2023

# INCREASING PARENT CONFIDENCE AND INVOLVEMENT IN THE NICU: AN OCCUPATIONAL THERAPY EDUCATIONAL GUIDE

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# INCREASING PARENT CONFIDENCE AND INVOLVEMENT IN THE NICU: AN OCCUPATIONAL THERAPY EDUCATIONAL GUIDE

By

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Occupational Therapy Doctorate, University of North Dakota, 2023

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A Scholarly Project

Submitted to the Graduate Faculty

of the

University of North Dakota

in partial fulfillment of the requirements

for the degree of

Occupational Therapy Doctorate

Grand Forks, North Dakota

May

2023

**APPROVAL PAGE**

This scholarly project, submitted by Megan Berginski in partial fulfillment of the requirement for the Degree of Occupational Therapy Doctorate from the University of North Dakota, has been read by the Faculty Advisor under whom the work has been done and is hereby approved.

Wanda Lauer

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4/10/23

Date

## PERMISSION

**Title:** Increasing Parent Confidence and Involvement in the NICU: An Occupational Therapy Educational Guide

**Title Department:** Occupational Therapy

**Degree:** Occupational Therapy Doctorate

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Megan Berginski

3/30/2023

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## ACKNOWLEDGEMENTS

I would like to express extreme gratitude to my advisor, Dr. Wanda Lauer, for all the hours she spent assisting and encouraging me through this process. I would also like to thank Dr. Julie Grabanski for her hard work in securing a Doctoral Experiential Placement in this setting for me to develop a product that would benefit both parents and infants in the neonatal intensive care unit. I would also like to express my gratitude to my DEP occupational therapy site mentor for his knowledge and time given during this scholarly project. Lastly, I would like to personally thank my family and friends who continue to be my support system and push me to always be the best that I can be.

## ABSTRACT

**Background:** Research shows that 40% of mothers with preterm infants in the neonatal intensive care unit (NICU) reported feelings of depression, and 23% reported experiencing post-traumatic stress symptoms, with that number increasing to 40% after discharge (Harris et al., 2018). Factors that contributed to this included a lack of social support, a lack of empowerment, perceived less capability in their new roles, and the stressful experiences that can happen in this setting (Matricardi et al., 2013; Sabnis et al., 2019). A similar study found that at discharge, 69.8% of parents reported that they were not confident in providing the necessary care to their infant without the support of the NICU providers and 47.2% reported that their infant required complex home care post-discharge. Parents also reported that returning to their daily routine took roughly 4 to 11 months post-discharge (Jiménez-Palomares et al., 2021). Occupational therapy has a significant role in this setting by facilitating parents' involvement in their care while also increasing their confidence to continue care at discharge (Harris et al., 2018; Reynolds et al., 2013).

**Purpose:** This project aimed to create occupation-based and evidence-based educational materials for parents with infants in the NICU that applies to their infant's NICU stay and after discharge. The goal of this project is to decrease parent stress, assist parents with developing into their new roles, and facilitate the bond with their infant.

**Methodology:** Before the project was created, a literature review and needs assessment were completed to identify gaps in services within this population. The product was influenced by the Model of Human Occupation (MOHO) and andragogy teaching and learning theory (Bastable et

al., 2020; Kielhofner, 2008). This product utilizes repetition, encouragement, and multidimensional learning and follows health literacy guidelines.

**Product:** The product, an educational guide, titled *"How to" Activities for Positive Parent Engagement and Empowerment Program,* or the *HAPPEE Program,* was created for parents with infants in the NICU. This guide includes handouts and QR codes for videos regarding various occupations in this setting and at home while safely adhering to their infant's medical status. A questionnaire for parents is included to measure the effectiveness of the program.

**Summary:** The literature shows that the NICU can cause parents to experience increased levels of psychological stress and alterations in their new parenting roles. Parents in this setting need increased support while learning how to engage with their infant as they progress through their NICU stay and after discharge. The *HAPPEE Program* was designed to provide demonstrations for various caregiving occupations while offering support throughout the entire process.

# Chapter I

## Introduction

The Centers for Disease Control and Prevention (2021) reports that in 2021, roughly one out of ten babies, or 10.5%, were born prematurely, which is defined as before 37 weeks gestation. These babies all have different lengths of stay in the neonatal intensive care unit (NICU) depending on their health status, which could be days, weeks, months, or over a year. Infants in the NICU are not the only ones affected by this stay. Research shows that parents with infants in the NICU experience high rates of psychological stress that last even after they go home (Cook et al., 2018; Purdy et al., 2015).

