

Supportive Comments of “Parents and family caregivers are not visitors.”

As the Director of a large, Level 4 NICU during the pandemic, it was my responsibility to enforce the hospital's visitor restrictions. The moral distress this created for me and the NICU healthcare team was significant, and I feel has been greatly under-appreciated. As a mother of a NICU graduate who had a 3-month NICU hospitalization, I cannot fathom undergoing that experience alone and cut off from my support system. Yet that is the scenario I was required to create for so many families. The emotional and psychological toll on NICU families was immense. I witnessed it daily and the impact that it had on my own mental wellbeing was significant. I also have great concern over the long-term impact the social isolation had on parent/infant bonding. How has that impacted long-term outcomes for NICU graduates? I also wonder how much of an impact the moral distress and resulting work-related stress has played a role in the nursing turnover so many NICU's have been experiencing. My greatest hope is that we learn from this recent pandemic that NICU parents are part of the care team and should NOT be treated like visitors. With the ongoing nursing shortage, it's more important than ever that parents be fully integrated into their child's NICU care and be made to feel that they are part of the care team.

Parents and babies need each other!

Every parent looks forward to the day their baby is born and their family grows. **Few of us anticipate that our babies' birth will be a medical emergency - or that we will require intensive care. But this is the reality for more than one in ten of us.**

Please appreciate that a NICU admission is an abrupt break in the birthing and bonding process.

When this happens, families need love and support.

If we have to be separated to provide emergency care, please reunite us as soon as possible. Help us reconnect and bond. Care for us together. And help us become the family we need to be.

If our baby and us are experiencing the signs and symptoms associated with perinatal substance exposure, please show us extra love and care. Reject stigmatizing attitudes and language, treat us with dignity and respect, and help us by employing evidence-based care models like Eat Sleep Console. **When you deliver this kind of respectful, trauma-informed care you not only interrupt the systems that oppress us, you help build stronger, more resilient dyads.**

Parents, as well as extended family and community members, are critical to optimizing neurodevelopment within the NICU and, for creating a supportive framework and structure that promotes long term neurodevelopment. In addition, their presence and participation mitigates the trauma associated with a NICU admission. **We will only achieve the best outcomes for each individual infant, and family, by recognizing the unique and important expertise and value of the family to the care team.**

It is not unusual for a parent of a baby in the NICU to forget that they are in fact a parent especially when their baby is on the edge of life and death. We at Graham's Foundation exist to help empower parents so they recognize their importance while their baby is in the NICU. **We believe that nothing is more important than promoting a bond between the baby and parent because that relationship will last a lifetime.**

I fully support that the NICU families should not have a limit on visitation rights for their child. My son spent 7 months in NICU March 2016 to October 2016. I spent most of my days at his bedside and giving him the care he needs. I helped clean his ostomy bag. I was able to do kangaroo care. This was all part of bonding. This was important to me and for my child's development. He was confined to tubing while in the hospital. He is now 7 years old. He is still mainly fed through a g-tube and working on his oral feeding skills with an SLP feeding specialist. There is a special bond as his mother caring for him.

I saw information about how important the mother's role is but nothing about the fathers. Fathers also play an important role and feel they are often neglected and overlooked. Research shows that when fathers are involved, mothers and babies both have better outcomes. This statement needs to include the important role fathers play

Parenting in the NICU is the most unnatural place to be a parent. No where else do parents have to ask to hold their baby and have physical barriers to comforting their child when they are in pain or scared. No where else are parents as terrified and traumatized as we are in the NICU. Too often the clinical care of the medically complex and fragile infant seems to neglect or forget that the powerful and necessary bond of the parent and infant is healing. As a mother of triplets born at 25 weeks 5 days gestation and a full term baby, I have firsthand knowledge to truly understand and appreciate how vastly different these experiences are. With my triplets I was separated immediately upon their delivery, did not see them for 48 hours, did not hold them for two months, and did not truly begin to bond with them for several months later. The toll on my mental health was significant as I suffered from PTSD, major depression, and generalized anxiety disorder, issues I still deal with to this day. As my surviving triplets, now 16 years old, struggle with their own mental health conditions (anorexia nervosa, depression, and anxiety), I can only wonder how that separation and delayed bonding may have played a role in what we are facing now. With my full term daughter, I held her skin to skin immediately after birth while still in the OR. She remained on my chest for the first several months of her life unless she was being dressed, changed, or bathed. Our nurturing connection is unlike anything I had with my triplets. The healing I have experienced through her birth and development are unmistakable. I urge the AAP to consider the long term impact those days, weeks, and months in the NICU have - not just on the baby but also on the entire family unit. YOU have the power to ensure families are kept together as early and as long as possible.

