

# Fragile Infant Forums for Implementation of IFCDC Standards: Developmentally Supportive Care Means Individualized Care...

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***“Providing developmental care during the ICU stay is challenging, partly because every baby and every family is unique. Care must be individualized to the ever-changing baby and family needs which require systems-thinking, advocacy, education, and teamwork.”***

## **Abstract:**

*Providing developmental care during the ICU stay is challenging, partly because every baby and every family is unique. Care must be individualized to the ever-changing baby and family needs which require systems-thinking, advocacy, education, and teamwork. This article explores the importance and the challenge of providing individualized care for the infant and the family. It highlights how the Recommended Standards, Competencies, and Best Practices for Infant and Family-Centered Developmental Care can help individualize care across the six identified evidence-based developmental care domains.*

The Infant and Family Centered Developmental Care (IFCDC)

***“The Infant and Family Centered Developmental Care (IFCDC) Consensus Committee and their Recommended Standards, Competencies, and Best Practices for Infant and Family-Centered Developmental Care focus on providing care within intensive care settings that exemplify best practices for neuroprotection of the baby’s developing brain.”***

Consensus Committee and their Recommended Standards, Competencies, and Best Practices for Infant and Family-Centered Developmental Care focus on providing care within intensive care settings that exemplify best practices for neuroprotection of the baby’s developing brain. These principles and evidence-based practices view the infant as an active partner in care, primarily championed within the Newborn Individualized Developmental Care and Assessment Program (NIDCAP®), which demonstrated improved outcomes for both the infant and the family. (1-8) A later meta-analysis and review of developmental care programs, in general, provide more recent data suggesting improved outcomes after discharge. (9)

***“IFCDC is grounded in designing and providing care to meet the needs of each infant – which will differ based on gestational age, medical comorbidities, socio-cultural, family, and environmental factors. Additionally, every family is unique, and therefore, the support that each family requires is different as well.”***

Family-centered care is a movement toward integrating families into the care of their hospitalized infants. (10) As developmental care and family-centered principles evolved and as evidence accumulated to demonstrate their effectiveness, so did the concept of Infant and Family-Centered Developmental Care (IFCDC), which includes both the infant AND the family. However, too often, the core principle of IFCDC, *individualized care*, is misunderstood or missed altogether.

**Box 1:**

Examples of integration of individualized care into the developmental care standards for infants in intensive care

**Systems Thinking:**

Standard 6: The interprofessional collaborative team should provide IFCDC through the transition to home and continuing care for the baby and family to support the baby's and family's optimal physiologic and psychosocial health needs.

- Competency 6.2: Procedures that engage the family in assessing the readiness of themselves and the baby for transition to the home environment should be developed, implemented, and evaluated.
- Competency 6.4: Assessment with the family of their confidence level for managing the baby in the home and community environment should be implemented.

**Positioning and Touch:**

Standard 1: Babies in intensive care settings shall be positioned to support musculoskeletal, physiological, and behavioral stability.

- Competency 1.0: Body position shall be individualized and monitored for the head, trunk, and extremity alignment and movement.

Standard 4: Babies in ICU settings shall experience human touch by family and caregivers.

- Competency 4.4: To avoid overstimulation, individualized frequency and duration of supplemental, gentle touch shall be determined by evaluating the baby's behavioral and physiological parameters before, during, and after the touch interaction.

**Sleep and Arousal:**

Standard 1: Intensive care units (ICUs) shall promote developmentally appropriate sleep, arousal, and sleep-wake cycles.

- Competency 1.3: The ICU shall implement a system to document the individual baby's sleep and arousal states and cycles.

**Skin-to-Skin Contact (SSC):**

Standard 1: Parents shall be encouraged and supported in early, frequent, and prolonged skin-to-skin contact (SSC) with their babies.

