

Interdisciplinary Guidelines and Recommendations for NICU Discharge Preparation and Transition Planning



Having your baby admitted to the neonatal intensive care unit (NICU) to receive critical care is inherently traumatic. While the rates of preterm birth and other complications mean that more than 1 in 10 births in the United States will require a NICU admission,¹ few families anticipate their baby's birth will become a medical emergency - and even fewer are familiar with the kind of care the NICU provides. Once a baby is admitted, however, we must remember that **our goal is not just to send a baby home healthier than when they arrived, it is to send them home to a family that is empowered and prepared.**

Background:

The American Academy of Pediatrics recommends the **transition from the NICU to home occur when an infant achieves physiologic stability and there is an active program for parental involvement and preparation for care of the infant at home,**² meaning the timing of a NICU discharge is primarily based on the physiologic maturity of the infant. Discharge planning also includes the assurance that arrangements for outpatient follow up have been completed and that the family has received the necessary teaching and training required to care for their baby and has demonstrated mastery of essential knowledge and skills. Adequate parent education can reduce the risk of readmission by ensuring that parents seek medical attention appropriately, administer medications and other therapies correctly, and show confidence in the home management of non-acute medical problems.² Still, there has only been limited guidance offered on what the content of a comprehensive discharge planning program for the family should be.^{3,4}

NICU Discharge Readiness – Process and Desired Outcome:

NICU discharge readiness is 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.⁴ NICU discharge preparation is the process of facilitating discharge readiness to successfully make the

transition from the NICU to home.⁴ **Discharge preparation is the process. Discharge readiness is the desired outcome.**⁴ Content for a comprehensive NICU discharge preparation program includes all of the following:

- Well-defined discharge teaching philosophy
- Structured education program
- Defined curriculum
- Family assessment of discharge readiness
- Process for the transition of care to a medical home

National Perinatal Association – Educate. Advocate. Integrate.

The National Perinatal Association (NPA) is an interdisciplinary organization and a leading voice in perinatal care in the United States. Our mission is to bring parents and professionals together to advocate for better policies and care practices.

In response to the unmet need for national guidelines for NICU discharge preparation and transition planning, in 2017 NPA convened a workgroup with the goal of creating comprehensive guidelines that **reflect the best available evidence** from across disciplines and are **informed by families' experiences**.

The process began with an **environmental scan** that reviewed existing standards for NICU discharge preparation. The work group then **collected and collated existing standards** and **conducted a literature review** of published medical and nursing literature related to the topic. The environmental scan became the basis to draft **evidence-based, multidisciplinary, and consensus guidelines**. Then the work group **determined where consensus exists, recognized differences in practice, identified gaps** with no guidelines available, and **created a course of action to address the gaps**.

In June 2019, the NPA hosted a national summit with content experts to review the draft guidelines created by the work group. Prior to the summit, the content experts were divided into four topic-based groups - **family and home assessments, special circumstances, support systems, and transfer and/or coordination of care**. Each group of content experts were given the following questions to consider as they reviewed the draft guidelines:

- Is the content **appropriate**?
- Is the content **complete**? Or is there information missing?

- Are the recommendations **appropriate, practical, and actionable**?
- Are the recommendations **clear and concise**?
- Are the recommendations **comprehensive and complete**?

The summit convened **sixteen multidisciplinary experts representing fourteen different organizations**. During the summit, the content experts reviewed their assigned sections of the guidelines. At the end of the summit, each group of content experts produced a report and devised next steps for the draft guidelines. Then a smaller, select group of content experts **verified each reference** associated with the guidelines from the original article or guideline and **assessed the level of evidence** for each item.

In January 2021, the NPA hosted a **second national summit of content experts to review the revised guidelines**. The summit was attended by twenty-two multidisciplinary experts representing nineteen organizations. Similar to the first summit, the content experts were assigned to one of five topic-based groups. During the summit, the content experts reviewed their assigned sections of the guidelines with the same questions for discussion as the first summit. At the end of the summit, each group of content experts produced a report and identified next steps for the draft guidelines. These reports were used to inform a final editorial review and create the final version of the guidelines for publication.

Our Vision

Upon publication of our work in the *Journal of Perinatology*, **NPA hopes that the readers will find the *Interdisciplinary Guidelines and Recommendations for NICU Discharge Preparation and Transition Planning* to be pertinent, useful, and beneficial**. We want these guidelines to facilitate and ensure **consistent and efficient comprehensive discharge preparation and transition planning** for NICU infants and their families. Ideally, these guidelines will assist providers in providing clear and consistent messages of both action and guidance for parents and families - as well as provide a systematic approach to required tasks and advanced planning of discharge teaching prior to anticipated discharge. Our desire is that these guidelines will provide **more uniformity in discharge preparation**, and consequently, **reduce uncertainty and stress with the discharge preparation and transition planning process**.