Curious about referencing supportive practice guidelines that encompass family-centered care practices such as the Baby-Friendly Initiative? Reduction of parental presence impacted many baby-Friendly practices that directly support many of the statements you have in your document. Thank you for this consideration.

Incredible work is being accomplished by numerous NICU Parent Leaders globally to improve the outcomes of the NICU patients and their precious families. Recently global event demonstrated how easily family caregivers were removed from NICU in one sweep while being viewed simply as visitors of NICU, rather than essential care provider. I support the resolution titled "Parents and Family Caregivers are Integral Members of the Patient Care Team" whole heartedly. I also believe that not acknowledging the parents and family caregivers today has the potential for a long-lasting negative impact on the babies and their families. We must unify our voice that medicine/science/technology alone will not bring the best outcomes to the families, but properly recognizing every stakeholder and valuable role for each, which includes parents and family caregivers' role is critically necessary today. Our parent and family colleagues are truly valuable in today's NICUs. Pandemic-led historic wrong against parents and family caregivers must never be repeated.

As Parent Support Coordinator, I hear over and over again how grateful parents/family caregivers are to be able to room in with their baby (ies) due to having couplet care and private rooms and how being close to their baby benefits their coping with the stress of being in the NICU. I also hear how difficult it is when mom and baby are separated after birth when mom needs a higher level of care and how hard it is for the other parent/caregiver having to go back and forth. We see the benefits of parents/caregivers being able to hold and talk to and care for their babies. They share how relieved they are when they are able to finally all be together. **Parents/caregivers are not visitors - they are an integral part of the care team and need to be treated as such. This benefits everyone, especially the baby (ies). My babies were born in the hospital I now work at and even though the NICU was an open bay back then, we were still encouraged to participate in care, and we were told how important we were to our babies' development. We need to make sure that parents/family caregivers are able to be present for their babies, even during a pandemic. It is what is best for everyone involved!**

I am the mother of twins girls born at 26 weeks in the year 2000. My experience led me to be a founding board member or develop the psycho social support programs of The Tiny Miracles Foundation in 2004. **I cannot express how important and essential it was for me as a mother and my husband as a father to be in the neonatal unit , advocating for and sharing in the care of our twins in the NICU . I know for a fact , that their recovery to typical children today, and our emotional recovery as parents had a lot to do with our specific involvement as parents.** I've been a Premie Parent mentor and advocate in five hospitals in CT for 20 years and mentored thousands of parents through the NICU and followed their kids progress into adulthood. I know first hand the difference of the outcome for the kids that didn't have their parents as involved, and also the difference in how those parents have recovered emotionally from trauma premature birth. It's staggering and the studies are clear the parents are "essential " caregivers in the NICU and in all healthcare of their child. Covid restrictions created catastrophic long term emotional trauma for parents and their children who have suffered physically and emotionally from the restrictions. **This cannot happen ever again.**

We know outcomes of neonates are largely impacted by family care - nursing, skin to skin, parental advocacy, etc. Further, forming attachments to their parents (which will impact them and their relationships throughout their life) is crucial during this time. This is just on the neonates end - parental trauma and mental health are an entire different ball game! **Parents and family caregivers are most definitely not visitors, but part of their baby's treatment and care. They MUST be included every single step of the way.**

Parents and Caregivers are an essential part of a baby's development and growth. The separation of parents from their newborn is detrimental to the newborn. Newborns and their parent/caregiver both benefit from being together, as study after study has shown. Just a mother's scent alone has been shown to stabilize heart rate and breathing of a distressed newborn. The separation of a mother from her baby can increase postpartum depression and add to the anxiety and stress of a NICU experience, as well as increase PTSD. Caregivers/Parents should not be separated from their children in the hospital.

