

A Comprehensive Approach to NICU Discharge Preparation and Transition Planning:

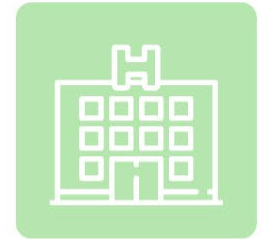
Supporting families on their journey home

The Importance of NICU
Discharge Planning Guidelines
and Standards

Vincent C. Smith, MD MPH

Homeward Bound Initiative

October 18, 2023



Disclosure

- Vincent C. Smith has no financial disclosures that are relevant to this discussion

Publication of this supplement is sponsored by National Perinatal Association (NPA).

The funding for this publication was provided to NPA by private donations and supported by an educational grant provided by Sobi.

The funding for implementation this project is provided to NPA by AngelEye Health.

Objectives

- Explain the importance of NICU discharge preparation and transition planning
- Describe the NPA guidelines for NICU discharge preparation and transition planning
- Identify step one can do locally to begin a discharge planning program

TODAY'S SESSION

What to expect.

INTRODUCTION

- Discharge Readiness
 - Discharge Preparation
-

*NPA guidelines for
NICU discharge
preparation and
transition planning*

- Development
- Content Purpose

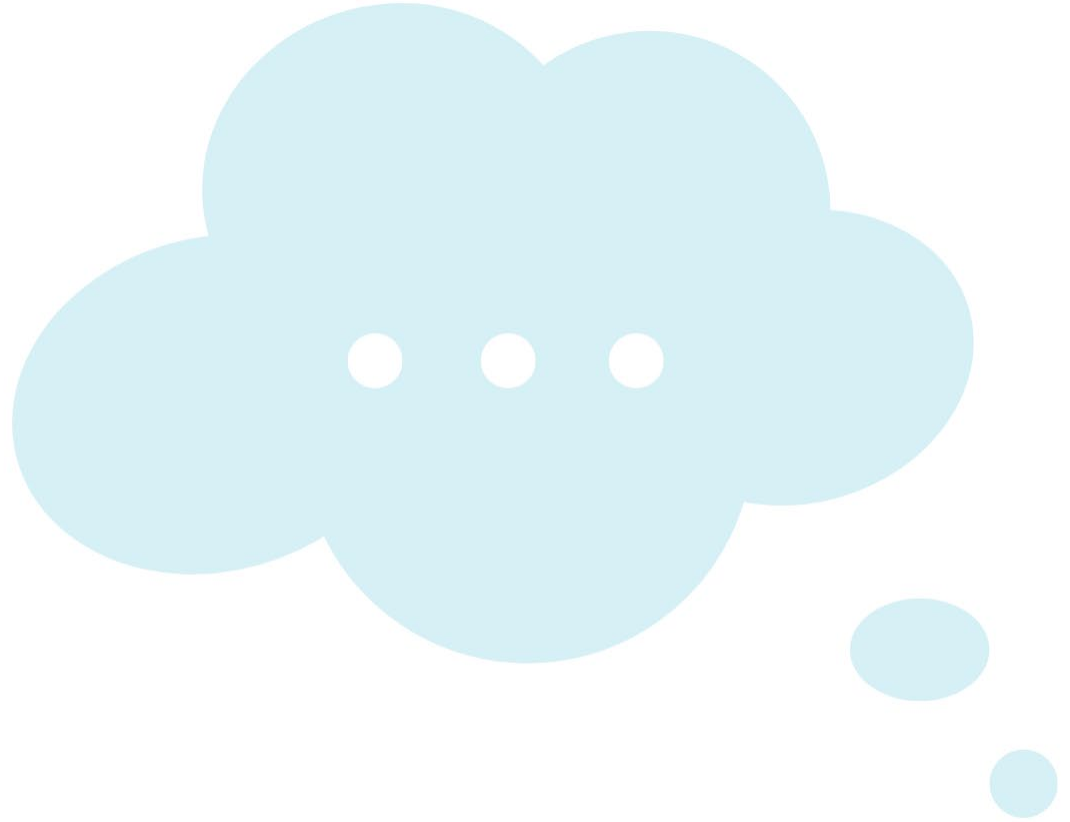
*Implementation of
guidelines*

Call to Action

The Importance of NICU Discharge Preparation and Transition Planning



What word
or phrase
best
describes
your NICU
discharge
experience?

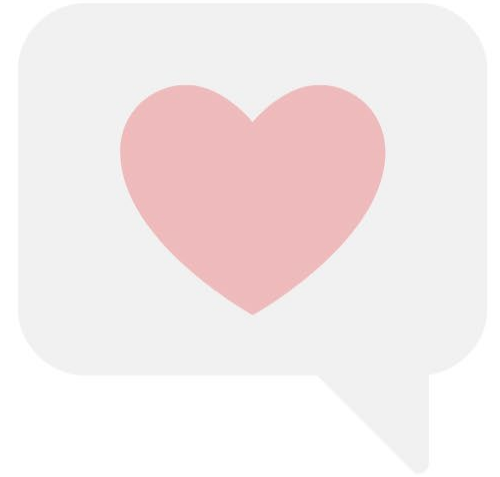


Was it...

EASY

joyful

perfect



Was it...

quick...
sudden

scary

*&#!

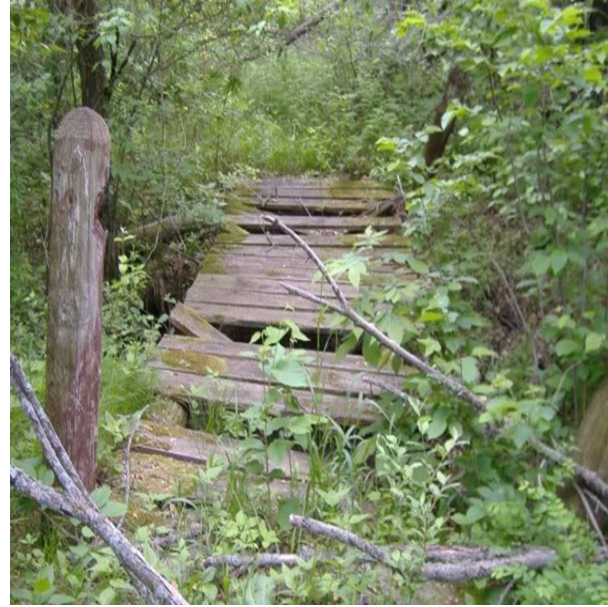
LONELY



“It is like being put out on the ocean on a raft without a sail, a rudder, or oars.”

Goyer, E. (2014). Personal communication, March 25, 2014

NICU Discharge: Parent Perspective



NICU discharge is really a transition from one team to another

WAIT...



Did we
have a
plan?

Discharge Readiness & Discharge Preparation



Discharge readiness

is the desired outcome.



Discharge preparation

is the process.



NICU Discharge Readiness

is the attainment of

- technical skills and knowledge
- emotional comfort
- confidence with infant care

by the primary caregivers at the time of discharge.

NICU Discharge Preparation

is the process of facilitating
discharge readiness

to successfully
make the transition
from the NICU to home.



