

NICU Parent-Led

Peer-To-Peer Support Services

POSITION PAPER



Acknowledgments

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Kristen Ezzo - The Tiny Miracles Foundation

Amanda Dickinson - Mighty Miracles Foundation

Special thanks to *Erika Goyer* of the National Perinatal Association for her work with developing the position paper template.

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Peer-to-peer support is critical for all NICU families, by families whose babies are born full term often need individualized, appropriate connections to peer support, especially if there is a specific diagnosis and that support organization exists. It is crucial for these families to connect, because for many, the NICU is truly just the beginning for their difficult journey and that specific support can empower families, forming lifelong connections.

Betsy Pilon, Executive Director
HOPE FOR HIE



Introduction

NICU parents are forced to experience the trauma of having their newborn baby admitted to the hospital instead of bringing them home. Many of these parents have also experienced a traumatic pregnancy and childbirth. These parents can be confused by the myriad of hospital policies and protocols to which they are exposed. Peer support can help these parents navigate hospital systems more effectively, give them a support system of other parents who have experienced a similar journey, and help them feel less isolated. Peer support can also help parents meet their baby's care needs more efficiently, and with greater confidence and hope.

As NICU graduate and bereaved parents, we have well-founded and invaluable knowledge from our lived experiences; therefore, we are the perfect group of experts to discuss such an important topic and advocate for the establishment of such programs.

Every parent of every baby admitted to a Special Care Nursery or Neonatal Intensive Care Unit (NICU) should be offered peer support from a “veteran” NICU parent mentor during their baby’s hospital stay. Ideally, this opportunity would be a part of a NICU’s comprehensive family support program.

The goal of our position paper is to show all Special Care and NICU physicians, nurses, and hospital management that peer-to-peer support services should be offered to each parent once their baby is admitted to the hospital. Hospitals are encouraged to take advantage of services and programs that already exist in their area, or create a program if the former is not an option.

We have included several other sources of information and previous research done on the topic to use as a reference and to support our position.

Please join NPN in sharing our position paper with hospital leadership, mental health advocacy groups, neonatal physicians, bedside nurses, therapists, and policymakers so that we can bring much-needed emotional support to a population of parents who need it.

Jennifer Degl & Stephanie Vaughan

NPN Standards & Review Committee Co-Chairs

Position

The NICU Parent Network (NPN) advocates for the establishment and funding of peer-to-peer support services and peer mentoring programs in all NICUs. To provide consistent support and continuity of care, NICU and follow-up care providers should partner with parent-led peer-to-peer support programs in their community or create their own.

Rationale

- NICU parents have unique psychosocial and mental health needs
- Parents are the primary caregivers for medically-fragile infants
- Addressing these unique mental health needs improves an infant's medical and developmental outcomes and lowers rates of postpartum mood and anxiety disorders (PMADs)
- Peer-to-peer support is a proven mental health intervention
- Peer-to-peer support services contribute to greater parent/patient satisfaction



Leelee Smith Klein, President Emeritus & Parent Peer Mentor with The Tiny Miracles Foundation pictured with her mentee at home, Tamnia, age 18, from Bridgeport with her daughter who was born at 28 weeks at Bridgeport Hospital

Peer Support: Research and Reports from Mental Health America

Peer support has existed in behavioral health for decades. Its rapid growth in recent years is for good reason. Research and experience show that peer support specialists have a transformative effect on both individuals and systems. Peer support has been shown to:

- Improve quality of life
- Improve engagement and satisfaction with services and supports
- Improve whole health, including chronic conditions like diabetes
- Decrease hospitalizations and inpatient days
- Reduce the overall cost of services



Peer support empowers people to make the best decisions for them and to strive towards their goals in their communities. Peers are an essential component of recovery-focused systems and are key across settings and stages of recovery.

[READ A SUMMARY OF THE RESEARCH HERE](#)

(May 2018)

[SEE THEIR COMPREHENSIVE BIBLIOGRAPHY](#)

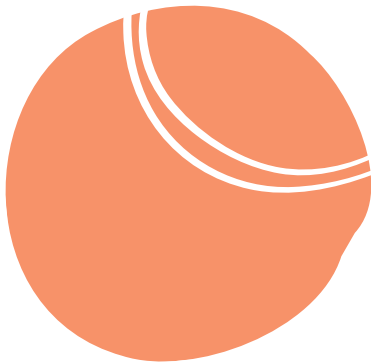
Peer Support: Research and Reports from Institute for Patient- and Family-Centered Care

Peer Support is intentional, personalized, relationship-based, and available as needed. Peer Support offers a real-life, real-time perspective, a view only an experienced patient or family member can provide.