- Competency 1.2: Information in a variety of appropriate formats and the parent's language should be provided about the SSC policy and how it applies specifically to them and their baby, including a) inclusion and exclusion criteria; b) indications and techniques for kangaroo care (KC) and hand containment (HC); and c) who may be designated by parents to participate in SSC.
- Competency 1.7: Parents shall be supported to recognize their baby's behavioral communications of stress and relaxation during SSC.

Standard 2: Education and policies in support of skin-to-skin contact between parents and their babies shall be developed, implemented, monitored, and evaluated by an interprofessional collaborative team.

- Competency 2.6: SSC educational content should include ways to individualize SSC according to the baby's medical condition, behavior, and state organization and should include: a) descriptions, techniques, and indications for KC or gentle supportive HC; and b) techniques and scripts for supporting the use of these options to parents.

**Pain and stress:**

Standard 1 (Families): The interprofessional team shall document increased parental/caregiver well-being and decreased emotional distress (WB/D) during the intensive care hospital (ICU) stay. The stress levels of the baby's siblings and extended family should also be considered.

- Competency 1.9: Appropriate emotional interventions and support shall be provided by social workers, psychologists, and psychiatrists within the ICU to parents/caregivers with debilitating symptoms or acute distress.

Standard 2 (Babies): The interprofessional collaborative team shall develop care practices that prioritize multiple methods to optimize baby outcomes by minimizing the impact of stressful and painful stimuli.

- Competency 2.9: Pain and stress management should be individualized based on each baby's behavioral and physiological communication and consideration of the parents' expressed preferences.

**Feeding, Eating, and Nutrition Delivery**

Standard 1: Feeding experiences in the intensive care unit (ICU) shall be behavior-based and baby-led. Baby-led principles are similar whether applied to enteral, breast-, or bottle-feeding experience.

- Competency 1.7: Baby behavior at the beginning (baseline) of feeding and changes during feeding for physiologic, motor, behavioral state, and interaction parameters shall guide the feeder's decision to continue or discontinue the feeding. While some loss of stability is common, the focus shall be on maintaining a minimal level of baseline physiologic stability and behavior throughout the feeding or regaining baseline stability when the baby loses stability during the feeding.
- Competency 1.9: Baby behavior and medical stability shall guide initiation of oral feeding attempts as gestational age does not address normal developmental variability or the impact of medical comorbidities.

IFCDC is grounded in designing and providing care to meet the needs of each infant – which will differ based on gestational age, medical comorbidities, socio-cultural, family, and environmental factors. Additionally, every family is unique, and therefore, the support that each family requires is different as well. These essential supports are not static. Infants and families evolve over time, requiring a system and staff that are attuned and flexible in their response to these unique needs.

Unfortunately, often the needs of infants and families are missed or mistimed when NICUs do not prioritize individualizing care. So despite the application of IFCDC, implemented with various interpretations and approaches, there is still room for improvement. Could individualization of care be the missing link?

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***“The Recommended Standards, Competencies, and Best Practices for Infant and Family-Centered Developmental Care provide individuals, units, and systems with the tools to help with individualized care.”***

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#### **The challenge to individualization**

Protocols are a mainstay of medicine, nursing, and ancillary care practice. (11) In many cases, protocols lead to improved outcomes. (12-14) How do systems and individual professionals achieve optimal outcomes with best practices that use standards and competencies while maintaining the need to individualize practices? The Recommended Standards, Competencies, and Best Practices for Infant and Family-Centered Developmental Care provide individuals, units, and systems with the tools to help with individualized care. Each of the six domains within these best practices includes standards and competencies focused on individualized care for the infant and the family. These standards can be accessed at <https://nicudesign.nd.edu/nicu-care-standards/>. Box 1 provides examples of how the Standards, Competencies, and Best Practices integrate individualized care.

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one “speaks the language of the newborn,” protocols can be implemented to reduce the variability of caregivers in their response to the infant’s needs.

