

Building Bridges for NICU Families

Deb Discenza

It was September 5, 2003 and I was 7.5 months pregnant with my first child. I was all alone in a grocery store bathroom an hour outside of town in hysterics because my water had broken and I knew it. I had had a few hiccups during my pregnancy but my OB seemed unconcerned about my jitters a month before about the potential for preterm labor. I noted to her that I had been born a little early myself and she ignored my concerns telling me I was a first time mother and would be late rather than early.

Remembering that, I felt betrayed as I cleaned up my tears and the gushing fluid as much as humanly possible to head out to the front office to call my doctor.

Fast forward I was rushed back to town (110 mph by my husband who should not have been driving) and to our hospital at the doctor's request. A little over 30 hours later, despite every intervention possible and getting the very traumatic live tour of the labor and delivery wing that coincided with the weekend I was supposed to have my maternity tour, my daughter was born at 30 weeks gestation at 2 lbs 15.5 oz. The tiny but fierce kitten cry erupting from my daughter's mouth gave me real hope. But little did I know that the shock and trauma of her 38-day stay in the NICU, the re-admission to the pediatric unit, almost a decade and a half of specialists would be the emotional and physical marathon of my life.

So a year ago, when I first met Rebecca South and heard about her program launch, Families' Bridge to Caring Hands®, I knew at last that someone was doing something to empower parents in a way that was clinically sound and emotionally strong. I felt it important to bring Rebecca's program to a higher level of attention because of its strength, its bottom-line hospital savings and its focus on finally giving NICU moms the attention they need and deserve.

Deb Discenza (DD): Rebecca, you came to this program with a unique perspective on the premie experience, yes?

Rebecca South (RS): I've been a NICU nurse since 1994 and have always loved working with premies and families. I am the

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mother of twin girls and so I have a unique perspective when it comes to the challenges our NICU parents face.

DD: Indeed you have understanding from all sides of the equation here. When did you conceive of this program's idea? Was it a "lightbulb" moment?

RS: In 2013, I saw a gap in the care of moms in the high risk OB arena—and these moms were not at all prepared for what was to come if they delivered early and had a baby in the NICU. I always called these moms 'the forgotten moms' as we never really paid attention to them until they delivered. So, as part of my work in our NICU and the career advancement program at my hospital, I conceived Families' Bridge to Caring Hands® and piloted the program in 2014-16. We worked with over 200 families during this time.

DD: Wow, impressive. Walk me through the program.

RS: Families' Bridge to Caring Hands® (FBCH) NICU Navigator Nurse program targets antepartum mothers with a high probability of delivering an infant who will be admitted into the NICU. The program methodology provides structured staff training, accompanied by parent resources to aid in lowering stress and providing potential parents of infants in the NICU with a clear view of what's ahead. Our goal is to prepare parents to become engaged members of the NICU care team.

This program provides evidence-based training to perinatal nurses (antepartum, labor and delivery, postpartum, and lactation), with additional training to NICU RNs as NICU Navigator Nurses, to give psychosocial support to families and mothers while on bed rest. Education content is derived from research and literature which indicates that lowering the stress levels of potential parents of infants in the NICU results in improved outcomes for both the parents and the infant following delivery. Our program trains designated NICU Navigator Nurses to work with potential parents of NICU infants by providing structured information throughout their stay in the antepartum unit and continues up to the infant's NICU admission. This one-on-one clinical support has improved staff-parent communication which allows for better parent focus on the infant's care post-delivery.

In addition to the clinical staff training, Families Bridge to Caring Hands provides antepartum mothers with various educational resources utilizing the patient portal on our website (login access required) at time of admission, during and after their hospital stay. This customized content can be accessed via

computer, tablet or smartphone and comes preloaded with educational material which correlates with the training provided to the mother by NICU Navigator Nurses and perinatal staff nurses.

DD: You really work hard to lessen a mother's stress, I really like that. I have to assume that this program saves time and money for the team, yes?

RS: Our preliminary data shows that babies whose mothers are in the Families Bridge program have a shorter length of stay in the NICU (as much as three days shorter) and mothers report improved bonding and less anxiety in taking their babies home. As for time savings, the program really supports the NICU staff, in that the parents, on admission, are already 'educated and prepared' and so the staff time in education and support is less.

DD: It appears that you have a lot of fans of this program. Let the voices of hospitals and parents commence:

"Families' Bridge to Caring Hands® provides such an amazing opportunity for our families and has a 'triple E effect.' As a result of participating and using the portal, we now have EDUCATED, EMPOWERED and ENGAGED parents." —Sheri, Nurse Supervisor/Navigator

"As a Neonatologist, I go into these families' room and explain what to expect when their baby is admitted into the NICU. It's nice to have a trained NICU nurse to follow up and answer clinical questions, reinforcing what was discussed during the consult."

"The Families' Bridge program has helped me to show my patients evidence-based, realistic information, which eases their stress." —Antepartum Nurse

"The program allowed us to have a glimpse into the possibilities, and our nurse was open and honest with us. We appreciated this so much and felt so much more aware and prepared." —Antepartum Mom

"This is an incredible resource and has really helped address many of my concerns. Having a Nurse Navigator made my transition to the NICU less intimidating and stressful." —Antepartum Mom

DD: Is there anything else you would like people to know about your program?

RS: We have a passion for impacting families/babies who are born in disproportionate share or underserved hospitals—many of which do not have budgets to offer these types of programs. Our goal is for hospitals to have access to this program for minimal cost, so our team is active in pursuing grant funding to assist in implementation and ongoing costs of the program.

DD: That is so important, Rebecca. Thank you for speaking with me.

Imagine a healthcare system that provides families with support pre-NICU and post-NICU to navigate the emotional and physical stressors involved. Imagine a family entering the NICU with far less trauma and more hope through information. Imagine better patient satisfaction and even better, improved post-NICU outcomes as a result of this program. Sadly I had to go through extensive trauma to get where I am today as an advocate. But I wouldn't wish that on anyone else. And you shouldn't wish that

on your families going forward. Families' Bridge to Caring Hands® is a real, well thought out program that requires minimal resources to implement in your hospital to save time and money and so much heartache. Please reach out today: <https://familiesbridge.com/>