

Family Centered Care Taskforce: National NICU Parent Support Organizations: An Essential Partner

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An abundance of research confirms that having a premature or critically ill newborn in the NICU leaves parents at risk for developing acute stress disorder (1,4), posttraumatic stress disorder (1), and postpartum depression (2,3). We also know that enduring a NICU stay can have long-lasting adverse effects on both the child and the parents (11), such as lack of bonding (5), lower breastfeeding rates (7,8), impaired decision-making of the parents (9,11), and may even lead to the neglect or abuse of the child (10).

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On November 15, 2022, the World Health Organization launched new recommendations based on new evidence that has emerged over the years that can improve the care of preterm or low birth-weight infants. (6) Notably, of the eleven new recommendations, five relate specifically to the inclusion of and support for NICU families: recommendation on immediate Kangaroo Mother Care, recommendation on family involvement, recommendation on family support, recommendation on home visits, and best practice statement on parental leave and entitlements.

Commentary (12) on the recommendations published in *The Lancet* on November 15, 2022, stated: *“These recommendations call for a ‘re-positioning of power’ within health systems, allowing the mother and family to take the pivotal role in their baby’s care. Families need to be empowered and supported to take their central place as providers of care for their preterm and LBS infants.”* We would add to this statement that all families in the NICU, regardless of gestational age or birth weight, deserve the same.

“Peer-to-peer support should be central to developing this holistic, individualized support system for parents. Peer support can be defined as ‘the provision of emotional, appraisal and informational assistance by a selected social network member who possesses experiential knowledge of a specific behavior or stress and similar characteristics as the target population’ (13).”

Peer-to-peer support should be central to developing this holistic, individualized support system for parents. Peer support can be defined as ‘the provision of emotional, appraisal and informational assistance by a selected social network member who possesses experiential knowledge of a specific behavior or stress and similar characteristics as the target population’ (13). Peer support has long been recognized and utilized as a proven mental health intervention for various medical conditions such as breast cancer (14), diabetes (15), Post-Traumatic Stress Disorder in military veterans (16), and addiction recovery (17). The evidence for the efficacy and effectiveness of peer-to-peer support in the neonatal intensive care unit is less established; however, as noted in the National Perinatal Association’s Recommendations on Providing Psychosocial Support to NICU Families (18), peer-to-peer support is a “unique form of support that can complement or supplement, but not replace, services provided by professional NICU staff.”

There are several ways in which peer-to-peer support can be implemented and delivered to NICU families, including bedside one-on-one support, in-person support groups, virtual support groups, moderated online messaging forums, and virtual one-on-one support sessions via phone, text, or video conference. Many hospitals have well-organized peer support groups, education, and resources for families that a veteran parent support navigator leads, often in collaboration with NICU staff. Unfortunately, the prevalence of such programs is not ubiquitous. As well, community-based organizations with a national reach exist that can either fill that gap if a unit cannot start or sustain one or become an additional resource to the existing local, in-hospital group.

The NICU Parent Network is a US-based collaborative of over 40 community-based NICU family support organizations, many of which have a national presence. These organizations share key characteristics that may allay NICU staff’s concerns in recom-

mending a national organization that does not have a local presence in their area.

1. Community-based organizations are 501c3, public nonprofits, or small businesses. This distinction is important to note as a level of legal, compliance, and fiscal responsibility must be embedded when running a business to ensure a 501c3 status or Certificate of Good Standing is not revoked.
2. Community-based organizations are not run by or owned by a hospital – though they may still contract with a hospital as a vendor or service provider to provide peer-to-peer support programs, education, and family resources. They are autonomous entities governed by their Board of Directors or leadership team.
3. Peer-to-peer support programs should always be provided through the organization by a trained, veteran NICU or loss parent. The importance of appropriate peer specialist screening and training cannot be understated. Having a NICU or loss experience is not enough to allow a parent to have one-on-one contact with a family currently in crisis. This is for the mental health protection of the mentor and the mentee. Meegan Snyder, co-author of this piece and Director of the Preemie Parent Mentor Program at Graham's Foundation, shares some highlights of their protocol below:

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At Graham's Foundation, I do all screening and training in-house. I am a veteran NICU parent myself and have undergone training as a Trauma-Informed Professional and peer support specialist. Organizations vary in the demarcation point as it relates to the distance a prospective mentor has from their personal experience. For our organization, if they are at least one year from discharge, they can fill out an application that will lead to an interview with the Director.

