according to patient needs and values, recognizing the patient as the source of control, and placing the patient and family in the center of choices about care—all principles consistent with family-centered care.

Changing the culture of care in NICUs is not easy. The experiences of centers in the family-centered care focus group illustrate challenges as well as successes. Family-centered care is more of a journey than a destination. Collaborating centers in this project found themselves at different places in that journey. Through perseverance in implementing the BBPs, all have moved further along the path.

### REFERENCES

1. Saunders RP, Abraham MR, Crosby MJ, Thomas K, Edwards WH. Evaluation and development of potentially better practices for improving family-centered care in neonatal intensive care units. *Pediatrics*. 2003;111(suppl):e437–e449
2. Nyqvist KH, Karlsson KH. A philosophy of care for a neonatal intensive care unit. *Scand J Caring Sci*. 1997;11:91–96
3. Montgomery LA, Kleiber C, Nicholson A, Craft-Rosenberg M. A research-based sibling visitation program for the neonatal ICU. *Crit Care Nurse*. 1997;17:29–39
4. White R, Martin GI, Graven SN. Newborn intensive care unit design: scientific and practical considerations. In: Avery GB, Fletcher MF, MacDonald MG, eds. *Neonatology: Pathophysiology and Management of the Newborn*. Philadelphia, PA: Lippincott Williams & Wilkins; 1999:49–59
5. Jeppson E, Thomas J. *Essential Allies: Families as Advisors*. Bethesda, MD: Institute For Family-Centered Care; 1995
6. Jeppson E, Thomas J. *Families as Advisors: A Training Guide for Collaboration*. Bethesda, MD: Institute For Family-Centered Care; 1995
7. Roman LA, Lindsay JK, Boger RP, et al. Parent-to-parent support initiated in the neonatal intensive care unit. *Res Nurs Health*. 1995;18:385–394
8. Harrison H. The principles for family-centered neonatal care. *Pediatrics*. 1993;92:643–650
9. AAP Committee on Bioethics Policy Statement. Ethics and the Care of Critically Ill Infants and Children. *Pediatrics*. 1996;98:149–152
10. AAP Committee Fetus and Newborn Policy Statement. The initiation or withdrawal of treatment for high-risk newborns. *Pediatrics*. 1995;96:362–363
11. AAP Committee on Fetus and Newborn and ACOG Committee on Obstetric Practice Policy Statement. Perinatal care at the threshold of viability. *Pediatrics*. 1995;96:974–976
12. Gordin P, Johnson BH. Technology and family-centered perinatal care: conflict or synergy. *J Obstet Gynecol Neonatal Nurs*. 1999;28:401–408
13. Meck NE, Fowler SA, Claflin K, Rasmussen LB. Mother's perceptions of their NICU experience 1 and 7 months after discharge. *J Early Interv*. 1995;19:288–301
14. Wereszczak J, Miles MS, Holditch-Davis D. Maternal recall of the neonatal intensive care unit. *Arch Psychiatr Nurs*. 1997;11:118–125
15. Stinson R, Stinson P. *The Long Dying of Baby Andrew*. Boston, MA: Little, Brown; 1983
16. Mehren E. *Born Too Soon: The Story of Emily, Our Premature Baby*. New York, NY: Doubleday; 1991
17. Woodwell WH Jr. *Coming to Term: A Father's Story of Birth, Loss, and Survival*. Jackson, MI: University Press of Mississippi; 2001
18. Institute of Medicine. *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, DC: National Academy Press; 2001



## **Appendix A Vision and Philosophy Statements**

### **Children's Hospital at Providence/Alaska Medical Center**

#### **VISION STATEMENT**

The Newborn Intensive Care Unit in the Children's Hospital At Providence strives to provide excellent care in a compassionate manner to newborn Alaskans and their families.

#### **MISSION STATEMENT**

Our mission is to provide state of the art care in an environment that is developmentally supportive and family-centered.

#### **NICU BELIEFS**

Recognizing that having a baby in the NICU is one of the most stressful events a family can experience; we are guided by the following beliefs:

- The family is the center in an infant's life. We welcome them as their baby's most important caregivers rather than as visitors.
- Decision making in the NICU reflects each family's culture, values, and priorities.
- Each baby deserves a developmentally supportive environment that is based on its strengths and abilities.
- Parents and health care professionals respect one another and work as a team to achieve the best possible outcome for each infant.
- The NICU needs to provide an environment for the family that is comfortable, safe, and supportive of their individual needs.
- We seek to continually improve our care, provide the most advanced technologies available, and use cost effective methods.
- We respect infant and family privacy and rights to confidentiality.
- Care in the NICU is provided by motivated, knowledgeable and expert multidisciplinary team members who are dedicated to the promotion of infant and family health.

## **Children's Hospital at Dartmouth**

### Philosophy:

We believe the parent-child relationship is *essential*.

We believe in providing a nurturing environment where the child is part of a family and the family is part of the care team.

### Vision:

We will know we are partners with families when the environment in the Intensive Care Nursery supports families to become confident and competent parenting their child and being their child's best advocate.

## **Fairview University Medical Center**

### Philosophy Statement for Family-Centered Care in the Newborn Intensive Care Unit

We recognize the family is the most important and constant factor in each baby's life. Our goal is to establish a collaborative partnership between parents and the health care team to promote communication, respect diversity, and empower families.

