

WHY FAMILY INTEGRATED CARE IS A VITAL NICU COMPONENT: A PARENT'S PERSPECTIVE



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The Neonatal Intensive Care Unit (NICU) is the first home for more than 1 out of every 10 babies born in the US each year.¹ These newborns come into the world with needs that cannot be met by their parents alone. They require physicians, nurses, therapists and an entire team of educated and knowledgeable specialists to treat and support them in their journey. But where does this leave the parent? All too often, parents like myself find ourselves incredibly grateful for the child's multidisciplinary team but feel as though their own role in their baby's life is unclear. The NICU is not just a first home for infants; it's also the first home for this new family unit.

We hold vigil at our child's isolette or bedside for hours each day, waiting and hoping for the chance to feel like a parent for a couple of moments. We wait for the opportunity to help change a diaper, take their temperature or give our child a steady, loving touch. We hold our breath with each visit by our doctors. We wait anxiously for an update or a new diagnosis. We hear the sounds of monitors in our sleep. It doesn't take long to learn the rhythm of each day, what each acronym means and when we can ask permission to hold our infant. We are not the primary caregiver for our baby in those NICU days. We can feel like the second string, waiting on the sidelines for our doctors and our primary nurses to give us the go-ahead to participate in our child's care. We are terrified but so hopeful for this beautiful, fragile new life.

A Parent's Experience:

My first experience as a mother was filled with trepidation and anxiety. I had just unknowingly spent 5 hours in labor and then delivered rapidly via emergency C-section at 25 weeks and 5 days of gestation. It was all so unexpected. I didn't even have my bag for the hospital ready. My sweet, tiny Owen was 2 lbs, 1 oz. He was resuscitated, intubated and needed the help of several machines to keep him alive. I was completely and utterly lost, isolated and overwhelmed. My husband and I felt unprepared that we could care for this tiny baby, born far too soon. I kept a journal during those long weeks in the NICU, as we prayed, cried and I apologized to him. Looking back through that notebook, **these are the phrases that I wrote repeatedly:**

'I can't believe you're really here!'

'I am so very sorry.'

'I can't believe how much I love you.'

'I have no idea what any of these wires are for.'

'I'm afraid to touch you, sweet boy.'

'My body has already failed you; what if I fail you again?'

Feelings of failure and guilt filled my mind those first few weeks. I wasn't confident enough on my own to know how to act as a mother around my child. I needed help. Despite my own desires to hold him, I didn't know how to touch him. I wasn't the one responsible for his care. I was an observer. I sat beside his isolette and realized that I had absolutely no control over what was happening in front of me. I was on the outside, looking at a different person handling 90% of the care of my child. A group of strangers could provide better care for my baby than I could. Thankfully, they wouldn't remain strangers for long.

My son came into the world long before Family Integrated Care (FICare) became a priority. Nurses and doctors' top priority was to care for our babies. They helped parents when needed and were kind and patient in most situations, but creating an environment where parents played an integral role in the daily lives of their children wasn't a common occurrence. There were still periods of the day when I was asked to leave the bedside so medical staff could give report to the oncoming shift. There were often moments, in the beginning, where I felt out of place or in the way.

Over time, we formed a powerful bond with our medical team, especially the nurses. They became our family, and it was a cherished relationship. However, this connection didn't develop without a good amount of effort and communication on both our parts. And not every mother is able to be in the hospital long enough for this relationship to naturally grow with her baby's care team. Now, thankfully, new mothers in the NICU can be met with a much different approach as FICare is now available and is becoming a more common practice.