[GLOBAL EVIDENCE FOR PEER SUPPORT: HUMANIZING HEALTH CARE](#)

Report from an international conference hosted by Peers for Progress and the National Council of La Raza

Peer Support presents a unique opportunity for health care planning and management. Clear evidence shows concrete benefits for individuals and systems, including cost-effectiveness. As an important humanizing force in health care, it changes the way we look at health. To bring peer support to diverse populations and settings, the key functions provide a framework for standardization and flexible adaptation. This report sets the course for scalable, feasible implementation that reaches whole populations, engages those too often left behind in health care, improves outcomes as well as quality of life, and reduces unnecessary burden and costs.



When Graham's Foundation was still in its beginning, Heather McKinnis reached out to me after my son Gavin died. We talked for hours and hours. Our talks and emails were the one thing I looked forward to during those early days of grief. They were integral to my survival.

Ashley Naveck Ortiz



Gavin Michael Ortiz
Born at 23 weeks & 6 days

NICU References: Institute for Patient- and Family-Centered Care

Neonatal Center Parent-to-Parent Partnership

Our goal is to make this experience a little easier. Together with the entire staff of the NICU, we offer a circle of caring for you, your family, and your baby.

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Applying Patient and Family-Centered Concepts to Bedside Rounds...

Increasingly, staff and faculty are including patients and families in the process of hospital rounds. In newborn intensive care units (NICU), families can offer their observations, questions, and expertise.

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Newborn Intensive Care

NICU: A parent education and support program. *Advances in Neonatal Care*, 13(2), 115-126. doi:10.1097/ANC.0b013e318285fb5b. Buehler, D. M., Als, H., Duffy ...

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Family Support Network™ of Eastern North Carolina (FSN-ENC) at ...

FSN-ENC started offering peer support to families in the NICU at Vidant Medical Center James and Connie Maynard Children's Hospital, the only Level III ...

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Family Support Network™ of Western North Carolina (FSN-WNC) at ...

Family Support Network™ of Western North Carolina (FSN-WNC) at Mission Children's Hospital. Vidant Medical Center. The Family Support Network™ of ...

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Sample Policies/Guidelines and Other Resources

...Invasive Procedures, and Emergent-Urgent Care Procedures · St. Joseph Mercy Health System—Criteria for Parent's Presence at NICU Medical Interventions/ ...

[CLICK HERE TO VIEW](#)

Changing the Concept of Families as Visitors Bibliography

...participation guidelines in the NICU: The experience of the Colorado consortium of intensive care nurseries. *Neonatal, Paediatric and Child Health Nursing*, 7(2) ...

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The role of peer support in perinatal anxiety and depression

by Jenny Reynolds, Independent Researcher; Celia Suppiah, CEO, Parents 1st; and Camilla Rosan, Development and Impact Manager, National Society for the Prevention of Cruelty to Children (NSPCC).

There is a growing evidence-base for the use of peer support with a wide-range of populations during pregnancy and the early years. This article gives an overview of peer support approaches in parents experiencing anxiety and depression in the perinatal period, drawing on current research and models of best practice.



Articles

Interdisciplinary Recommendations for the Psychosocial Support of NICU Parents.
S L Hall, D J Ryan, J Beatty & L Grubbs. Journal of Perinatology volume 35, pages S9–S13 (2015)

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The Differential Impact of WIC Peer Counseling Programs on Breastfeeding Initiation across the State of Maryland.

Susan M. Gross, PhD, MPH, RD, Amy K. Resnik, MS, RD, CSP, LDN, IBCLC, Caitlin Cross-Barnet, MA, MA, ...First Published August 3, 2009 Research Article

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Support Like a Walking Stick: Parent-Buddy Matching for Language and Culture in the NICU.

Ardal F, Sulman J, Fuller-Thomson E. Neonatal Netw. 2011 Mar-Apr;30(2):89-98.

[CLICK HERE TO VIEW](#)

Peer support for parents of children with chronic disabling conditions: a systematic review of quantitative and qualitative studies.

Val Shilling, Christopher Morris, Jo Thompson-Coon, Obioha Ukoumunne, Morwenna Rogers, Stuart Logan. First published: 19 February 2013

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Peer support during pregnancy and early parenthood: a qualitative study of models and perceptions.

McLeish J, Redshaw M. BMC Pregnancy Childbirth. 2015 Oct 12;15:257. doi: 10.1186/s12884-015-0685-y.

[CLICK HERE TO VIEW](#)

Mothers' accounts of the impact on emotional wellbeing of organised peer support in pregnancy and early parenthood: a qualitative study.