Why is the transition important?

Discharge Readiness



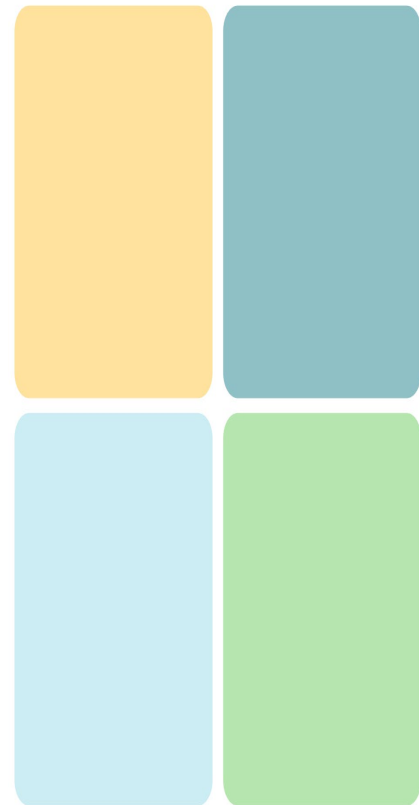
Less ready parents had more post-discharge difficulties

Newborns' parents who are perceived either by themselves or their providers as less prepared for discharge experience more difficulty post-discharge

-Splingaire JM. Readiness for Hospital Discharge: Predictors and Outcomes in NICU Parents Paper presented at: Sigma Theta Tau International 38th Biennial Convention - Scientific Sessions; 2011-10-17, 2005; Indianapolis, IN.

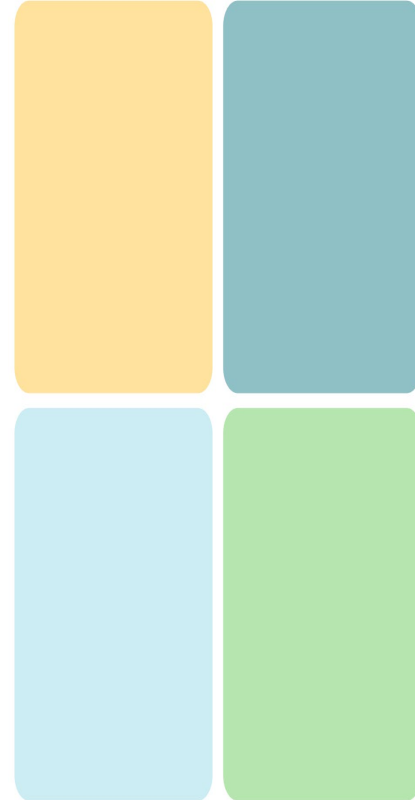
-Bernstein HH, Spino C, Baker A, Slora EJ, Touloukian CL, McCormick MC. Postpartum discharge: do varying perceptions of readiness impact health outcomes? *Ambul Pediatr* 2002;2:388-395.

-Bernstein HH, Spino C, Lalama CM, Finch SA, Wasserman RC, McCormick MC. Unreadiness for Postpartum Discharge Following Healthy Term Pregnancy: Impact on Health Care Use and Outcomes. *Acad Pediatr* 2012; e-pub ahead of print 22 October 2012; pii: S1876-2859(12)00204-5



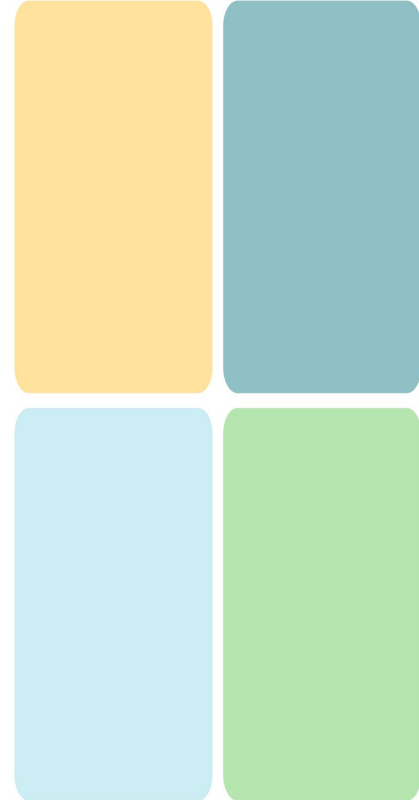
Mothers of term infants who felt less ready for discharge

- Reported greater difficulties with
 - confidence with self-care management abilities
 - coping with challenging family related issues
 - stress, recovery, and self-care
 - obtaining necessary help and emotional support
 - overall adjustment in the first three weeks after discharge



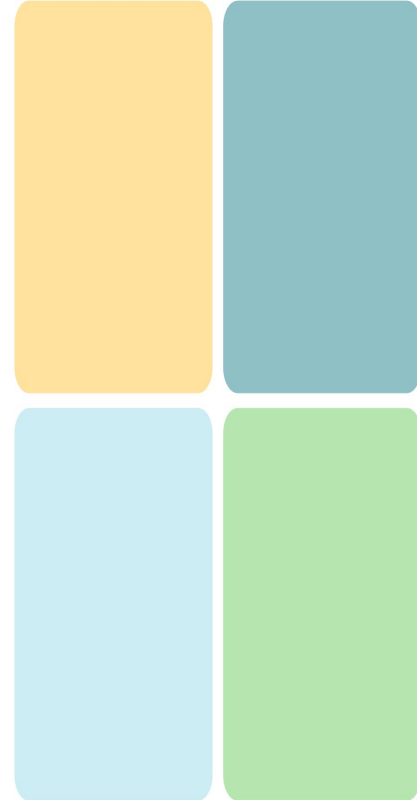
Mothers of term infants who felt less ready for discharge

Even after accounting for maternal sociodemographic, prenatal, perinatal and postpartum factors, discharge unreadiness was still associated with increased infant-related calls to health care providers and infant symptom days



Among families with preterm infants

Lack of readiness for NICU discharge was associated with more infant feeding-related issues in the days after NICU discharge



Risk factors for not being ready for NICU discharge



Higher risk families

- Substance use disorder
- Inadequate prenatal care
- Teenage parents
- History of intimate partner violence
- Marital instability
- Limited socioeconomic resources

-Bernstein HH, Spino C, Lalama CM, Finch SA, Wasserman RC, McCormick MC. Unreadiness for Postpartum Discharge Following Healthy Term Pregnancy: Impact on Health Care Use and Outcomes. *Acad Pediatr* 2012; e-pub ahead of print 22 October 2012; pii: S1876-2859(12)00204-5. doi: 10.1016/j.acap.2012.08.005

-Robison M, Pirak C, Morrell C. Multidisciplinary discharge assessment of the medically and socially high-risk infant. *J Perinat Neonatal Nurs* 2000;13:67-86.

-Miquel-Verges F, Donohue PK, Boss RD. Discharge of infants from NICU to Latino families with limited English proficiency. *J Immigr Minor Health* 2011;13:309-314.