I am in complete support of ensuring that parents are at the center of patient care when it comes to their child(ren) in the Neonatal Intensive Care Unit. As a NICU mother myself, I can not imagine being told that I was unable to be with my daughter during cares, or unable to do kangaroo care to help regulate her temperature and encourage breastfeeding. It is also unfathomable to think of doing it alone without my husband by my side had one of us only been allowed in the room. These are stories that I have heard time and time again from parents that found themselves in the NICU during the Covid-19 pandemic. Birthing and non-birthing parents are essential to the well being of not only their child(ren), but to their mental health as well. Parents should be at the center and involved in as much as possible while in the NICU with their child(ren).

Considering that parents and caregivers bear the responsibility of caring for NICU babies for a much longer duration than any other hospital provider, it seems most logical that the medical team would, as a whole, work to foster and support parents and caregivers in any way possible. When hospital team help in this way, it might make the transition to home much more seamless, as caregivers have already begun to see themselves in an essential light and might provide further encouragement and confidence for them where it once was lacking, thereby enabling them to be both more prepared and more knowledgeable caregivers.

We were well informed of our children's progress & felt at ease when we were educated on their conditions. This is never easy for families, but there was a lot of emotional support & resources made available to us to help get us through the challenges. The teams that cared for our children were amazing and sensitive to our needs.

The physical bond between parent and infant is biological. It is also paramount for their physical and mental health and can have long-term negative consequences when denied. As a NICU parent, I understand firsthand the anguish of this physical separation and the long-term impact on my mental health and that of my son.

In the NICU setting, the infant-parent bond becomes even more important because of the proven medical benefits to the medically fragile infant and the improved mental health outcomes for parents. As the Founder of Hand to Hold, a national non-profit that provides direct mental health support services to more than 40,000 NICU and bereaved parents each year, I can confirm the significant impact the restrictive visitation policies enacted in response to COVID-19 was unmistakable had on the mental health of NICU parents across the country.

I urge the AAP to acknowledge, affirm and protect parents' rights to be with their children to not only serve as their advocate but to provide the loving, healing power of their presence. It is imperative that parents not be seen as visitors, but as essential care team members - because they are!

The involvement of parents/guardians of a NICU baby makes a huge difference in the baby's health and life. Kangaroo care, or "skin-to-skin," from both parents/guardians helps with bonding; temperature regulation; and improvement in attention, response, reflexes, and other markers for the baby. Baby's respond to their parents' touch and voice, and the parents learn to care for their medically fragile child by being involved in the baby's care during the NICU stay. Breastmilk is lifesaving for NICU babies, but breastmilk supply is often low in breastfeeding parents whose baby is premature or NICU-bound. A parent who is able to pump breastmilk in the NICU near their baby or while touching their baby is able to produce more milk. So long as both parents/guardians are in excellent health, there is far more benefit than risk in allowing them both to be present as often as possible while their baby is admitted to the ICU.

Parents and family caregivers are essential to their infants' health and development in the NICU. Positive and repetitive bonding experiences and care interactions support infant neurodevelopment, attachment, and parental competence and confidence. Parents and family caregivers are an integral part of the healthcare team. Ensuring 24/7 access, inclusion in medical rounds on their infant, and supportive integration into bedside care (diapering, skin-to-skin holding, feeding, human touch, graded sensory input, reading, non-pharmacological pain strategies, etc.) are examples of the many ways parents and family caregivers can bond, learn early parenting skills, advocate, and come to know their infants' unique cues. This critical period of survival and development demands a full spectrum of support for optimal experiences and outcomes. Parents and family caregivers play an elemental role in providing the highest level of care and fundamentally humane care.

Parents are also the patient. **When children cannot speak for themselves, parents should be allowed and encouraged to be at their bedside as much as possible so that they can be a large part of the caregiving team. Parents will be the long-term caregivers after discharge and should be present as much as possible to learn and bond. There should never be a time where a parent is considered a visitor. They are not visiting their child. They are parenting their child and should have full access, at all times, unless surgery is required. Parents are the patients.**