Jenny McLeish and Maggie Redshaw. BMC Pregnancy and Childbirth BMC series – open, inclusive and trusted 201717:28

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Similar Program Design: Case Study - Parent to Parent USA

Parent to Parent USA -

[A PARTNER IN FAMILY INVOLVEMENT: AN INTERVIEW WITH NANCY DIVENERE](#)

Parent to Parent USA - Provides emotional & informational support for families of children who have special needs.

[VISIT WEBSITE](#)

In response to requests from parents and program directors of Parent to Parent programs for efficacy data on Parent to Parent, a participatory action research team of parents and researchers conducted a 3-year national study to determine the effectiveness of parent to parent support for Referred Parents. Parents and researchers worked together to design the study, write the grant application, and carry out this important study involving 400 parents nationally. George Singer, PhD, was the Director of the study (later becoming a P2P USA Board Member). The results indicated that parent to parent support increases parents' acceptance of their situation and their sense of being able to cope.

Moreover, parent to parent support helps parents to make progress on the need they present when they first contact a Parent to Parent program. Over 80% of the parents found parent to parent support to be helpful. In fact, the data indicated a direct correlation between the number of contacts Referred Parents had with their Supporting Parent and how satisfied referred parents were with the support they received; and, the greater the number of contacts, the greater their satisfaction. Interviews with parents suggest that the kind of support Parent to Parent offers is unique and cannot come from any other source. Based upon this significant data, the research team recommended that parent to parent support should be an essential component of a comprehensive family support system.

Based on this national study, Parent to Parent USA endorses and promotes the following evidence-based practices. View the following in PDF format:

P2P USA ENDORSED PROGRAM PRACTICES – SUMMARY

P2P USA ENDORSED PROGRAM PRACTICES – DETAILED

P2P USA ENDORSED PROGRAM PRACTICES FOR SUPPORT PARENT RECRUITING AND TRAINING

P2P USA ENDORSED PRACTICES FOR MATCHING AND FOLLOW-UP

NEWLY PUBLISHED RESEARCH: P2P SUPPORT PROVIDERS: HOW RECRUITS ARE IDENTIFIED

Recommendations: American Academy of Pediatrics

THE PEDIATRICIAN'S ROLE IN FAMILY SUPPORT AND FAMILY SUPPORT PROGRAMS

PATIENT- AND FAMILY-CENTERED CARE AND THE PEDIATRICIAN'S ROLE

Recommendations: NICU Parent Network & National Perinatal Association

As a contributing member of the National Perinatal Association's workgroup to develop Interdisciplinary Recommendations on Psychosocial Support for NICU Families, the NICU Parent Network fully supports the following recommendations: <https://www.nature.com/articles/jp2015143>

VIEW ARTICLE

Every parent of every baby admitted to a Special Care Nursery or NICU should be offered peer support from a 'veteran' NICU parent mentor during their baby's hospital stay. Ideally, this opportunity would be a part of a NICU's comprehensive family support program.

While in-person peer support during the baby's hospital stay may be viewed as best practice, peer support can be offered to parents in a variety of different ways including email or phone support, virtual group support, or through an online community support site for NICU families.

Peer support in any form is best started in the antepartum period when appropriate (as when mothers are hospitalized during the antepartum period), continued through the baby's NICU stay, as well as after baby's discharge from the NICU. Having a consistent peer mentor throughout a NICU parent's journey may be desirable.

Parents whose baby dies should be offered the opportunity to be paired with a bereavement mentor who has also experienced a neonatal loss of similar circumstances.

Peer support is one element of a comprehensive family support program. Other elements should include:

- a. An institutional and administrative champion for peer and family support;
- b. A facilitator/coordinator who could be:
 - i. A hospital employee (psychologist, social worker, nurse, pastoral care, physician),
 - ii. A trained parent and/or family support specialist,
 - iii. A former NICU parent or volunteer from one of the many non-profit peer-to-peer parent support organizations across the country;
- c. A menu of types of support available (individual and/or group in-person support, email, phone, and online support);
- d. Parent education classes and written materials, as well as social activities;
- e. Staff education to promote understanding of NICU families' psychosocial needs, family-centered care practices, and methods of communicating and providing support (see 'Recommendations for enhancing psychosocial support of NICU parents through staff education and support', this issue).



It is so important for parents to understand that they are not at fault. Having a preemie is life-changing. Remember to take it one day at a time and ask for help, especially from a trained peer mentor, whenever you feel you need it.

*Ashley Randolph, President
GLO PREMIES*


It is imperative that any family support program that utilizes peer volunteers should provide evidence-based training in peer support to the volunteers to ensure that they are capable of carrying out the peer support role in a responsible and culturally sensitive way that is fully compliant with both Health Insurance Portability and Accountability Act (HIPAA) regulations and hospital policies.

