

Fragile Infant Forums for Implementation of IFCDC Standards: A Collective Effort to Improve the Experience of NICU families between the National Perinatal Association's Discharge NICU Discharge Preparation and Transition Planning Guidelines and Recommendations as well as the Standards, Competencies, and Recommended Best Practices for Infant and Family-Centered Developmental Care in the Intensive Care Unit

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Overview

When families think about their experience preparing to transition from the NICU (Neonatal Intensive Care Unit) to home, most families generally do not use the terms “joyful,” “easy,” or “perfect.” More often, families use terms like “quick...sudden,” “lonely,” and “scary.” Some families wonder if they even had a discharge preparation plan at all. Several organizations have worked to improve the overall experience for families in the NICU and the progress at home.

The healthcare professional's responsibility is to create supportive environments for families to experience a comprehensive and smooth transition from the NICU to home. The objective is to create opportunities for the families to participate in discharge and transition activities and build confidence in their ability to care for their babies at home. In this article, we discuss the following standards:

- NICU Discharge Preparation and Transition Planning (1, 2): Guidelines and recommendations.
 - <https://www.nicutohome.org/>

- For the sake of this article, we will refer to these as the “Discharge Planning Guidelines.”

- Recommended Standards, Competencies, and Best Practices for Infant and Family Developmental Care in Intensive Care in the Intensive Care Unit (3, 4).

- <https://nicudesign.nd.edu/nicu-care-standards/>

- For the sake of this article will refer to these as the “Developmental Standards”

“In this article, we discuss the following standards: NICU Discharge Preparation and Transition Planning: Guidelines and recommendations and Recommended Standards, Competencies, and Best Practices for Infant and Family Developmental Care in Intensive Care in the Intensive Care Unit.”

Because both sets of recommendations have been described in detail in previous Neonatology Today articles (7-10) and other press 11, we will assume the reader is familiar with both. The current article aims to address the interplay and parallel process between the Developmental Standards and the Discharge Planning Guidelines. For the sake of this article, “Standards” are defined as safe, evidence-based expectations or measures of best practice. Similarly, “Competencies” refer to the action, or sequence of actions, that constitute the performance of the standard.

Developmental Standards are divided into the following domains:

- Systems thinking in complex adaptive systems
- Positioning and touch for the newborn
- Sleep and arousal interventions for the newborn
- Skin-to-skin contact with intimate family members
- Reducing and managing pain and stress in newborns and families
- Management of feeding, eating, and nutrition delivery

Discharge Guidelines are divided into the following sections:

Basic information for all families

Anticipatory guidance

Family and home needs assessment

Transition and coordination of care

Other important considerations

Families with limited English proficiency

Military families

LGBTQIA+ headed families

Parents with disabilities

Families with distinct cultural and/or philosophical beliefs

The Developmental Standards and Discharge Planning Guidelines followed a similar process for their creation. Both took between 3 and 5 years to develop using multidisciplinary teams, using the best evidence available at the time of development. They both make evidence-based statements about best practices. Both sets of recommendations were also designed to address literature gaps and be actionable at multiple levels (bedside, administration, etc.). They provide details about the topic but have enough flexibility to be implemented with locally appropriate resources.

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Both sets of recommendations emphasize the importance of including families as key stakeholders in applying the recommendations. Similarly, they make recommendations that include the transition from the NICU to home, emphasizing the importance of parental involvement. These recommendations provide a wonderful opportunity to ensure a smooth transition from the developmental and family-centered practices in the NICU to support at home. (9)

“At present, neither set of recommendations directly addresses the implementation of the recommendations. Formulating recommendations and guidelines that will apply to each clinical setting and environment can be very challenging.”

Implementation guidance

At present, neither set of recommendations directly addresses the implementation of the recommendations. Formulating recommendations and guidelines that will apply to each clinical setting and environment can be very challenging. Neither set of recommendations is intended to be prescriptive. Instead, both recommendations describe the concepts and factors that should be considered. The work involved in implementing the recommendations at any local institution or clinical setting would have to be done by someone familiar with the resources available at the institution or clinical setting and the stakeholders who would participate in the process. To that end, the Fragile Infant Forums for Implementation (FIFI-S) workshops were initiated recently, guiding small groups of professionals on evidence-based systems change, assuring that conditions and local resources are considered. (7, 8)

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Although implementing the recommendations is a process that requires planning and collaboration, it is attainable, and the result will be a significant contribution and benefit to the recipients of the services. The organizations that created both sets of recommendations are available and willing to provide individual consultations to clarify the meaning of any specific recommendations.

“One common challenge that must be addressed as part of implementing the recommendations is ambivalence. Even if they agree with the need for evidence-based practice, it will not be apparent to some individuals or systems that they can bring about change. For progress towards a comprehensive model at an institution, sentiments like ‘there is nothing that I can do’ or ‘this is someone else’s problem’ will have to be anticipated and addressed.”

Implementation challenges

One common challenge that must be addressed as part of implementing the recommendations is ambivalence. Even if they agree with the need for evidence-based practice, it will not

be apparent to some individuals or systems that they can bring about change. For progress towards a comprehensive model at an institution, sentiments like “there is nothing that I can do” or “this is someone else’s problem” will have to be anticipated and addressed, perhaps at different stages of the process. To support your organization in the implementation process, we would like to offer the following suggestions:

- Include families as key stakeholders in the process
- Use a multidisciplinary team approach of invested stakeholders
- Be open to input from the stakeholders by readily including simple suggestions that can be implemented tomorrow
- Be willing to engage in honest conversations with team members and families about system factors challenging implementation and commit to addressing them
- Consider environmental and contextual factors that are supports and/or barriers during assessment and intervention planning (12)
- Develop a process that is structured and organized, and avoid making it too prescriptive
- Focus on what can be accomplished with existing resources
- Make use of free publicly available resources such as <https://www.nicutohome.org>.
- Partner with another organization for help with implementation.
- Use the two organizations that created both sets of recommendations as resources—<https://www.nationalperinatal.org/programs> and <https://nicudesign.nd.edu/nicu-care-standards/>. They are available and willing to provide individual consultations to clarify the meaning of any specific recommendations.

“Both resources emphasize how parents and family members should be included and involved in all aspects of their baby’s care and discharge planning. The charge is to build capacity instead of expecting families to conform to the NICU structure (e.g., environment) and its discharge planning and transition processes or accept what is considered appropriate or right.”

Summary and conclusions:

The two resources described above are available and provide evidence-based guidelines for NICU developmental care and discharge planning. Both resources emphasize how parents and family members should be included and involved in all aspects of their baby’s care and discharge planning. The charge is to build capacity instead of expecting families to conform to the NICU structure (e.g., environment) and its discharge planning and

transition processes or accept what is considered appropriate or right. Together, these standards and guidelines provide guidance that, with acknowledgment of locally available resources, can and should be implemented to improve the care and support of babies and families.

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Respiratory Syncytial Virus

Really Serious Virus

Here's what you need to watch for this RSV season

Coughing that gets worse and worse



Breathing that causes their ribcage to "cave-in"

Rapid breathing and wheezing



Bluish skin, lips, or fingertips

RSV can be deadly. If your baby has these symptoms, don't wait. Call your doctor and meet them at the hospital.



Thick yellow, green, or grey mucus

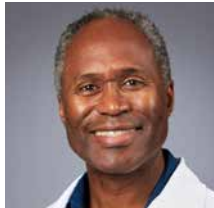


that clogs their nose and lungs, making it hard to breathe

Fever that is more than 101° Fahrenheit



which is especially dangerous for babies younger than 3 months



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