## **Legacy Emanuel Children's Hospital**

### Philosophy of Family-Centered Care:

Our goal is to care for children in a way that supports our belief that the family is the foundation of a child's life.

We respect and honor the diverse values, structures, and needs of families in our care, and strive to support the empowerment of the family in caring for their child.

We believe families deserve privacy, our respect and trust, as well as ongoing information about the course of their child's care.

We will work to be flexible, caring, compassionate, and gentle.

We understand that we are here to serve and support during times of crisis, not to take the place of a family.

We choose to do this work because we care, we need families to help us learn how to meet their needs.

## **Miami Valley Hospital**

### Vision Statement:

The Neonatal Intensive Care Unit at Miami Valley Hospital strives to provide excellent care in a compassionate manner to newborns and their families.

### Mission Statement:

Our mission is to provide high quality care in an environment that is developmentally supportive and family-centered.

### Philosophy:

- We commit to caring for our patients in a way that supports our belief that the family is the foundation of an infant's life.
- We believe in providing a comfortable, safe, and supportive environment where the infant is a part of the family and the family is a part of the team, in order to achieve the best possible outcome for each infant.
- We respect and honor the diverse values, structures, and needs of families in our care and strive to support and encourage each family in caring for their infant.
- We recognize that each infant and family has the right to experience life with dignity.
- We respect infant and family privacy and rights to confidentiality.
- We seek to continually improve our care and provide the most advanced technologies available through motivated, knowledgeable, and expert multi-disciplinary team members.

## **The Women's Hospital of Greensboro**

The Mission of the Neonatal Intensive Care Unit at the Women's Hospital of Greensboro is to provide high quality, complete health care for the high-risk newborn in order to promote the best possible growth and development for infants and their families

### We are guided by these beliefs:

- Each infant is a special, blossoming person.
- The parent-child relationship is essential.
- We respect and honor the diverse values and needs of the families in our care.
- The role of the Neonatal Intensive Care Unit is to provide a nurturing environment where the child is a part of a family and the family is part of the care team.
- Families need complete, accurate information to make informed decisions and participate in their infant's care
- Professional development is essential in promoting the highest quality of care.
- The infant's and family's smooth transition into the community begins here.

## **Yakima Valley Memorial Hospital**

### VISION STATEMENT

Memorial and families: Partners in care

## Implementing Potentially Better Practices for Improving Family-Centered Care in Neonatal Intensive Care Units: Successes and Challenges

Kimberly A. Cisneros Moore, Kara Coker, Allison B. DuBuisson, Betsy Swett and William H. Edwards  
*Pediatrics* 2003;111:e450

<b>Updated Information &amp; Services</b>	including high resolution figures, can be found at: <a href="http://pediatrics.aappublications.org/content/111/Supplement_E1/e450">http://pediatrics.aappublications.org/content/111/Supplement_E1/e450</a>
<b>References</b>	This article cites 11 articles, 4 of which you can access for free at: <a href="http://pediatrics.aappublications.org/content/111/Supplement_E1/e450#BIBL">http://pediatrics.aappublications.org/content/111/Supplement_E1/e450#BIBL</a>
<b>Subspecialty Collections</b>	This article, along with others on similar topics, appears in the following collection(s): <b>Fetus/Newborn Infant</b> <a href="http://www.aappublications.org/cgi/collection/fetus:newborn_infant_sub">http://www.aappublications.org/cgi/collection/fetus:newborn_infant_sub</a> <b>Hospital Medicine</b> <a href="http://www.aappublications.org/cgi/collection/hospital_medicine_sub">http://www.aappublications.org/cgi/collection/hospital_medicine_sub</a>
<b>Permissions &amp; Licensing</b>	Information about reproducing this article in parts (figures, tables) or in its entirety can be found online at: <a href="http://www.aappublications.org/site/misc/Permissions.xhtml">http://www.aappublications.org/site/misc/Permissions.xhtml</a>
<b>Reprints</b>	Information about ordering reprints can be found online: <a href="http://www.aappublications.org/site/misc/reprints.xhtml">http://www.aappublications.org/site/misc/reprints.xhtml</a>

# American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN®





# PEDIATRICS®

OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

## **Implementing Potentially Better Practices for Improving Family-Centered Care in Neonatal Intensive Care Units: Successes and Challenges**

Kimberly A. Cisneros Moore, Kara Coker, Allison B. DuBuisson, Betsy Swett and  
William H. Edwards

*Pediatrics* 2003;111;e450

The online version of this article, along with updated information and services, is  
located on the World Wide Web at:

[http://pediatrics.aappublications.org/content/111/Supplement\\_E1/e450](http://pediatrics.aappublications.org/content/111/Supplement_E1/e450)

Pediatrics is the official journal of the American Academy of Pediatrics. A monthly publication, it has been published continuously since 1948. Pediatrics is owned, published, and trademarked by the American Academy of Pediatrics, 345 Park Avenue, Itasca, Illinois, 60143. Copyright © 2003 by the American Academy of Pediatrics. All rights reserved. Print ISSN: 1073-0397.

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN®