The need for this new directive is strong. While we formed a close bond with our nurses and others on our medical team, it wasn't always an easy relationship. Communication could be a challenge in a busy, high-risk pod like Owen's as things often moved quickly. One of the most potent memories of our NICU journey happened during a very busy afternoon. I was cherishing a couple of moments of touch with my baby through his isolette when Owen's heart rate dropped suddenly. As I began to panic, a nurse I wasn't familiar with rushed to our bedside and let me know that my touch may be one of the reasons he was struggling. I was devastated. She delivered the news quickly and patted my shoulder before tending to a baby alarming nearby. Her words were simple and matter of fact, not unkind. But they had a devastating impact on my confidence as a first-time mother. This experience was so new and overwhelming. And now, even my touch was a detriment to my son. How can I learn his cues? When was touch helpful and soothing to him, and when was it harmful? This experience altered my outlook on parenting in the NICU from that moment on.

My confidence had been shaken, and I was anxious about asking questions during the early weeks of our NICU journey. It took some time to find my voice. As I became more comfortable, I shed my anxiety about asking for clarification more than once and began educating myself on the care of my child. My nurses, therapists and neonatologists played a huge role in that education. They took the time to sit down and answer my questions. Our therapist taught me proper positioning and how to hold Owen skin-to-skin to encourage breastfeeding. Our staff allowed me to check his chart when I walked in the door so I could catch up on what the day had been like. They worked hard to make me a part of his care team. My confidence in my abilities as a parent grew. It was our own version of FICare before the need had been thoroughly explored. But I still never fully felt as though I had anything to contribute.

As overwhelming as our NICU journey was, there were also many moments of care and compassion. Baths and skin-to-skin cuddles were the two most anticipated events in our daily routine. My son was connected to multiple tubes, wires and a PICC line for a good portion of his 75-day hospital stay. I lived for the closeness I felt during those moments caring for and loving on my baby. But the NICU is a difficult home. I wanted so desperately to care for my child without help, and his fragility made it impossible. Each precious moment of bathing or skin-to-skin care required the assistance of one or many of our medical team. Everything I wanted to do as a parent, as limited as my options were, revolved around someone else's ability to help me.

Our NICU journey required a team effort. I became very used to depending on our nurses, doctors and therapists for help. As discharge day grew closer, our hospital offered a few options to prepare us for the day when we took over Owen's care completely. We took CPR training, learned to use his apnea monitor, and fed, bathed and changed him as often as possible. We were also given the option to stay with him overnight in a postpartum room near the NICU. It was a trial run, just myself and my little boy. But, we had the comfort of knowing help was just the push of a button away. This one night skyrocketed my confidence and gave me an experience close to what I missed when Owen came so early. It greatly prepared me for life outside the NICU with my baby.

Encouraging Parents to Find Their Voice:

FICare in the NICU is the idea that parents and medical professionals create a partnership in the care of the baby. It is a collaboration, bringing together the concerns, thoughts and input of the parent into the final consideration. The goal is to give parents a voice, to enable better communication, build their confidence and promote as much parent participation as possible.² FICare is one step beyond the Family-Centered Care (FCC) model. While FCC encouraged more involvement from parents in the care of their baby, FICare provides a tangible approach for how to educate, encourage and empower parents to contribute to the care of their baby. Thus, parents become their child's advocate.

FICare strives to let parents parent their baby, even in a hospital setting. It encourages hands-on participation in as much caregiving as is safely possible: helping give baths, changing diapers, checking stats, understanding what every monitor, lead, tube and beep means. Parents can move from outside observers to part of their child's care team. They can receive the education they need to understand their baby's cues and proper touch.

The goal is a noble and necessary one. **Research shows that FICare lowers parent stress and anxiety levels and showed improved weight gain in infants.** Exclusive breastfeeding rates of parents who were in hospitals facilitating FICare were also higher.³ "The results indicated that the mothers were provided with the tools to parent their infants in the NICU, recognize their own strengths, increase their problem-solving strategies and emotionally prepare them to take their infant home."⁴ Creating a partnership with parents in the NICU has great benefits for both parents and babies.