-Glazebrook C, Marlow N, Israel C, Croudace T, Johnson S, White IR et al. Randomised trial of a parenting intervention during neonatal intensive care. *Arch Dis Child Fetal Neonatal Ed* 2007;92:F438-443



Higher risk families

- Mental health issues
 - Anxiety
 - Depression
- Limited English Proficiency
- Lacking function health literacy

-Zelkowitz P, Papageorgiou A, Bardin C, Wang T. Persistent maternal anxiety affects the interaction between mothers and their very low birthweight children at 24 months. *Early Hum Dev* 2009;85:51-58.

-Miquel-Verges F, Donohue PK, Boss RD. Discharge of infants from NICU to Latino families with limited English proficiency. *J Immigr Minor Health* 2011;13:309-314.

-Maroney D. How family centered care affects preterm infants (including late-preterms) and their families. 2010; <http://www.premature-infant.com/centered.pdf> Accessed 12/15/2011, 2011.



Moderate risk families

- Parental history of chronic disease
- First time parents
- Unexplained inadequate prenatal care
- Delivery during non-routine hours
- Infants with complex medical needs
- Intent to breastfeed
- Lacking adequate discharge teaching
- Lacking a skilled teacher

-Bernstein HH, Spino C, Finch S, Wasserman R, Slora E, Lalama C et al. Decision-making for postpartum discharge of 4300 mothers and their healthy infants: the Life Around Newborn Discharge study. *Pediatrics* 2007;120:e391-400

-Robison M, Pirak C, Morrell C. Multidisciplinary discharge assessment of the medically and socially high-risk infant. *J Perinat Neonatal Nurs* 2000;13:67-86.

-Splingaire JM. Readiness for Hospital Discharge: Predictors and Outcomes in NICU Parents Paper presented at: Sigma Theta Tau International 38th Biennial Convention - Scientific Sessions; 2011-10-17, 2005; Indianapolis, IN.

-Weiss ME, Lokken L. Predictors and outcomes of postpartum mothers' perceptions of readiness for discharge after birth. *J Obstet Gynecol Neonatal Nurs*



Why is the transition important?

Discharge Preparation



Homeward Bound Initiative:

NICU's develop a comprehensive, multidisciplinary, family-centered discharge preparation program



Multidisciplinary Discharge Planning Team

- The family
- Bedside clinical nurses
- Physicians
- Mid-level providers
 - (e.g. neonatal advance practice nurses and/or physician assistants)
- Discharge planner
- Case managers
- Social work
- Family support staff
- Other providers as appropriate



Why is the transition important?

Discharge Guidelines



AAP Guidelines

American Academy
of Pediatrics
Committee on
Fetus and Newborn.

Pediatrics. 2008;
122(5):1119-26

American Academy
of Pediatrics



DEDICATED TO THE HEALTH OF ALL CHILDREN™

POLICY STATEMENT

Hospital Discharge of the High-Risk Neonate

Organizational Principles to Guide and
Define the Child Health Care System and/or
Improve the Health of All Children

Committee on Fetus and Newborn

ABSTRACT

This policy statement updates the guidelines on discharge of the high-risk neonate first published by the American Academy of Pediatrics in 1998. As with the earlier document, this statement is based, insofar as possible, on published, scientifically derived information. This updated statement incorporates new knowledge about risks and medical care of the high-risk neonate, the timing of discharge, and planning for care after discharge. It also refers to other American Academy of Pediatrics publications that are relevant to these issues. This statement draws on the previous classification of high-risk infants into 4 categories: (1) the preterm infant; (2) the infant with special health care needs or dependence on technology; (3) the infant at risk because of family issues; and (4) the infant with anticipated early death. The issues of deciding when discharge is appropriate, defining the specific needs for follow-up care, and the process of detailed discharge planning are addressed as they apply in general to all 4 categories; in addition, special attention is directed to the particular issues presented by the 4 individual categories. Recommendations are given to aid in deciding when discharge is appropriate and to ensure that all necessary care will be available and well coordinated after discharge. The need for individualized planning and physician judgment is emphasized. *Pediatrics* 2008;122:1119–1126

INTRODUCTION

The decision of when to discharge an infant from the hospital after a stay in the NICU is complex.¹ This decision is made primarily on the basis of the infant's medical status but is complicated by several factors. These factors include the readiness of families for discharge, differing opinions about what forms of care can be provided at home, and pressures to contain hospital costs by shortening the length of stay. Insofar as possible, determination of the readiness for discharge should be based on peer-reviewed scientific evidence. Shortening the length of a hospital stay may benefit the infant and family by decreasing the period of separation of infant and parents; moreover, the infant may benefit from shortening its exposure to the risks of hospital-acquired morbidity. However, the over-

www.pediatrics.org/cgi/doi/10.1542/peds.2008-2174

[doi:10.1542/peds.2008-2174](https://doi.org/10.1542/peds.2008-2174)

All policy statements from the American Academy of Pediatrics automatically expire 5 years after publication unless reaffirmed, revised, or retired at or before that time.

Key Words

discharge, high risk, premature, neonate, infant

AAP Guidelines

The transition should occur when the **INFANT**

- achieves physiologic maturity
- can coordinate breathing and oral feedings
- ingests adequate volumes and can gain weight
- can maintain a normal body temperature



STABILITY



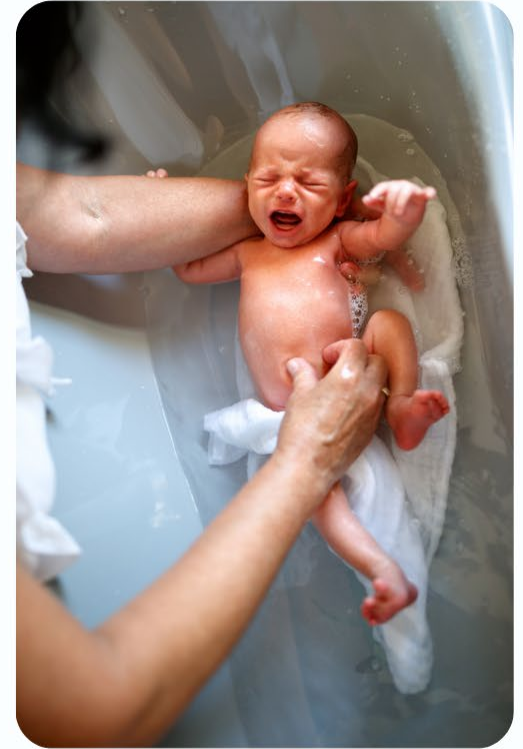
AAP Guidelines

The transition should occur when the

PARENTS

have participated in an active preparatory program for care of the infant at home.