We quote the words of Heather Cohen Padratzick, author, workgroup member, and mother to Owen who was born at 28-weeks gestation and spent 81 days in the NICU, **“These discharge guidelines include a social-emotional component that is extremely necessary and important for parents of**

preemies and medically-complex infants. Hospitals, physicians, and staff should recognize and address the potential emotional toll these transitions and experiences take on parents. Recognition of this - and follow up with caretakers as necessary - will allow these individuals to be better parents in the long term. “

Going home from the NICU should be a time of joyous celebration. We hope these guidelines ensure that discharge planning and teaching occur in a timely, organized, and consistent manner, thereby improving family and staff satisfaction, as well as patient care. Families and babies deserve nothing less.

Special Thanks to Our Steering Committee

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Coming in 2022, 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

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2. American Academy of Pediatrics Committee on Fetus and Newborn. Hospital discharge of the high-risk neonate. *Pediatrics*. 2008 Nov;122(5):1119-26.
3. Sheikh L, O'Brien M, McCluskey-Fawcett K. Parent preparation for the NICU-to-home transition: staff and parent perceptions. *Children's Health Care*. 1993 Jul 1;22(3):227-39.
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Executive Summary of the Interdisciplinary Guidelines and Recommendations for NICU Discharge Preparation and Transition Planning

While we know that a NICU stay is traumatic for most parents, the consequences of a family's time spent in the NICU do not need to be negative ones. **Supportive NICU teams can use the time a family is in the NICU to engage in a well-designed discharge preparation and transition planning program.**

These programs can have a lasting positive impact on both the infant's health and the family's wellbeing.

The foundation for these guidelines and recommendations is based on existing literature, practice, and policy. Given the range of topics we cover, in some situations there is no published literature specific to a recommendation. In some situations, we relied on the lived experiences of families and providers to inform our recommendations. While there may not be supporting references for some of these recommendations, all of the recommendations are based on expert opinion and consensus.

Our guidelines are divided into the following sections:

- Basic Information
- Anticipatory Guidance
- Family and Home Needs Assessment
- Transfer and Coordination of Care
- Other Important Considerations

Each section includes brief introductory comments, followed by the text of the guidelines and recommendations in table format. After each table, there may be further details or descriptions that support a guideline or recommendation.

Using the Guidelines

It is impossible to create a comprehensive discharge preparation and transition planning program that will work for every family in every NICU setting. Rather, what we propose are 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 be dependent on the unique makeup and skills of their team, as well as the availability of local programs and resources.

Basic Information

The content of the first section emphasizes basic information that every family will need, without taking into consideration each family's and infant's specific, unique needs. In other words, a comprehensive discharge preparation and transition program must consider the following:

Discharge Education

- discharge education content
- family's preferred educational modality
- family comprehension
- timing of discharge education
- family education support

Discharge Planning Tools

- discharge summary
- NICU roadmap
- discharge planning folder
- written discharge information
- supplemental discharge educational materials
- journal

Discharge Planning Team

- infant care givers
- consistent nursing provider
- family support people
- discharge coordinator/discharge planner/case manager
- sibling resources

Discharge Planning Process

- discharge planning timing
- discharge planning meeting
- discharge planning goals

Educational Philosophy

Anticipatory Guidance

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.

Home and Family Life

Infant Behavior

Coping with a Crying Infant

Emergency Planning

Parental Mental Health

Paying for a NICU Stay

Family And Home Needs Assessment

This section discusses family and home needs assessment to inform discharge planning.

Family and Home Needs Assessment Process

Family And Home Needs Assessment Content

- family living arrangement assessment
- home supplies assessment
- home assessment
- transportation assessment
- childcare needs
- nutrition assistance
- social support needs
- family coping style
- parental mental health
- social or safety concerns

Transfer and Coordination of Care

This section discusses transfer and coordination of care from NICU providers to community providers and the medical home.

- Primary Care Involvement
- Primary Care Contact
- NICU Contact with the Family After Discharge
- Parental Mental Health
- Community Resources
- Community Notification

Other Important Considerations

This section discusses some important topics to consider when doing discharge planning. We are mindful of families who are: limited English proficient, active military, lesbian, gay, bisexual, transgender, queer, intersex, and asexual (LGBTQIA+) headed, disabled, and/or culturally and/or philosophically distinct in ways that need to be considered in NICU discharge transition planning.

Families with Limited English Proficiency

- interpreter use
- family members used as interpreters
- patient-related information
- computer translation services
- hospital navigation
- social support
- primary care involvement
- parental mental health

Military Families

- follow up considerations
- primary care contact
- discharge summary
- support programs
- home visitations
- TRICARE Insurance

LGBTQIA+ Headed Families

- inclusive culture
- parental rights

Parents with Disabilities

- family literacy
- accessibility
- home environment
- caregiver ability

Families with Distinct Cultural and/or Philosophical Expectations

- family belief systems
- family support people
- cultural practice
- community resources

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 can not be limited to how to perform 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.