

Gravens By Design: The Importance of NICU Discharge Planning Guidelines and Standards

Vincent C. Smith, MD, MPH; Kristy Love; Erika Goyer, BA

“They, however, should have had a plan because the American Academy of Pediatrics (AAP) has set clear expectations. The AAP recommends that the transition to home occur when the infant achieves physiologic maturity, and there is an active program for parental involvement and preparation for care of the infant at home. (1)”

Background

When families reflect upon their experiences preparing to transition from the NICU (Neonatal Intensive Care Unit) to home, most families generally do not use the terms “joyful,” “easy,” “perfect,” or “stress-free.” More often, families use terms like “abrupt,” “sudden,” “lonely,” and “scary.” In truth, some families wonder if they even had a discharge preparation plan at all.

They, however, should have had a plan because the American Academy of Pediatrics (AAP) has set clear expectations. The AAP recommends that the transition to home occur when the infant achieves physiologic maturity, and there is an active program for parental involvement and preparation for care of the infant at home. (1) The AAP does not, however, provide much detail about the program for parental preparation. This may be the crux of the issue or source of the problem. While we know that parents need to be prepared, we have not put programs in place to prepare them.

“The National Perinatal Association (NPA) hopes to help fill that gap. NPA formed an interdisciplinary work group that developed universal, adaptable, evidence-informed guidelines for NICU discharge preparation and transition planning in response to the unmet need for a program for thoughtful discharge preparation and transition planning.”

The National Perinatal Association (NPA) hopes to help fill that gap. NPA formed an interdisciplinary work group that devel-

oped universal, adaptable, evidence-informed guidelines for NICU discharge preparation and transition planning in response to the unmet need for a program for thoughtful discharge preparation and transition planning. NPA hopes that NICU families and staff will find the guidelines beneficial, useful, and pertinent. Ideally, these guidelines will assist staff in providing clear and consistent messages of both action and guidance for parents and families and provide a systematic approach to required tasks and advanced planning of discharge teaching prior to their anticipated discharge. NPA hopes these guidelines will provide **more uniformity in discharge preparation and reduce uncertainty and stress with the discharge preparation and transition planning process.**

Using the guidelines

Smith et al. (2013) defined NICU discharge readiness as “the attainment of technical skills and knowledge, emotional comfort, and confidence with infant care by the infant’s primary caregivers at the time of discharge”; and NICU discharge preparation as “the process of facilitating discharge readiness to make the transition from the NICU to home successfully.” (2) Discharge readiness is the desired outcome, and discharge preparation is the process.

“We understand that it is impossible to create a comprehensive discharge preparation and transition planning program that will work for every family in every NICU setting. Instead, we propose guidelines and recommendations that focus on content and process.”

We understand that it is impossible to create a comprehensive discharge preparation and transition planning program that will work for every family in every NICU setting. Instead, we propose guidelines and recommendations that focus on content and process. **We strived to create recommendations that are both general and adaptable while also being specific and actionable.** Each NICU’s implementation of this guidance will depend on the unique makeup and skills of their team and the availability of local programs and resources. Our guidelines are divided into the following sections:

- **Basic information** that emphasizes the content that every family will need, without taking into account each family’s and infant’s specific needs
 - o Discharge Education
 - Discharge Education Content
 - Family Preferred Educational Modality
 - Family Comprehension

- Timing Of Discharge Education
- Family Education Support
- o Discharge Planning Tools
 - Discharge Summary
 - NICU Roadmap
 - Discharge Planning Folder
 - Written Discharge Information
 - Supplemental Discharge Educational Materials
 - Journal
- o Discharge Planning Team
 - Infant Care Givers
 - Consistent Nursing Provider
 - Family Support People
 - Discharge Coordinator/Discharge Planner/Case Manager
 - Sibling Resources
- o Discharge Planning Process
 - Discharge Planning Timing
 - Discharge Planning Meeting
 - Discharge Planning Goals
- **Anticipatory guidance** in the context of NICU discharge preparation and transition planning--refers to helping the family develop a realistic idea of what their life will be like with their infant. This means in the immediate future following discharge as well as over their life course
 - o Home and Family Life
 - o Infant Behavior
 - o Coping with a Crying Infant
 - o Emergency Planning
 - o Parental Mental Health
 - o Paying for a NICU Stay
- **Family and Home Needs Assessment** reviews family and home needs assessment to inform discharge planning
 - o Family and Home Needs Assessment Process
 - o Family And Home Needs Assessment Content
- **Transfer and Coordination of Care** deliberate transfer and coordination of care from NICU providers to community providers and the medical home
 - o Primary Care Involvement
 - o Primary Care Contact
 - o NICU Contact with the Family After Discharge
 - o Parental Mental Health
 - o Community Resources
 - o Community Notification
- **Other Important Considerations** examines some important topics to consider when doing discharge planning. We are mindful of families who are