●●●●●●●● PREPARATION



AAP Guidelines

The transition should occur

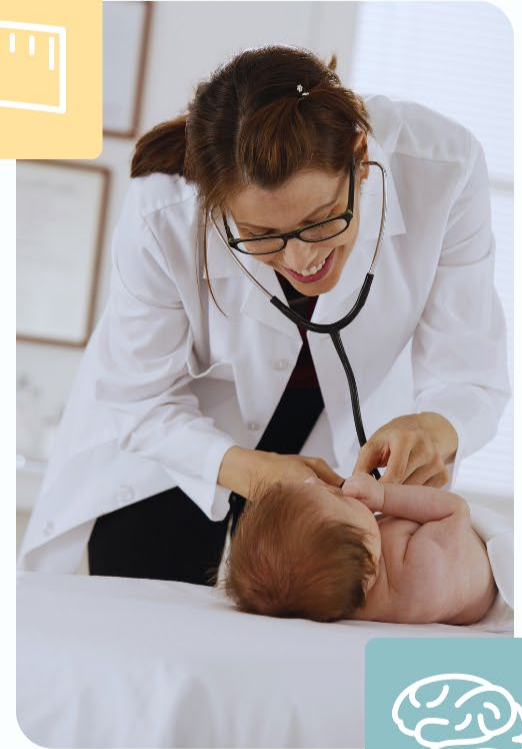
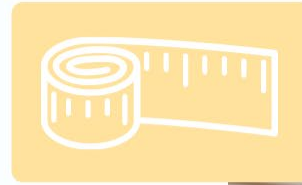


AFTER

- follow-up with a pediatric provider arranged
- a program for tracking infant growth and development established



PLANNING



Published

Interdisciplinary Guidelines and Recommendations

NICU Discharge Preparation and Transition Planning

Spring 2022



www.NICUtoHome.org

NEW Guidance

NICU discharge preparation and transition planning: guidelines and recommendations

Journal of Perinatology.
2022.

Journal of Perinatology

www.nature.com/jp

PERSPECTIVE

NICU discharge preparation and transition planning: foreword

Heather Cohen Padratzki^{1,2} and Kristin Love^{2,3}

© The Author(s), under exclusive licence to Springer Nature America, Inc. 2022

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. While we know 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 plan. These resources can have a lasting positive impact on both the infant's health and the family's wellbeing.

Journal of Perinatology, h

Journal of Perinatology

www.nature.com/jp

www.nature.com/jp

Discharge Preparation and Transition Planning: Editorial

June 2022

Instruction for preparing feeds, tools for preventing and treating infections, information on applying for the Supplemental Nutrition Assistance Program and the Women, Infants and Children program on the timing, safety, and instruction for safety administration of medications is essential to discharge and transition planning.

Resources should be reviewed and revised as needed to ensure they are up to date. Assisting caregivers as they are an essential component of the discharge process.

www.nature.com/jp

INTRODUCTION

Having your baby admitted (NICU) to receive critical care can be a very stressful experience. You may not be able to anticipate their baby's birth and even fewer are family provides. Once there, parents may not be able to come to the NICU for preparation and the first day of a family's NICU that our goal is not just to see them arrive, it is to see them empowered and prepared. Confident and competent care guidance and support. The NICU can not be limited to how to expand to meet their fragile child. It has to meet it to welcome them into a care team that is smart, timely, coordinated and ready to deliver.

HEATHER

Being the parent of a baby is both exciting and terrifying. My son, Owen, was born a fragile, two-pound preemie. After 81 very long days and met milestones, he was finally discharged only 2 days prior. He was finally coming home overwhelmed at the thought of all the wonderful staff that into the strong baby he had heart-apnea monitor to be. After only a 15-min explain

¹Board of National Perinatal Associa

CONSENSUS STATEMENT

NICU discharge preparation and transition planning: guidelines and recommendations

Vincent C. Smith^{1,2}, Kristin Love^{2,3} and Erika Goyer³

© The Author(s), under exclusive licence to Springer Nature America, Inc. 2022

In this section, we present Interdisciplinary Guidelines and Recommendations for Neonatal Intensive Care Unit (NICU) Discharge Preparation and Transition Planning. The foundation for these guidelines and recommendations is based on existing literature, practice, available policy statements, and expert opinions. These guidelines and recommendations are divided into the following sections: Basic Information, Anticipatory Guidance, Family and Home Needs Assessment, Transfer and Coordination of Care, and 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. Our goal was 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. The recommendations based only on expert opinion could be topics for future research.

Journal of Perinatology; <https://doi.org/10.1038/s41372-022-01313-9>

ABOUT THE GUIDELINES

The foundation for these recommendations is based on existing literature, practice, and available policy statements. Given the range of topics we cover, there are some situations where 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 and the readers are requested to note this issue while adapting them into their practices, if they choose to. The recommendations based only on expert opinion could be topics for future research.

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.

NICU setting. Rather, what we propose are guidelines and recommendations that focus on content and process. We strove 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

Discharge planning is the process of working with a family to help them successfully transition from the NICU to home. To do this, each family will need to participate in a comprehensive discharge planning program that has been tailored to their and their infant's specific needs. The first section is basic information and is meant to emphasize content that every family will need, without taking into account each family/infant's specific needs.

In preparing for discharge, your team will have to set clear criteria for what each family and infant need to accomplish to be ready to transition from the NICU to home. The NICU team should work with the family and confirm that the family understands the NICU discharge planning process. It is important that families understand that it is difficult to plan for a specific discharge date because

SUPPORTING REFERENCES

- 1. Timing of discharge. (1, 2, 7, 14, 16-21)
- 2. Discharge. Common infant care topics that families need to know. (1-4, 6, 8, 14, 16, 22-24)
- 3. Your baby to have each day. (1, 2, 7, 14, 16-21)
- 4. Discharge. Common infant care topics that families need to know. (1-4, 6, 8, 14, 16, 22-24)
- 5. Medical or developmental
- 6. (1, 5, 14, 16, 18, 20, 22, 23)
- 7. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 8. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 9. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 10. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 11. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 12. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 13. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 14. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 15. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 16. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 17. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 18. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 19. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 20. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 21. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 22. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 23. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 24. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 25. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 26. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 27. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 28. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 29. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 30. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 31. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 32. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 33. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 34. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 35. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 36. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 37. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 38. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 39. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 40. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 41. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 42. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 43. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 44. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 45. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 46. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 47. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 48. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 49. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 50. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 51. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 52. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 53. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 54. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 55. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 56. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 57. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 58. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 59. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 60. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 61. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 62. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 63. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 64. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 65. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 66. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 67. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 68. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 69. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 70. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 71. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 72. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 73. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 74. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 75. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 76. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 77. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 78. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 79. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 80. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 81. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 82. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 83. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 84. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 85. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 86. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 87. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 88. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 89. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 90. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 91. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 92. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 93. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 94. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 95. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 96. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 97. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 98. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 99. (1, 5, 8, 14, 16, 18, 20, 22, 23)
- 100. (1, 5, 8, 14, 16, 18, 20, 22, 23)



Goals of a discharge preparation program include the following:

- Educating, equipping, and enabling parents to care for their infant
- Addressing health-related social needs of caregivers and family through referral and coordination with community resources
- Arranging for the infant health care and support services families will need after NICU discharge

basic information

anticipatory guidance

family + home
needs assessment

transfer +
coordination of care

- What every family needs to know
- What families need to be ready for
- What day-to-day life looks like
- Who will be a part of the family's team

CONTENTS:

- basic information
- anticipatory guidance
- family and home needs assessment
- transition and coordination of care



basic information

Basic information involves supporting the family to assure they have the skills, knowledge, and confidence needed to make a successful transition

basic information

- goals and timeline
- **CURRICULUM**: skills and knowledge
- discharge education strategy
- discharge supplementary
 - websites
 - digital
 - videos
 - paper
 - folders
 - binders



basic information

- infant care skills
DEMONSTRATION
- Safer Sleep
- car seat installation and safety
- typical and atypical behavior



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

family and home needs assessment

Help families understand their needs and meet them -
SOCIAL DETERMINATES OF HEALTH.