For example, painful and invasive procedures negatively affect preterm infant brain growth and developmental outcomes. (17) However, preterm infants at different gestational ages have different behavioral responses to pain. For instance, Gibbins and colleagues documented facial responses and physiological changes during heel lances in preterm infants stratified by gestational ages. (18) Physiological responses were similar across ages, but facial responses differed based on gestational age, with the youngest infants showing the least change. (18) Fabrizi and colleagues demonstrated that infants less than 34 weeks of gestation had similar neuronal activity to noxious (heel lance) and non-noxious (tactile) touch. In contrast, infants older than 34 weeks did not. (19) This suggests that the ability to discriminate touch inputs emerges between 35 and 37 weeks gestation. Pain and stress are managed best when treatments are offered based on the baby’s communicative signs and responses. (20)

In another example, the NICU setting and other intensive care settings for infants often separate infants from their families. Separation is stressful and has consequences that negatively influence the infant and the family. (15, 16) The best exemplar of the benefit of non-separation of babies and mothers is the practice of skin-to-skin (STS) care. Within SSC, positioning and touch protocols are encouraged to support appropriate interactions and minimize stress. These protocols are individualized by considering the infant’s gestational age, medical comorbidities, and needs and observing the infant’s responses.

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Other caregiving approaches that show different responses from each baby include the respiratory status or gastrointestinal functions that may improve with changes in position or with positional aids for some but not all infants. (21, 22) Swaddling is associated with more stable cardiorespiratory function during and after painful as well as routine procedures for some infants and may be especially beneficial for infants with Neonatal Abstinence or Neonatal Opioid Withdraw Syndromes. (23, 24) In a study published in 2020, preterm infants with lower PMAs demonstrated more motor and autonomic stress during weighing and bathing. (25) Since infants demonstrate different responses to the same activities, routine caregiving protocols should be designed with the ability to individualize based on infant behaviors. Not all touch or oral stimulation protocols may be beneficial; some infants may have apnea or bradycardia in response to these protocols. (26, 27) Bembich and colleagues concluded that recognizing adaptive and maladaptive responses to caregiving by each baby allows nurses to individualize and personalize their interactions with pre-



term infants. (25)

### **The evidence-based exemplar of individualizing Feeding, Eating, and Nutrition delivery**

Perhaps the domain where individualization is most needed is Feeding, Eating, and Nutrition Delivery (FEND). There is mounting evidence that feeding advancement guided by protocols leads to improved growth, nutrition, metabolic and developmental outcomes. (28) In a recently published Quality Improvement (QI) study, a standard feeding protocol was developed to decrease the time to achieve full enteral feeds. (29) This protocol decreased the mean number of days to reach full feeds from 13 days to 9 days, with a decrease in central line use from 8.5 days to 5.7 days. (29) Clearly, with these protocols, the infant's response to enteral feedings also guides decisions within the protocol. The key is to have a system to determine whether the infant tolerates the advancement – a standardized response to the infant's reactions. Nevertheless, in a recent review, Lubbe found that feeding regimes and protocols for advancing to oral feedings are inconsistent and often contradictory. (30) Often with the transition from tube to oral feedings, "what we have done" is the norm rather than evidence-based practice. (30)

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***“Protocols provide structure and limit variability due to practices. The key is to find structure and limit variability due to practice, while allowing flexibility to meet the infant's needs.”***

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How can these principles of practice standardization within the framework of individualized care for infants and families be applied to the questions swirling around oral feedings? What gestational age to start oral feedings with an infant? Shall oral feedings begin with bottle feeding or breastfeeding? When to introduce the complement to the initial feeding mode? Can preterm infants achieve exclusive direct breastfeeding without increased lengths of stay? These questions and many more have different answers depending on the system, unit, staff, infant, and family factors.

Protocols provide structure and limit variability due to practices. The key is to find structure and limit variability due to practice, while allowing flexibility to meet the infant's needs.