- o Limited English proficient
- o Active military
- o Lesbian, gay, bisexual, transgender, queer, intersex, and asexual (LGBTQIA+)-headed
- o Disabled
- o Culturally and/or philosophically distinct in ways that need to be considered in NICU discharge transition planning

Implications

This is a call to action. In implementing these guidelines, we need to address diversity, equity, inclusion, accessibility, and belonging. That may mean that policies need to change. Community connections may need to be adapted. "How we are" may need to change.

Conclusion

We know that parents whose babies are admitted to the neonatal intensive care unit (NICU) need support. Whether their baby's stay is brief or long, uncomplicated or complex, a NICU stay changes how they care for their infant and how they will parent once they are discharged.

If parents are going to become confident and competent caregivers for their infants, they need guidance and support. The education they receive while in the NICU cannot be limited to performing caregiving tasks. It has to expand to meet their need to become a parent to a medically-fragile child. It has to meet their social and emotional needs. It must welcome them into a community of parents and providers. This is what a smart, timely, coordinated NICU discharge preparation and transition planning program implemented by an interdisciplinary NICU team can deliver.

"If parents are going to become confident and competent caregivers for their infants, they need guidance and support. The education they receive while in the NICU cannot be limited to performing caregiving tasks. It has to expand to meet their need to become a parent to a medically-fragile child. It has to meet their social and emotional needs."

The guidelines are available as a supplement in the *Journal of Perinatology* and on the NPA website <https://www.nationalperinatal.org/>

We invite you to contribute to this effort. Have you developed policies and strategies that have improved the discharge process in your NICU? Do you know about programs and resources that are underutilized? Do you have insights that can improve the outcome for babies and families? We want to know. Please email us and contribute to a growing body of evidence-informed interventions.

Contact Dr. Vincent C. Smith and Erika Goyer, NICU Family Advocate, at egoyer@nationalperinatal.org

Coming soon: NICUtohome.org is your source for the tools and information you need to put the Interdisciplinary Guidelines and Recommendations for NICU Discharge Preparation and Transition Planning into action.

References:

1. American Academy of Pediatrics Committee on Fetus and Newborn. *Pediatrics*. 2008;122(5):1119-26
2. Smith VC, Hwang SS, Dukhovny D, Young S, Pursley DM. Neonatal intensive care unit discharge preparation, family readiness and infant outcomes: connecting the dots. *J Perinatol* 2013 Jun;33(6):415-21.

Special Thanks to Our Steering Committee: Vincent C. Smith, MD, MPH (Chair), Kristy Love, Erin Armknecht, BA, Patti Bridges, MSW, LCSW, Joy Browne, Ph.D., PCNS, IMH-E (IV), Brigitte Desport, DPS, ATP, OTR/L, Jenene Craig PhD, MBA, OTR/L, Heidi Gates, RN, Cristal Grogan, Carol Jaeger, DNP, RN, Trudi Murch Ph.D., CCC-SLP, Heather Cohen Padratzik, MHA, JD, Cuyler Romeo, M.O.T., OTR, SCFES, CLC, Betty Vohr, MD, Tiffany N Willis, PsyD, Julia Yeary, LCSW, IMH-E®

Sponsorship: The funding for the discharge guidelines was provided to National Perinatal Association by private donations and supported by an educational grant provided by Sobi.

Disclosure: The authors have no conflicts of interest

NT



Corresponding Author



Vincent C. Smith, MD, MPH
Professor of Pediatrics
Boston University, School of Medicine
Boston Medical Center
Boston, MA
(617) 414-3989 (T)
(617) 414-3833 (F)
Email: Vincent.smith@bmc.org



Erika Goyer, BA
Family Advocate
National Perinatal Association
Email: egoyer@nationalperinatal.org



Kristy Love
Executive Director
National Perinatal Association (NPA)
Email: klove@nationalperinatal.org