- What does the family look like? What roles do people play?
- What are their resources? What are their unmet needs?



Timing of the Assessment

All families should be assessed for risk factors upon admission to NICU and again as part of the discharge planning process.



Support Systems



Communication
Post-Discharge



Mental Health
Support



Community
Programs



Peer-to-Peer
Programs



How to Use
Tech Safely



Social
Workers

transfer +
coordination of care

Families transition from having all their babies' care needs met in the NICU → to having to piece together care in the community. We all have a role in **HELPING FAMILIES ESTABLISH A MEDICAL HOME.**

- primary care providers
- specialty care
- county, state, federal, and tribal agencies
- community-based programs
- mutual aid and community-specific support groups

transfer +
coordination of care

DELIVERING COMPREHENSIVE CARE

requires that we think beyond the discharge summary and warm handoff...

- **BUILD RELATIONSHIPS**
reach out to our colleagues...
- **ESTABLISH OPEN COMMUNICATION**
meet together... seek each other's input...
- **CULTIVATE COLLABORATION**
respect each other's expertise... learn together...
create new strategies

Every family needs a Medical Home

A medical home is not a building.
It's not a place.

It is a partnership that you build
with your baby's primary care provider.

It extends beyond the walls of
a clinical practice.



When families transition from NICU to Home
the **Medical Home** provides continuity of care.



- family-centered
- accessible
- compassionate
- coordinated
- comprehensive
- culturally competent



A medical home builds partnerships with clinical specialists, families, and community resources.

The medical home recognizes the family as a constant in a child's life and emphasizes partnership between health care professionals and families.



AAP Technical Assistance Center
www.aap.org/en/practice-management/medical-home

There are resources for professionals and families who care for children and youth with special health care needs (CYSHCN) and want to achieve the best possible outcomes for their health, well-being, and success.



Medical Home Portal

www.medicalhomeportal.org



other important
considerations

- families with limited English proficiency
- military families
- LGBTQIA+ headed families
- parents with disabilities
- families with distinct cultural
and/or philosophical expectations

other important considerations

Families who prefer speaking
other languages



hablamos español

你会说汉语吗

Nou vle pale kreyòl



other important considerations



Military Families



Call 1-800-538-9552

or go to [milConnect](#)

tricare.mil/ContactUs/AskBenefitQuestion

other important considerations

LGBTQIA+

Headed Families



other important considerations

Parents with Disabilities



IF YOU EMBRACE
DIVERSITY
BUT IGNORE
DISABILITY
YOU'RE DOING IT WRONG

UREVOLUTION

other important considerations



Families with Distinct Cultural and/or Philosophical Expectations



NEW Guidance

NICU discharge preparation and transition planning: guidelines and recommendations

Journal of Perinatology.
2022.

PERSPECTIVE

NICU discharge preparation and transition planning: foreword

Heather Cohen Padratzki^{1,2} and Kristin Love^{2,3}

© The Author(s), under exclusive licence to Springer Nature America, Inc. 2022

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. While we know 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.

Journal of Perinatology, h

INTRODUCTION

Having your baby admitted (NICU) to receive critical care can anticipate their baby's birth and even fewer are family provides. Once there, parent baby will be able to come discharge preparation and the first day of a family's NK that our goal is not just to see they arrived, it is to see empowered and prepared confident and competent guidance and support. The NICU can not be limited to h to expand to meet their nee fragile child. It has to meet it to welcome them into a care is what smart, timely, coor NICU team can deliver.

HEATHER

Being the parent of a baby j both exciting and terrifying. my son, Owens, was born a fragile, two-pound preemie After 81 very long days and met milestones, he was final discharge only 2 days prior. was finally coming home overwhelmed at the thought all of the wonderful staff the into the strong baby he had heart-apnea monitor to be s After only a 15-min explaini

¹Board of National Perinatal Associa

CONSENSUS STATEMENT

NICU discharge preparation and transition planning: guidelines and recommendations

Vincent C. Smith^{1,2}, Kristin Love^{2,3} and Erika Goyer³

© The Author(s), under exclusive licence to Springer Nature America, Inc. 2022

In this section, we present Interdisciplinary Guidelines and Recommendations for Neonatal Intensive Care Unit (NICU) Discharge Preparation and Transition Planning. The foundation for these guidelines and recommendations is based on existing literature, practice, available policy statements, and expert opinions. These guidelines and recommendations are divided into the following sections: Basic Information, Anticipatory Guidance, Family and Home Needs Assessment, Transfer and Coordination of Care, and 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. Our goal was 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. The recommendations based only on expert opinion could be topics for future research.

Journal of Perinatology, <https://doi.org/10.1038/s41372-022-01313-9>

ABOUT THE GUIDELINES

The foundation for these recommendations is based on existing literature, practice, and available policy statements. Given the range of topics we cover, there are some situations where 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 and the readers are requested to note this issue while adapting them into their practices, if they choose to. The recommendations based only on expert opinion could be topics for future research.

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.

NICU setting. Rather, what we propose are guidelines and recommendations that focus on content and process. We strove 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

Discharge planning is the process of working with a family to help them successfully transition from the NICU to home. To this end, each family will need to participate in a comprehensive discharge planning program that has been tailored to their and their infant's specific needs. The first section is basic information and is meant to emphasize content that every family will need, without taking into account each family/infant's specific needs.

In preparing for discharge, your team will have to set clear criteria for what each family and infant need to accomplish to be ready to transition from the NICU to home. The NICU team should work with the family and confirm that the family understands the NICU discharge planning process. It is important that families understand that it is difficult to plan for a specific discharge date because

Discharge Preparation and Transition Planning: Editorial

June 2022

instruction for preparing feeds, tools for preventing and treating infections, information on applying for the Supplemental Nutrition Assistance Program and the Women, Infants and Children (WIC) program, and information on the timing, safety, and administration of safety administration medications is essential to discharge preparation and transition planning.

These resources should be reviewed and revised as needed. Assisting caregivers as they are an important component of the discharge process.

SUPPORTING REFERENCES

1. Timing of discharge. (1, 2, 7, 14, 16-21)
2. Discharge. Common infant care topics that families need to know. (1-4, 6, 8, 14, 16, 22-24)

3. How baby to have each day.

4. 5.

6. 7.

8. 9. 10. 11. 12. 13. 14. 15. 16. 17. 18. 19. 20. 21. 22. 23. 24.

15. Medical or developmental

16. 17. 18. 20.

19. 20. 21. 22. 23. 24.