Key Ingredients for Integrated Family Care:

While a study based out of Canada, Australia and New Zealand has set guidelines for the best way to implement FICare, hospitals will introduce the program in various ways. **Their research identifies four FICare Pillars:**²

1. Staff Education and Support:

Providing adequate education and training for those who are caring for both babies and their parents is a key component in changing the overall NICU experience. The personality and workload of the nurse or doctor caring for your baby plays a large role in the day-to-day interaction between staff and parents. Nurses and doctors have an incredible position to support and care for both the baby and the family. Moving parents from bystanders to active participants in the care of their child involves a huge effort by everyone in the NICU. Training is necessary to ensure that the best care can be given, not just to their tiny patient, but to the family who loves them.

These education tools are vital. As a NICU parent advocate, I've mentored several parents over the years who have expressed concerns about speaking up and asking questions to their medical team. They worry that they will be a nuisance to the doctors and nurses. Or they become concerned that asking too many questions or questioning certain decisions will have a negative impact on their child. This is how proper education on FICare for both medical professionals and parents removes a barrier. When parents know that they are on the same team as the doctors and nurses treating their children and when open and honest communication is encouraged, the fears and anxiety are lessened. Everyone on this team has the same goal: a healthy and happy baby.

2. Parent Education:

Much like the training that NICU staff receives, parents also need education in how to care for their medically fragile child. FICare strives to provide parents “with the knowledge, skills, and confidence required to care for their infants in the NICU setting.”² Parents are joining the care team for their baby. FICare recommends that parents be involved in medical rounds and receive small-group and bedside education.

A great challenge for parents is finding the confidence to care for their child after a traumatic birth. Hands-on education, encouragement and guidance from a couple of very kind and patient nurses can make a huge impact in preparing parents to take a more active role during their NICU journey. It can also prepare parents for their role as primary care giver for their medically fragile child at home. Some FICare programs are encouraging parents to be present at rounds, contribute to medical chart notes and become an active partner in the care of their baby.

3. NICU Environment:

Certain environments are more accommodating to the implementation of a FICare model than others. Some NICUs have limitations concerning parent visitation. Rounds and shift change are often times for doctors and nurses to discuss the care of a patient openly. That period may interrupt a skin-to-skin session or other bonding experiences between parent and baby. The space and layout of a NICU can also be a challenge in parent privacy. This pillar encourages the hospital to re-evaluate procedures and make accommodations for parents who will be spending many hours each day sitting bedside. Is there ample room and privacy for mothers to pump beside their child? Are the chairs comfortable for hours of skin-to-skin care? Can parents feel comfortable in this space while still allowing NICU staff to carry on in an efficient manner?

4. Psychosocial Support:

This is the pillar that stresses the need for peer-to-peer support and the active encouragement for parents to participate in a more integrated care model. Research has shown that peer mentor support has a huge impact on the psychological wellbeing of a parent in the NICU.⁵ Creating an environment where a parent is encouraged and supported by veteran NICU parents reduces stress and builds confidence as well as a sense of community. This approach also stresses the need for interdisciplinary collaboration and continuity of care.⁵

Conclusion:

This is a team effort. My husband and I worked hard to develop a strong relationship with those caring for our child. It was a conscious effort to be as active in Owen’s care as we could. But that process took a good deal of time and effort to build, for both us and our medical team. FICare provides the opportunity for this kind of relationship from the start. Owen is now a healthy and happy nine-year-old boy. He is thriving in every way. I still look back on our time in the NICU as one of incredible growth. Our care team touched our lives and helped to make us better parents because of their time and passion. Every parent should have that experience.

Each person involved in the care of a baby in the NICU has the same goal: to provide the highest level of care for each infant. FICare calls on doctors, nurses, therapists, staff and parents to work together toward the best possible outcome. Parents are pulled off from the sidelines and become an active player in the care of the baby. They should be encouraged, empowered and given the tools necessary to feel competent and capable for the transition home. The NICU is an overwhelming place to call home for any period of time. FICare strives to make that experience as inclusive and positive as possible.

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