During this stay, families will interact with numerous NICU team members. The NICU team may include neonatology, nursing, occupational therapists, speech-language pathologists, physical therapists, child-life specialists, and case management. This team collaborates to progress the infant to discharge. If the NICU team includes an occupational therapy practitioner, their job is to assist both the infant and caregiver in completing activities known as occupations. Occupations are meaningful activities that a person or group of people engage in to increase performance (American Occupational Therapy Association, 2020). An infant's primary occupations are feeding, sleeping, and playing, whereas caregiving occupations with this population are feeding, eating, and providing comfort (American Occupational Therapy Association, 2020; Cardin, 2020; Smith et al., 2019). Occupational therapy practitioners address the infant's environment and skills needed to facilitate development in occupations while also educating families on how to interact and engage with their infant (Craig et al., 2018).

The *"How to" Activities for Positive Parent Engagement and Empowerment*, or the *HAPPEE Program*, is an evidence-driven, occupation-based program that helps fill a gap identified in the literature. The purpose of this program is to get parents involved in caring for

their infant while in the NICU and after discharge, increasing their confidence and bond with their infant while decreasing their stress. This program incorporates easily accessible educational materials and a variety of learning styles to facilitate the comprehension of adult learners. The program also includes various caregiving occupations they experience while in the NICU and at home.

The occupation-based model that guided the research and the creation of the program was the Model of Human Occupation (MOHO). A foundational principle of MOHO includes changing one's perceptions of their abilities to enhance their performance (Kielhofner, 2008). Integrating this theory provides parents with repetition and support through education and opportunities to build skill development.

Parents with infants in the NICU have a variety of learning styles and educational needs so it was important to include aspects from andragogy teaching and learning theory to facilitate adult comprehension of the material (Bastable et al., 2020). Incorporating this theory assists parents with learning the skills needed to safely engage in different occupations with their medically complex infant.

Throughout these chapters, the author discusses the evolution of this scholarly project. The succeeding chapter, Chapter II, identifies themes and gaps in services found in the literature review. Chapter III, Methodology, discusses the research process, databases utilized, and search terms that were used. Chapter IV, the Product, explains what the *HAPPEE Program* is, how to use it, and who may use the program. This program is made up of handouts and short videos that parents can access with a QR code at any point during their infant's NICU stay and after discharge. Lastly, Chapter V summarizes the scholarly project, strengths and limitations of the program, implications for occupational therapy practice, and future recommendations and

development. The program is available for viewing in Appendix A. The end of Appendix A includes a parent satisfaction survey for the facility to use if desired to measure the effectiveness of the program. The facility can also use the feedback from the surveys to modify the program if need be. Appendix B includes photo release form consent statements from parents for infants used in the product. Lastly, Appendix C includes a plan for implementing the program.

## Chapter II

## Literature Review

Parents with infants in the NICU experience high levels of stress, anxiety, depression, and post-traumatic stress disorder (PTSD) due to their infant's complex behaviors, the medical equipment, the use of medical jargon by the healthcare team, and the overall safety of their infant during their NICU stay (Berns & Drake, 2021; Givrad et al., 2021; Harris et al., 2018; Purdy et al., 2015).

A questionnaire surveying 53 parents in the NICU found that during their stay, 86.8% reported they were fearful for their infant's life (Jiménez-Palomares et al., 2021). Harris et al. (2018) identified that of 84 mothers, 40% with preterm infants in the NICU reported feelings of depression, and 23% reported experiencing post-traumatic stress symptoms, with that number increasing to 40% after discharge. The results also showed that mothers who had a Cesarean section delivery with a preterm infant experienced a significant increase in psychological stress compared to mothers who had a Cesarean section delivery with a full-term infant. Mothers were not the only ones being affected by having an infant in the NICU as fathers also experienced higher rates of depression and struggled with maintaining the appropriate amount of sleep, affecting their overall well-being (Salazar, 2022).

Previous studies identified factors that contributed to parents experiencing post-traumatic stress disorder, which included a lack of social support, a lack of empowerment, perceived less capability in their new roles, and the stressful experiences that can happen in this setting (Matricardi et al., 2013; Sabnis et al., 2019). It has been shown that parents experience their highest level of stress when preparing for discharge, which can lead to experiencing symptoms of post-traumatic stress disorder for 3-6 months post-discharge (Cook et al., 2018; Garfield et al.,

2018). This can be attributed to parents' decreased confidence and feeling unequipped to care for their infants (Garfield et al., 2018). Occupational therapy practitioners have a significant role in this setting in providing interventions to facilitate parents' involvement in their care while also increasing their confidence to continue care at discharge. The Model of Human Occupation (MOHO) is used to guide the development of this review. The succeeding literature review will discuss altered parental identities in the NICU, inhibited parent-infant relationships and the consequences that can have on the infant, barriers to parental involvement, and current evaluations and interventions that occupational therapy practitioners use to address these issues in this setting.