25. Used for the discharge. [9]

26. Technology with a preference. [16]

27. 28. 29. 30. 31. 32. 33. 34. 35. 36. 37. 38. 39. 40. 41. 42. 43. 44. 45. 46. 47. 48. 49. 50. 51. 52. 53. 54. 55. 56. 57. 58. 59. 60. 61. 62. 63. 64. 65. 66. 67. 68. 69. 70. 71. 72. 73. 74. 75. 76. 77. 78. 79. 80. 81. 82. 83. 84. 85. 86. 87. 88. 89. 90. 91. 92. 93. 94. 95. 96. 97. 98. 99. 100.

36. Knowledge of medical and nursing. (1, 3, 5, 14, 20)

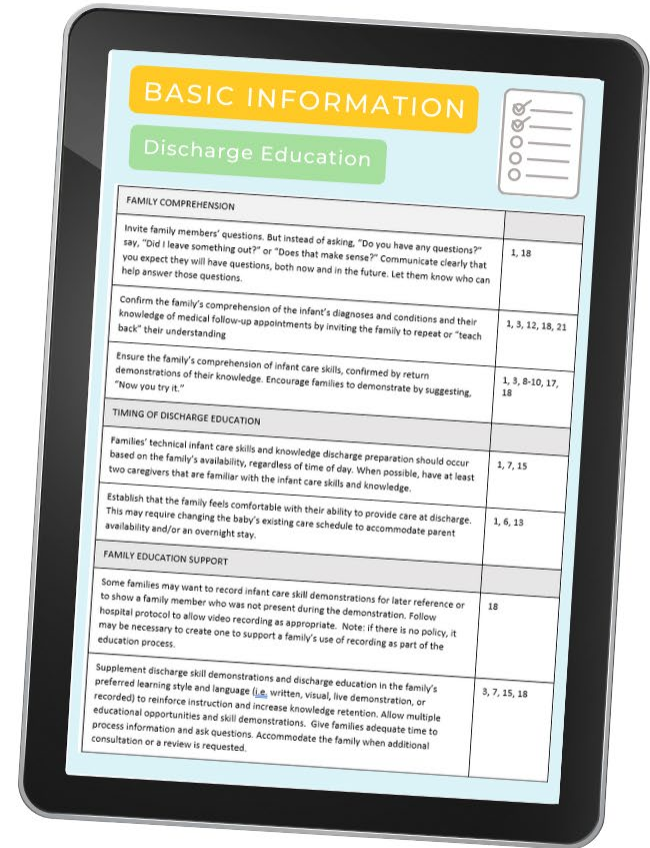
37. 38. 39. 40. 41. 42. 43. 44. 45. 46. 47. 48. 49. 50. 51. 52. 53. 54. 55. 56. 57. 58. 59. 60. 61. 62. 63. 64. 65. 66. 67. 68. 69. 70. 71. 72. 73. 74. 75. 76. 77. 78. 79. 80. 81. 82. 83. 84. 85. 86. 87. 88. 89. 90. 91. 92. 93. 94. 95. 96. 97. 98. 99. 100.

39. 40. 41. 42. 43. 44. 45. 46. 47. 48. 49. 50. 51. 52. 53. 54. 55. 56. 57. 58. 59. 60. 61. 62. 63. 64. 65. 66. 67. 68. 69. 70. 71. 72. 73. 74. 75. 76. 77. 78. 79. 80. 81. 82. 83. 84. 85. 86. 87. 88. 89. 90. 91. 92. 93. 94. 95. 96. 97. 98. 99. 100.

OPEN ACCESS

SPECIAL SUPPLEMENT

- online at www.nature.com/jp/
- limited number of print copies
- NPA member get a steeply-discounted rate on the Journal of Perinatology
nationalperinatal.org/journal-of-perinatology



companion

WEBSITE

guidance into

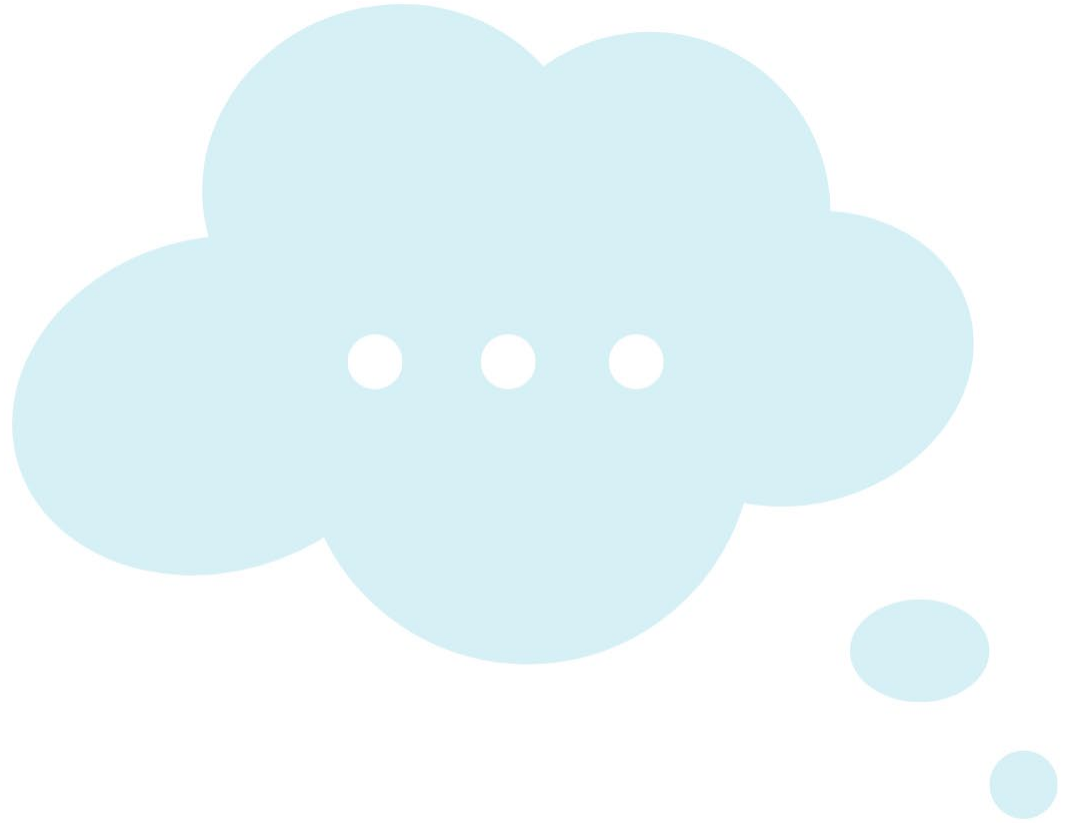


ACTION

- tools
- resources
- community of experts



But what
do **we** do
next?



IMPLEMENTATION



How do you turn
recommendations
into actions?

**What do
we do next?**



We're not asking you to boil the ocean.
We're asking you to get a pot.
We all have a pot.

Boil your pot. 



Mia Malcolm

NICU Parent Advocate



Discharge
planning process

thoughts

Call to **ACTION**



Discharge
planning
begins at
admission.