Each infant is a competent communicator, another core principle for IFCDC. They can help individualize pathways to meet their needs. Unlike nutritional guidelines based primarily on numbers, learning to eat is a developmental skill. Like all developmental skills, infants achieve skills within windows of time, but not based on a strict age. For other developmental milestones, such as walking, there may be a five or six-month window for acquisition and another six to twelve months for mastery. (31-33)

Nevertheless, professionals and parents frequently feel infants should eat and go home at the same age. The window of time that the majority of healthy preterm infants eat everything and go home is 34.5 to 38.5 weeks in most research studies, with the mean GA being 36.5 weeks. (34, 35) Infants with medical comorbidities will be in the hospital longer. (34, 35)

The difference in timing for developmental milestones is a significant factor that often is overlooked. This variability in maturation leads to infants being challenged to eat when they are not ready. Studies have shown the potential dangers of beginning oral feedings too early, with poor pharyngoesophageal function noted in infants younger than 35-36 weeks. (36, 37) However, some babies can begin oral feedings at younger ages than others. So how does the professional individualize cue-based programs while respecting the maturation of the infant? The baby is the best person to listen to when navigating these differing and changing abilities.

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Because of the neurodevelopmental nature of learning to eat, most FEND standards and competencies address the need to individualize care based on the infant and family needs. The first standard expects that “feeding experiences in the intensive care unit (ICU) shall be behavior-based and baby-led. Baby-led principles are similar whether applied to enteral, breast, or bottle feeding experience.” (38) Feeding outcomes have improved with programs focusing on attending, interpreting, and responding to baby behaviors. (30, 39-53) Ten of the twelve competencies within this standard address the need to individualize care to both the infant's and the family's needs.

### **How to implement individualized IFCDC**

Making changes to practice is hard, and it is challenging when the outcomes are varied with so many factors influencing success. Individualizing to the needs of both babies and families makes this challenge even harder. Therefore, the IFCDC Consensus Committee has begun Fragile Infant Forums for Implementation to support professionals in integrating the standards and competencies within their unit. The first workshop focused on the FEND domain, with a white paper written after this first workshop. [https://nicudesign.nd.edu/assets/491808/fifi\\_s\\_white\\_paper\\_version\\_5\\_10\\_19\\_22\\_ibckjb\\_final\\_2022.pdf](https://nicudesign.nd.edu/assets/491808/fifi_s_white_paper_version_5_10_19_22_ibckjb_final_2022.pdf). It provides strategies to determine where their unit is and what they might strive towards when considering feeding, eating, and nutrition delivery for infants in ICU settings.

The six current principles within the IFCDC Principles-Concept Model consider the need to individualize through systems thinking in complex adaptive systems. The family also needs to be heard. Every family will have different backgrounds, cultures and languages, educational needs, and physical/tangible needs. Furthermore, every family will have different emotional and social needs. Intensive care units need to provide comprehensive individualized family support, which is difficult until we ask the family what they need. (54-57)

By attending to, listening, and responding to the infant's commu-

nication, care can be individualized even for the tiniest of humans who are non-verbal, yet through their behavior, they can have a voice in their care. This leads to improved neuroprotection of the developing brain and infant mental health, two additional principles within the concept model. By doing the same with families within Intensive Care settings, true partnerships can be formed for the benefit of the infant and the family.

Developmental care is not a “one-size-fits-all” program. While research studies provide data to inform pathways and programs, every baby and every family requires individualized care. With this kind of thoughtful, well-designed care that “fits” the baby and family, our long-term outcomes may look even brighter.

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**“The IFCDC principles-concept model can be accessed online at: [https://nicudesign.nd.edu/assets/425320/ifcdc\\_concept\\_model\\_revised\\_design\\_by\\_zj\\_nov\\_2020\\_1\\_.pdf](https://nicudesign.nd.edu/assets/425320/ifcdc_concept_model_revised_design_by_zj_nov_2020_1_.pdf)”**

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Disclosures: Dr. Ross owns intellectual property related to feeding infants in the NICU setting (SOFFI®)

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