As both a NICU Mom and a NICU Parent Advocate employed by a hospital, I could not agree more that parents are not and are never visitors. The love and experience parents and family caregivers bring is unique and an essential part of the growth and development of the baby, and critical to the growth and development of the family, as well. We know that the integration of a baby's family into all aspects of their care improves outcomes, shortens stays, and helps build connection at a time of crisis. Parents are actively involved in their baby's care in the NICU. They may participate in activities such as skin-to-skin contact (kangaroo care), feeding, and even assisting with medical procedures under the guidance of healthcare professionals. **By being present, parents learn how to care for their baby's unique needs and are better prepared for their transition home. Parents are advocates for their baby in the NICU. They have the right to be involved in discussions about treatment plans, interventions, and decisions affecting their child's care. By being present and engaged, parents can actively participate in these discussions and contribute their insights and preferences. To use the language visitor with respect to NICU parents/caregivers is to frame families as outsiders, which denies the importance of the parent-child relationship at its most vulnerable and delicate stage.** And we know just how vulnerable NICU parents are, how traumatic the separation of parent and child is, how much more at risk they are for things like PTSD and other perinatal mood disorders – coupled with the anxiety of the unknown outcomes for their fragile baby, and the guilt, trauma, and emotions they may be feeling about their pregnancy or delivery only add to the heightened state of distress NICU family caregivers find themselves in. NICU parents have no choice but to leave our hearts in the hospital every day – to trust these excellent providers with our babies. The trust has to work both ways- where families are seen as valued and necessary as the clinical providers. **If parents can be seen and FEEL that they are valued as caregivers in the hospital, and staff recognize and treat them as such, I can't see how it would do anything other than empower parents to be the best caregiver they can be for their child both in the hospital and after discharge home—which is what everyone wants in the long term. It feels like a win/win for all involved.** And perhaps most importantly, for some parents, the time in the NICU with their child may be the only time they will ever have with their child and that is certainly not visiting. **Language matters, particularly during a time of crisis, and we have an opportunity to make a simple change that will validate NICU parents, make them feel more included, and demonstrate the critical role they play in their infants lives starting at the bedside in the NICU and hopefully beyond the doors of the unit with time. I cannot see any downside to empowering parents and welcoming them as an integral part of the care team. "One doesn't have to operate with great malice to do great harm. The absence of empathy and understanding are sufficient."** – Charles Blow (and quoted frequently at the Graven's Conference mid pandemic while talking about the impact of COVID restrictions to NICU Parents) I know that no NICU provider would ever intend to cause harm to a parent/family and here we have the chance to make a change that would impact the next generation of NICU parents and show they are truly vital, involved, necessary collaborators.

Parents are not considered visitors in our NICU and shouldn't be considered as such in any NICU or SCN. They are an integral part of the baby's care team. I have seen a parent's love and healing touch help their baby survive and thrive when medical care was at it's maximum and there was nothing else to offer. They provide insight and perspective about their baby that no one else can, and they understand the interpersonal dynamics of the family that the baby will go home to. This is a no-brainer. Parents are NOT visitors. They are the whole world to the baby.

NICU patients are not individual patients. Rather they come with parents and family members who are critical components to their care and wellbeing. Parents learn to support and tend to their baby's medical needs as important members of the care team and they provide emotional connection for the baby. It is important to remember that no parent is a "visitor" when their child is in the hospital; they are thrust into a world of caregiving that many are not prepared for. My son was a 23-weeker and my husband and I became experts on mundane things like temperature-taking and weighings, but also in complex medical conditions such as ostomies, stomas, and g-tubes. Supporting families and reminding them of the important role they play as part of their baby's care team sets up families for success.

The Tiny Miracles Foundation was established to provide the emotional, practical and financial needs of the families of premature babies. Our foundational approach is to be a complete resource for parents during the initial hospital stay and in the years immediately after. For nearly 20 years, we have been helping families in our community (southwestern CT) throughout their preemie journey.

A major pillar of Tiny Miracles is providing personal one-on-one mentoring for parents beginning in the days immediately following a baby's early arrival. Our hospital partners permit us to be bedside with families and support them as they struggle with frantic questions and misplaced guilt associated with a preterm birth. We see the challenges of the NICU experience through our connections with the families we support. We also see the moments of hope and joy that exist in the NICU. Simple moments and major milestones are all celebrated in the NICU; no moment is taken for granted.

The Tiny Miracles Foundation strongly believes that parents and family caregivers need access to every moment in the NICU and strongly supports the proposed resolution as we know the critical role that parents and family caregivers play in patient care in the NICU.