Need to
meet family
where they are
- instead of where
you want them to be.

Our Family's Plan



- health information
- follow-up appointments
- community resources

NICU Follow Up Clinic (555)123-4567
Pediatrician Dr. Smith (555)234-5678
Early Intervention www.cdc.gov/ncbddd/actearly
In an EMERGENCY 911

PSI

IF I have questions
I can call:

- Dr. Smith
- discharge nurse
- follow up team
- early intervention specialist
- NICU family support (peer-to-peer program)



Concerned about Development?
How to Get Help for Your Child

PERINATAL MOOD AND ANXIETY DISORDERS (PMADS)

Definition: Anytime during pregnancy through the first year postpartum

SYMPTOMS

- Disturbances of sleep and appetite
- Crying and sadness, constant worry or racing thoughts
- Physical symptoms like dizziness, hot flashes, and nausea
- Possible thoughts of harming the baby or yourself
- Financial stress or poverty

TREATMENT OPTIONS

- Counseling
- Medication
- Support from others
- Exercise
- Adequate sleep
- Healthy diet
- Bright light therapy
- Yoga
- Relaxation techniques

FACTORS

- History of Abuse
- Unwanted or unplanned pregnancy
- Abrupt discontinuation of breastfeeding

Download CDC's Milestones Tracker App

Early Intervention

JOIN US
NICU Family Support Group
Fridays - online

Support International | www.postpartum.net | 800.944.4773 (call or text)

A place where
families feel safe
and welcomed.



ACT

We need to be
INTENTIONAL
in addressing
diversity, equity
inclusion,
accessibility,
and belonging.

ACT



Policies
may need
to change.

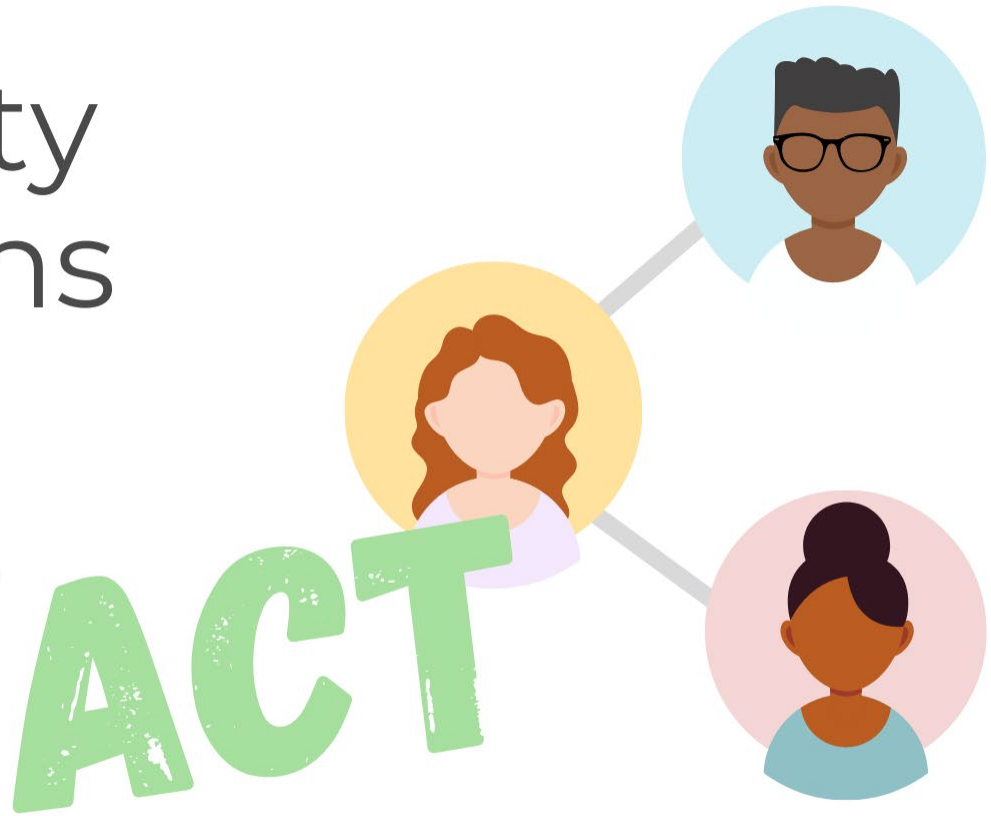
ACT

POLICIES:

The Way
We've Always
Done It



Community connections may need to change.



“How we are”
may need to
change.



companion website

NICUTOHOME.ORG

guidance into



ACTION

- tools
- resources
- community of experts



References

- American Academy of Pediatrics Committee on Fetus and Newborn. Pediatrics. 2008;122(5):1119-26 - Bernstein HH, Spino C, Lalama CM, Finch SA, Wasserman RC, McCormick MC. Unreadiness for Postpartum Discharge Following Healthy Term Pregnancy: Impact on Health Care Use and Outcomes. Acad Pediatr 2012; e-pub ahead of print 22 October 2012; pii: S1876-2859(12)00204-5. doi: 10.1016/j.acap.2012.08.005
- Barkmeier-Kraemer JM, Linn C, Thompson HL, et al. Preliminary Study of a Caregiver-based Infant and Child Feeding and Swallowing Screening Tool. *J Pediatr Gastroenterol Nutr.* 2017;64(6):979-983. doi:10.1097/MPG.0000000000001442
- Bernstein HH, Spino C, Baker A, Slora EJ, Touloukian CL, McCormick MC. Postpartum discharge: do varying perceptions of readiness impact health outcomes? *Ambul Pediatr* 2002;2:388-395.
- Broedsgaard A, Wagner L. How to facilitate parents and their premature infant for the transition home. *Int Nurs Rev* 2005;52:196-203.
- Bruder MB, Cole M. Critical elements of transition from NICU to home and follow-up. *Child Health Care* 1991;20:40-49.
- Bull MJ, Engle WA. Safe transportation of preterm and low birth weight infants at hospital discharge. *Pediatrics* 2009;123:1424-1429.

References

- Carbaugh SF. Understanding shaken baby syndrome. *Adv Neonatal Care* 2004;4:105-114.
- Damschroder LJ, Aron DC, Keith RE, Kirsh SR, Alexander JA, Lowery JC. Fostering implementation of health services research findings into practice: a consolidated framework for advancing implementation science. *Implement Sci* 2009;4:50.
- Dunn MS, Reilly MC, Johnston AM, Hoopes RD, Abraham MR. Development and dissemination of potentially better practices for the provision of family-centered care in neonatology: the family-centered care map. *Pediatrics* 2006;118:S95-107.
- Glazebrook C, Marlow N, Israel C, Croudace T, Johnson S, White IR et al. Randomised trial of a parenting intervention during neonatal intensive care. *Arch Dis Child Fetal Neonatal Ed* 2007;92:F438-443
- Goday PS, Huh SY, Silverman A, et al. Pediatric Feeding Disorder: Consensus Definition and Conceptual Framework. *J Pediatr Gastroenterol Nutr.* 2019;68(1):124-129. doi:10.1097/MPG.0000000000002188
- Griffin T. Family-centered care in the NICU. *J Perinat Neonatal Nurs* 2006;20:98-102
- Griffin JB, Pickler RH. Hospital-to-home transition of mothers of preterm infants. *MCN Am J Matern Child Nurs* 2011;36:252-257
- Hotaling AJ, Zablocki H, Madgy DN. *Int J Pediatr Otorhinolaryngol.* Oct 1995;33(2):113-126.