In NICUs without the resources to develop a local and comprehensive family support program of their own, parents should be referred to regional or national parent support organizations that have been evaluated by their NICU staff.

Peer support organizations working with NICU families should consider offering support services to members of the baby's family including siblings, grandparents, and others, as needed and desired.

 nicuparentnetwork.org

 connect@nicuparentnetwork.org

 (601) 345-1772



Appendix

PAGE 3

Read a summary of the research here. (May 2018)

<http://www.mentalhealthamerica.net/sites/default/files/Evidence%20for%20Peer%20Support%20May%202018.pdf>

See their comprehensive bibliography.

<http://www.mentalhealthamerica.net/conditions/peer-support-research-and-reports>

Global evidence for peer support humanizing health care

<http://www.ipfcc.org/bestpractices/global-evidence-for-peer-support.pdf>

PAGE 4

Neonatal Center Parent-to-Parent Partnership

www.ipfcc.org/bestpractices/helen-devos-neonatal-ppp.pdf

Applying Patient and Family-Centered Concepts to Bedside Rounds...

www.ipfcc.org/resources/PH_RD_Applying_PFCC_Rounds_NIC.pdf

Newborn Intensive Care

www.ipfcc.org/resources/BI-Newborn-Intensive-Care.pdf

Family Support Network™ of Eastern North Carolina (FSN-ENC) at ...

www.ipfcc.org/bestpractices/profile-vidant.html

Family Support Network™ of Western North Carolina (FSN-WNC) at ...

www.ipfcc.org/bestpractices/profile-fsn-wnc.html

Sample Policies/Guidelines and Other Resources

<http://www.ipfcc.org/bestpractices/changing-policies-sample-guidelines.html>

Changing the Concept of Families as Visitors Bibliography

<http://www.ipfcc.org/bestpractices/Changing-the-Concept-of-Families-as-Visitors-Bibliography.pdf>

PAGE 5

Interdisciplinary Recommendations for the Psychosocial Support of NICU Parents.

[http://nationalperinatal.org/resources/Documents/JP%20Psychosocial%20Support%20SupplementFinal%20\(1\).pdf](http://nationalperinatal.org/resources/Documents/JP%20Psychosocial%20Support%20SupplementFinal%20(1).pdf)

The Differential Impact of WIC Peer Counseling Programs on Breastfeeding Initiation across the State of Maryland.

<https://doi.org/10.1177/0890334409342070>

Support Like a Walking Stick: Parent-Buddy Matching for Language and Culture in the NICU.

<http://www.academyofneonatalnursing.org/WritingCenter/SupportLikeAWalkingStick.pdf>

Peer support for parents of children with chronic disabling conditions: a systematic review of quantitative and qualitative studies.

<https://doi.org/10.1111/dmcn.12091>

Peer support during pregnancy and early parenthood: a qualitative study of models and perceptions.

<https://www.ncbi.nlm.nih.gov/pubmed/26459281>

Mothers' accounts of the impact on emotional wellbeing of organised peer support in pregnancy and early parenthood

<https://doi.org/10.1186/s12884-017-1220-0>

Parent to Parent USA - A Partner in Family Involvement: An Interview with Nancy DiVenere

<http://www.amchp.org/AboutAMCHP/Newsletters/Pulse/Archive/2011/October2011/Pages/Feature3.aspx>

Parent to Parent USA

<http://www.p2pusa.org/>

PAGE 6

P2P USA Endorsed Program Practices – Summary

<http://www.p2pusa.org/wp-content/uploads/2017/03/Summary.EndorsedPractices.2.07.17.pdf>

P2P USA Endorsed Program Practices – Detailed

<http://www.p2pusa.org/wp-content/uploads/2017/03/EndorsedPractices.2.07.17.pdf>

P2P USA Endorsed Practices for Support Parent Recruiting and Training

<http://www.p2pusa.org/wp-content/uploads/2017/03/Support-Parents.Recruiting-and-Training.2.07.17.pdf>

P2P USA Endorsed Practices for Matching and Follow-up

<http://www.p2pusa.org/wp-content/uploads/2016/01/Endorsed-Practices-for-Matching-and-Follow-up.pdf>

Newly Published Research: P2P Support Providers: How recruits are identified

http://www.p2pusa.org/wp-content/uploads/2015/12/Dodds_et_al-2017-Journal_of_Applied_Research_in_Intellectual_Disabilitie.pdf

The Pediatrician's Role in Family Support and Family Support Programs

<https://pediatrics.aappublications.org/content/128/6/e1680>

Patient- and Family-Centered Care and the Pediatrician's Role

<https://pediatrics.aappublications.org/content/129/2/394>

PAGE 7

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<https://www.nature.com/articles/jp2015143>

