

Gravens By Design: Addressing Challenges to Fully Incorporating Families into the NICU Care Team

Robert D. White, MD

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Family-centered neonatal care is rapidly becoming the declared standard of practice in NICUs worldwide. Several barriers still exist, however, that make this goal more aspirational than realistic in many NICUs – as much or more so in the United States as in nations with more limited resources. An open evaluation of these barriers may help plan the way forward to fully implementing this ideal. (1)

Structural: Most NICUs were designed in an era when neonatal intensive care was not family-centered. Sufficient space and privacy at the bedside to allow extended time for skin-to-skin care, for example, was not contemplated during the design process for many of our existing NICUs, so while exemplary efforts have been made in many units to accommodate this practice, it is still far from optimal for families and therefore difficult to fully implement. (2) The trend toward single-family rooms has strengthened over the past 20 years, but even now, NICUs are being built with limited support for full family participation – some of these rooms do not have a bathroom or a comfortable sleep surface, for example, making it more difficult for families to commit to being fully engaged with the care of their baby. Until NICUs are designed to accommodate families in the best way possible, including couplet care rooms in hospitals with a delivery service, family-centered care will not reach its full potential. (3)

Operational: More often than not, including families in caring for their newborns requires extra effort. Sometimes this investment produces tangible benefits to the bedside nurse and the nursing administration when a family can take on care duties usually provided by a nurse, which may also result in a shorter stay. (4) Nevertheless, most of the time, working with families adds to a caregiver’s responsibilities and time commitment. In addition, bedside providers are not usually trained to provide the type of family support provided by social workers, psychologists, and other support specialists, so hospitals are required to provide these individuals who may be able to help with barriers that families are experiencing that limit their ability to fully participate in their baby’s care. It is often easier for a caregiver to complete their assigned tasks after which providing additional nurturing care to the infant or helping

the family to do so can be seen as a burden. Other operational barriers may include challenges to family access because of arcane hospital rules such as parking fees or limited “visiting” hours.

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Families: Sometimes families are unable to fully participate in the care of their infants, even when they desire to do so, because of lack of paid family leave from work or limitations in transportation and child care, all of these more significant challenges in the US than in most other developed countries. In other cases, parents are unwilling to participate fully in their baby’s care, even when all other barriers have been removed. A more subtle but pervasive factor is that minority families who do not see many caregivers like themselves can feel alienated or judged.

“Every NICU team that aspires to be fully family-centered can use the items on this list to evaluate its current status and to plan future initiatives. (5)”

Initiatives to Consider when Implementing and Strengthening Family-Centered Care: Some of the barriers mentioned are far beyond an individual’s or even a team’s ability to influence – but many are not. This list will begin with those most easily addressed at the level of an individual NICU and finish with those we will need to advocate for as citizens and professionals. Every NICU team that aspires to be fully family-centered can use the items on this list to evaluate its current status and to plan future initiatives. (5)

- Choose a formal program of family-centered care to provide the framework for all subsequent efforts
 - There are many good programs available, several of which will be presented during the 2023 Gravens Conference – e.g., VON, FiCare, NIDCAP, Family Nurture Intervention, and more.

- Make developmental and family-centered care a measured and monitored expectation of every patient encounter.
 - Developmental and family support should be elements of each patient care encounter - i.e., of equal importance to vital signs and feedings. Regular audits are necessary to ensure these practices become part of the NICU culture.
- Remove barriers to a family's access to their baby
 - Allow 24/7 presence
 - Provide free parking
 - Include couplet care and single-family (as opposed to single-patient) rooms in all new construction or renovation
- Provide ongoing training for all staff on implicit bias in neonatal care
- Promote community efforts to increase training and employment of minority individuals in neonatal care
- Employ sufficient support personnel (e.g., social worker, psychologist, family advocate) to meet families' needs.
- Advocate for paid family leaves for all parents of newborns requiring NICU care.

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Corresponding Author



Robert D. White, MD
 Director, Regional Newborn Program
 Beacon Children's Hospital
 615 N. Michigan St.
 South Bend, IN 46601
 Phone: 574-647-7141
 Fax: 574-647-3672
 Email: Robert.White@pediatrix.com