References

- Kovacic K, Rein, ScM LE, Bhagavatula P, Kommareddy S, Szabo A, Goday PS, Pediatric Feeding Disorder: A Nationwide Prevalence Study, *The Journal of Pediatrics* (2020), doi: <https://doi.org/10.1016/j.jpeds.2020.07.047>.
- Maroney D. How family centered care affects preterm infants (including late-preterms) and their families. 2010; <http://www.premature-infant.com/centered.pdf> Accessed 12/15/2011, 2011.
- Maroney D. Evidence-based practice within discharge teaching of the premature infant. 2005; <http://www.premature-infant.com/evidencebased.pdf>. Accessed 12/15/2011, 2011.
- Merritt TA, Pillers D, Prows SL. Early NICU discharge of very low birth weight infants: a critical review and analysis. *Semin Neonatol*2003;8:95-115.
- Miquel-Verges F, Donohue PK, Boss RD. Discharge of infants from NICU to Latino families with limited English proficiency. *J Immigr Minor Health* 2011;13:309-314.
- Moore KA, Coker K, DuBuisson AB, Swett B, Edwards WH. Implementing potentially better practices for improving family-centered care in neonatal intensive care units: successes and challenges. *Pediatrics*2003;111:e450-460.

References

- Powell, B.J., Waltz, T.J., Chinman, M.J. *et al.* A refined compilation of implementation strategies: results from the Expert Recommendations for Implementing Change (ERIC) project. *Implementation Sci* **10**, 21 (2015). <https://doi.org/10.1186/s1301201502091>
- Proctor E, Silmere H, Raghavan R, Hovmand P, Aarons G, Bunger A, Griffey R, Hensley M. Outcomes for implementation research: conceptual distinctions, measurement challenges, and research agenda. *Adm Policy Ment Health*. 2011 Mar;**38**(2):65-76. doi: 10.1007/s10488-010-0319-7. PMID: 20957426; PMCID: PMC3068522.
- Robison M, Pirak C, Morrell C. Multidisciplinary discharge assessment of the medically and socially high-risk infant. *J Perinat Neonatal Nurs* 2000;**13**:67-86.
- Scherf RF, Reid KW. Going home: what NICU nurses need to know about home care. *Neonatal Netw* 2006;**25**:421-425.
- Shieh SJ, Chen HL, Liu FC, Liou CC, Lin YI, Tseng, HI *et al.* The effectiveness of structured discharge education on maternal confidence, caring knowledge and growth of premature newborns. *J Clin Nurs* 2010;**19**:3307-3313.
- Silverman AH, Kristoffer BS, Linn C, *et al.* Psychometric Properties of the Infant and Child Feeding Questionnaire. *Journal of Pediatrics*. 2020 August;**223**:81-86.e2. DOI: 10.1016/j.jpeds.2020.04.040.

References

- Smith VC, Dukhovny D, Zupancic JA, Gates HB, Pursley DM. Neonatal Intensive Care Unit Discharge Preparedness: Primary Care Implications. *Clin Pediatr (Phila)* 2012; e-pub ahead of print 25 January 2012; doi: 0009922811433036
- 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.
- Smith, V.C., Love, K. & Goyer, E. NICU discharge preparation and transition planning: guidelines and recommendations. *J Perinatol* **42** (Suppl 1), 7–21 (2022). <https://doi.org/10.1038/s4137202201313-9>
- Smith VC, Young S, Pursley DM, McCormick MC, Zupancic JA. Are families prepared for discharge from the NICU? *J Perinatol* 2009;29:623-629.
- Sneath N. Discharge teaching in the NICU: are parents prepared? An integrative review of parents' perceptions. *Neonatal Netw* 2009;28:237-246.
- Spingaire JM. Readiness for Hospital Discharge: Predictors and Outcomes in NICU Parents Paper presented at: Sigma Theta Tau International 38th Biennial Convention
- Scientific Sessions; 2011-10-17, 2005; Indianapolis, IN.

References

- Vigod SN, Villegas L, Dennis CL, Ross LE. Prevalence and risk factors for postpartum depression among women with preterm and low-birth-weight infants: a systematic review. *BJOG* 2010;117:540-550.
- Weiss ME, Lokken L. Predictors and outcomes of postpartum mothers' perceptions of readiness for discharge after birth. *J Obstet Gynecol Neonatal Nurs* 2009;38:406-417
- Weitzman M, Rosenthal DG, Liu YH. Paternal depressive symptoms and child behavioral or emotional problems in the United States. *Pediatrics* 2011;128:1126-1134.
- Zelkowitz P, Papageorgiou A, Bardin C, Wang T. Persistent maternal anxiety affects the interaction between mothers and their very low birthweight children at 24 months. *Early Hum Dev* 2009;85:51-58

Resources

- Nicutohome.org
- Nationalperinatal.org
- Cfirguide.org
- Dissemination-implementation.org
- Feedingmatters.org
- Swhd.org/programs/disabilities-services/smooth-way-home/

Steering Committee

Erin Armknecht, BA
Patti Bridges, MSW, LCSW
Joy Browne, PhD, PCNS, IMH-E (IV)
Jenene Craig PhD, MBA, OTR/L
Brigitte C. Desport, DPS, OTR/L, BCP, ATP
Erika Goyer, BA
Cristal Grogan

Andrea Werner Insoft, LICSW, ACSW
Kristy Love
Cheryl Milford, EdS
Steve Richardson
Tiffany Willis, PsyD
Julia Yeary, LCSW, IMH-E®

Interdisciplinary Guidelines and Recommendations Development Workgroup

Erin Armknecht, BA
Patti Bridges, MSW, LCSW
Joy Browne, PhD, PCNS, IMH-E (IV)
Jenene Craig PhD, MBA, OTR/L
Brigitte C. Desport, DPS, OTR/L, BCP, ATP
Heidi Gates, RN
Erika Goyer, BA
Cristal Grogan
Andrea Werner Insoft, LICSW, ACSW
Carol Jaeger, DNP, RN

Judi Kleekamp, PT
Kristy Love
Cheryl Milford, EdS
Trudi N. Murch, PhD, CCC-SLP
Heather Cohen Padratzick, MHA, JD
Steve Richardson
Cuyler Romeo, MOT, OTR, SCFES, CLC
Betty Vohr, MD
Tiffany Willis, PsyD
Julia Yeary, LCSW, IMH-E®

Additional Content Expert Contributors

Michael T. Hynan, PhD
Carole Kenner, PhD, RN, FAAN
Jonathan S. Litt, MD, MPH, ScD

Nicole Lomerson, MPH
Molly Fraust Wylie

NPA Staff

Erika Goyer, BA
Kristy Love



Thank You



Questions?