In what service industry does the person paying for the service get treated like a visitor or a non-human? None. So parents and caregivers are essential members of the NICU team and without them facilities do not get access to the best medicine possible in the form of a Mother's breastmilk. To date, it truly is the best medicine for the baby. No other treatment can do what it does. Add to this, the baby knew the parents first and foremost unless there is a situation surrounding adoption. And because of this, the parents knew that baby first and can provide in the moment comfort to the infant. That affects the infant's ability to function, fight infection, and so much more. **As some one that advocates on the behalf of Adult Premies, I can tell you the ramifications of separating families from the baby for whatever time has a truly brutal outcome for that infant and that family.**

We support resolution #36, "Parents and Family Caregivers are Integral Members of the Patient Care Team". As a national nonprofit working with a serious high risk pregnancy complication which is the leading identifiable cause of preterm birth, The PPROM Foundation acknowledges the critical importance of family caregivers in the perinatal and neonatal space. In addition, this inclusion and involvement should continue post discharge. **Ensuring that parents and families are active participants in the interdisciplinary care team results in better outcomes for all involved.**

My daughter was born 3 months premature in 2019. We spent 112 days in the NICU. Having your baby in the NICU is traumatic...walking into the NICU for the first time to see your baby is intimidating. I learned very quickly that I was my daughters voice. I have about 10 years in the medical field so I was not shy voicing what she needed...didn't need...who I felt comfortable with caring for her and certain staff that I did not want caring for her. I feel like the majority of families that are in the NICU are too intimidated and/or scared to speak for their baby. These families should be welcomed with open arms and encouraged to advocate for their babies. Communication between families and staff must be constant and consistent.

FCC Task Force is a modern approach of sharing expertise from NICU parents and NICU providers in the common goal of improving Family Centered Care in NICUs around the world. Each and every family deserves a family centered-family supported experience during their NICU journey. FCC Task Force effortlessly brings the tools, awareness and expertise to anyone who feels passionate about improving the NICU experience for their patients and their families.

As a former NICU mom, I can attest to the integral role that parents and caregivers play in their children's health care team. In the beginning of a NICU stay, medical professionals are often the first to interact with our children, however as we (parents) spend more time with our children in the hospital, we begin to pick up their ticks and tendencies. We learn their mannerisms and their cries are recognizable to us. **As we connect with our children, we begin to establish a connection, a bond. You know the saying, a mother's love knows no bounds and its true. We are their greatest advocate. Their fiercest protector. It may take some time to get to that point in the NICU, but being there day in and day out only helps us gain confidence, self-efficacy, and strength to support our children outside of the NICU.**

Parents spend countless hours in the NICU at their baby's bedside and are essential members of their baby's care team. They know their babies better than anyone else and are often the first to recognize when something is wrong.

Shared decision-making is critical in the NICU, where parents and providers must work together to optimize decisions that can have lifelong health implications for the infant. Because things can change so rapidly in a sick newborn, parents need to be at their child's bedside so they can be informed and participate in these vital health decisions.

Bonding during this developmentally fragile newborn period is crucial. Extensive research has shown that for vulnerable newborns, particularly premature and sick newborns, their mother's milk is a lifesaving intervention. Skin to skin time promotes infant growth and healthy developmental milestones. **Limiting parents' access disrupts the nurturing interactions that are necessary for an infant's cognitive development and that are also essential to parents' mental health.**

We need to ensure that all NICU families receive high-quality care by giving parents access to their medically fragile infants. Parents' basic rights to see and care for their own child are infringed upon when they are inaccurately categorized as visitors. Health care providers and parents should work together at local and state levels to assure safe practices that honor the unique situation and needs of sick newborns. The way families experience care in the NICU remains with them for their lifetimes.

Parents and family members are not visitors in the NICU - they are a fundamental part of the NICU ecosystem. Parents need to be an integral extension in the health care decision making and hands on involvement in the care of NICU babies.

I fully support this resolution. Caregivers need education and support while in the NICU. This will improve health outcomes and integrate caregivers into the care team instead of labeling them as visitors.

As a physical therapist providing direct bedside care in NICU for over 20 years, I cannot emphasize enough the importance of including the parents/caregivers in the NICU as true team members. Parents often feel intimidated in the NICU. They sometimes feel "in the way." But in truth, they are the most important people in the NICU. We must change our culture around this and make parents feel that they are needed and wanted in the NICU. Thank you.