## Model of Human Occupation (MOHO)

### *Defining the Concepts*

MOHO is a theory that analyzes how occupational therapy practitioners provide purposeful and relevant interventions to target occupations that are inhibited by disease, injury, or disability (Kielhofner, 2008). MOHO identifies how motivation influences occupations. Kielhofner explains that occupations, such as self-care, work, and play, can be affected by one's volition (interests and motivation), habituation (roles and routines), performance capacity (skills and abilities that one possesses), and environment. This theory incorporates six components: occupational identity, occupational competence, volition, habituation, performance capacity/performance skills, and environment. These components interact systematically and influence how one engages in occupations (Kielhofner, 2008).

Kielhofner (2008) asserted that occupational identity involves who the person was in the past, who they are in the present time, and who they want to be in the future. Whereas occupational competence is the skills and capabilities one feels confident completing with their

valued occupations. Habituation involves habits, roles, and routines one engages in, while volition is the interests, values, and personal causation, or how one perceives their abilities and skills. While performance skills and performance capacity are related, they are different. Performance skills are the physical skills or abilities, whereas performance capacity is the cognitive skills or abilities one possesses to complete desired occupations. Lastly, the environment is the physical and social surroundings where one engages in occupations (Kielhofner, 2008).

### *Applying the Concepts to this Population*

For this setting, the occupational identity is the parents before they had an infant in the NICU, how they thought parenting was going to be, who they are during their NICU stay, and who they want to become as parents. The parent's occupational competence is challenged when building the confidence in new skills required to take care of an infant in the NICU and post-discharge. This correlates with performance skills and performance capacity as first-time parents with infants in the NICU must demonstrate their newly learned skills in an unfamiliar environment.

Parents in the NICU face changes to their habits, routines, and roles, and while they may value being involved in their parental role, they may not feel confident in their abilities with a medically complex infant. These changes inhibit their occupational performance in caregiving occupations. Occupational therapy practitioners can provide interventions to assist parents with establishing these new roles while also educating how to perform the skills needed to complete the various components of caregiving for their infant in this setting, therefore increasing parents' occupational identity and competence (Kessler et al., 2020; Smith et al., 2013).

## Themes Identified

### *Altered Identity, Competence, and Routines*

Parents experience an altered occupational identity and occupational competence while their infant is in the NICU and post-discharge regarding their parental roles (Berns & Drake, 2021; Gibbs et al., 2016; Kessler et al., 2020). Jiménez-Palomares et al., (2021) identified the effects of premature infants in the NICU on parents' identity, competence, and daily routines. The results found that of the 53 participants, 53.6% of parents reported that they experienced a delay in developing their new parental roles, which also affected their emotional states. Parents reported they stopped engaging in leisure activities, experienced a lack of sleep, and had drastic changes to their day-to-day routines. With these high reports of inhibited parental emotional states, only six out of the 53 respondents pursued professional help during their infant's stay in the NICU. At discharge, 69.8% of parents reported that they were not confident in providing the necessary care to their infant without the support of the NICU providers and 47.2% reported that their infant required complex home care post-discharge. Parents also reported that returning to their daily routine took roughly 4 to 11 months post-discharge (Jiménez-Palomares et al., 2021). This is extremely crucial as Smith et al., (2013) found that parents who are not prepared for discharge show adverse effects, including medication errors, failure to understand follow-up care, and increased hospital readmission.

Harris et al. (2018), found that while both mothers of full-term and preterm infants experience stress, mothers of preterm infants and mothers who delivered preterm infants via Cesarean sections experienced a heightened level of psychological stress. The results from the study found that increased psychological stress related to lower confidence in parenting roles, which delayed the parent-infant relationship. This study found that mothers experiencing

psychological stress tend to show less positive parental behaviors, including discipline, going to appointments, and supplementing activities that stimulate the infant's cognition. The data from this study provided that these mothers are shown to have a decrease in sensitivity and an increase in controlling behaviors during interactions (Harris et al., 2018).

Occupational therapy practitioners can address these factors by collaborating with the parents on developing a new routine, which assists with their identity and competence (Harris et al., 2018). Although, for parents with infants in the NICU, having an altered occupational identity, occupational competence, and routines due to psychological stress can lead to an impediment in the development of the parent-infant relationship (Harris et al., 2018; Jiménez-Palomares et al., 2021; Kessler et al., 2020).

***Parent-Infant Relationship***

Pineda et al., (2018) identified that the parent-infant relationship, or the development of the bond between the parent and infant, is affected during the NICU stay and post-discharge. Results from this study found that an early establishment of the parent-infant relationship is crucial as there are long-term effects on the infant's development, such as altered brain development, delayed motor development, and possible behavior issues. The parent-infant relationship is developed when parents are present and involved during their infant's NICU stay and have learned their premature infant's distinct communication.