The interview is one of the most important parts of our mentor screening. Prospective mentors are invited to share their stories with the Director and then listen to the Director share her own story. So much can be learned

from this interaction. The interview is set up this way for multiple reasons, a few of which are: can the parent be an active listener, can they listen to someone else's story and not make comparisons, and it offers an opportunity for the Director to have a first-hand understanding of their current emotional state while sharing their story.

Not all parents that are interviewed will go on to become a mentor. Often the parent may realize they are not ready to be a mentor. If it is decided that the parent is a good fit, they then start the training to become a mentor. The training starts with an online video and quiz and continues throughout their time as mentors via monthly meetings. We firmly believe in continuous learning and the support of our mentors. Our training program is designed to help prepare parents to interact with potential mentees in the best way possible. All our training is conducted virtually as a national organization with mentors across the country. We include topics such as Trauma Informed language, matching etiquette, knowing when a mental health professional should become involved, and more in these monthly meetings.

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4. Community-based organizations often expand their peer-to-peer support services to encompass the maternal healthcare journey from high-risk pregnancy through NICU, loss if it occurs, and post-discharge. This is a gap filled by many national organizations if hospital-run parent peer-support services do not formally extend beyond the baby's discharge from the NICU.
5. Community-based organizations often have deep networks of trained, veteran peer mentors with a wide variety of medical experiences, conditions, and experiences that allow the parent receiving support to be matched with a mentor who can most closely relate to the shared experience. These mentor networks may number from 20 to over 200 trained peer mentors.
6. Community-based organizations are likely equipped to provide services anytime, anywhere, regardless of the parents' location.
7. Community-based organizations often provide a variety of services in addition to peer-to-peer support that may include but are not limited to: counseling by mental health professionals, education through podcasts, webinars, apps, and

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printed materials, essential and emergent needs care packages and devices, financial assistance programs, and others.

8. Community-based organizations will often partner with local support organizations to ensure a holistic support network for the family is established. The overarching goal is for every parent to receive the individualized support, education, and resources they need.

Understanding the importance of peer-to-peer support for NICU families and the key characteristics of a national, community-based organization can enable hospital teams to feel confident in seeking partnerships with such organizations. There are a variety of ways in which these partnerships can be constructed. However, the NICU Parent Network strongly supports the provision of a relationship bound by a contract to define the expectations, roles, responsibilities, and consistency of the relationship clearly and thoroughly. The COVID-19 pandemic highlighted how critical having a contract in place can be as only those organizations in the NPN membership with a Business Associate Agreement were deemed essential by all levels of hospital and NICU administration and therefore did not see an interruption in their ability to provide much-needed services to families. Avoiding the volunteer designation in these instances proved to be a notable differentiation.

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As with any partnership with an entity outside the hospital, it is essential to thoroughly vet the organization, their leadership, and those who provide direct services to the families. Below is a list of questions and recommendations to help determine if an organization is credible, established, and operating as a business. Organizations should be transparent and have no problem providing complete and thorough responses to the following:

1. A 501c3 designation letter from the IRS or a copy of their Certificate of Good Standing from the Secretary of State should be provided.
2. References from clinicians they have partnered with and from families who have received their services.
3. Find out what their processes and programs are to support their mentors to avoid burnout and mitigate vicarious trauma & compassion fatigue.
4. Communication between the organization and unit staff leadership is critical. Ask how often they debrief with their unit point person.
5. Ask how they handle concerns where a mental health professional is needed.

6. Ask what the organization needs from *you* to ensure a successful relationship or partnership.
7. Ask about their screening and training protocols for their peer mentors. Ask what the qualifications are for their mentors to have direct contact with families.
8. Ask what their written policies and agreements are regarding confidentiality, liability, and boundaries with families. Organizations should have policies around social media interaction and privacy for the mentor and the family receiving services.
9. If the organization utilizes a Facebook group or other online community as part of its support services, they should be moderated by trained peer support staff or volunteers.

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HIPAA and fears about privacy and liability are often the number one roadblock for hospitals to connect with, partner with, or refer families to an outside organization. This is another reason the Business Associate Agreement is important, as this contract is the legal document to afford these protections and legal compliance.

Preterm and sick newborns will continue to be admitted to the NICU, and this traumatic life experience will significantly impact families. We must never forget that these infants are new members of families, new citizens of our global community, and precious humans entering life with the odds stacked against them. As professionals in perinatal and maternal-infant health, we must ensure that we fully embrace and put into practice elevating the family as the central and essential member of that baby's care team. As such, we must ensure every family has equitable access to the variety of support, education, and resources available through local and national organizations and programs so that a holistic, individualized support system can be firmly in place for each of them.

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