Parents being present during their infant's NICU stay can also assist with role competency (Pineda et al., 2018). A similar study found that higher rates of parental visitations and frequent holding, or skin-to-skin, had major benefits for the infant as well. This correlated with enhanced movement patterns, an increase in hypotonia with a decrease in hypertonia, less stress, and decreased levels of arousal (Reynolds et al., 2013). While the data shows that being

involved in their infant's care is important for development, parents with more medically complex infants were shown to have less parent participation, predominately in holding, an intervention routinely provided by occupational therapy practitioners (Pineda et al., 2018).

Research shows that while parents are interested in being involved in their infant's care, they are not due to factors including insufficient family-centered care, ineffective communication between healthcare disciplines, and overall barriers in this setting (Givrad et al., 2021; Purdy et al., 2015). These barriers include how traumatic births can interrupt the process of developing the parent-infant relationship, NICU infants' unfamiliar communication styles, parents' lack of confidence in partaking in their infant's care, parents' struggle with mental health, being separated from their infant, and the general environment of the NICU (Givrad et al., 2021). While most parents are affected by these barriers, parents of color also have another obstacle that they face when in this setting.

### *Additional Barriers*

Research shows that Black or African American women in the United States have a 49% higher rate of experiencing a preterm birth (Sigurdson et al., 2019). The study found that infants in high-Black care-serving hospitals were provided with lower-quality standard care and had worse outcomes. It was also determined that Black infants had twice the rate of neonatal death rates compared to White infants (Sigurdson et al., 2019). The data showed that Black and Hispanic infants had a lower rate of referrals for high-risk follow-up care compared to White infants and that Black families noted dissatisfaction with comfort from staff, insufficient sympathetic communication, and decreased vigilant care with their medically complex infant. The findings recognized an increase in mothers of color who noted being deterred from skin-to-skin, compared to White mothers. The results found inequality in NICUs at the structural,

process, and outcome level and generally disadvantaged infants of color. To address these additional barriers, the development of a new measure for quality in the NICU should be created. Quality improvements that are targeted toward this issue are crucial in improving racial equality in the NICU (Sigurdson et al., 2019).

## Occupational Therapy Process

### *Evaluations*

While postpartum depression affects about 10-15% of mothers nationally, studies show that mothers with infants in the NICU are 40% more likely to experience postpartum depression and have a higher chance of experiencing post-traumatic stress disorder and anxiety compared to mothers without infants in the NICU (Berns & Drake, 2021; Shovers et al., 2021). In NICUs today, Berns and Drake (2021) identified that mothers continued to be unscreened for postpartum depression.

The American College of Obstetricians and Gynecologists and the American Academy of Pediatrics advocates for using the Edinburgh Postnatal Depression Scale (EPDS) for screening for postpartum depression, which can be used as early as the first week postpartum (Berns & Drake, 2021). Of the 25 mothers that participated in the study, 24% were found to have this mood disorder. These results elicited the institution for early screening and treatment for postpartum depression in mothers in the NICU as the earlier stages are more treatable (Berns & Drake, 2021; Cherry et al., 2016). Recommendations include providing screening and treatment in the same setting which would decrease costs, the need for transportation, and finding childcare (Berns & Drake, 2021). This study reiterates that mothers in the NICU are not being screened for this mood disorder, even though it is known that these mothers have an increased likelihood of experiencing postpartum depression, post-traumatic stress disorder, and anxiety.

Another psychometric evaluation study found the Persian Readiness for Hospital Discharge Scale is reliable and valid to use with parents in the NICU to identify if parents are ready for discharge (Salmani et al., 2020). While there is an American one, it is unsure if NICUs are utilizing this resource. Therefore, these facilities are not getting supplemental information determining areas parents may struggle with. Occupational therapy practitioners can administer and advocate facilities to complete these screenings for early identification and treatment for mothers with infants in the NICU. Occupational therapy practitioners can also provide interventions to facilitate parents transitioning into their new role as a parent of a medically complex infant, the development of the parent-infant relationship, and the building of trust between parents and the healthcare team.

### *Current Interventions*

One intervention occupational therapy practitioners use to address the aforementioned items is to discuss with parents that increased visitations and holding can be beneficial not only to the baby, which correlates with more fluid movement patterns and a calmer temperament, but also with parents as engaging with their infant may help alleviate psychological stress (Harris et al., 2018; Reynolds et al., 2013). A similar study recognized another intervention occupational therapy practitioners can use is to advocate for parents to have full access to the infant and systems for them to interact with the infant when not in the NICU, assisting with the physical closeness between parents and infant, which then accelerates emotional closeness (Thomson et al., 2020, p. 11).

Occupational therapy practitioners can help parents work through their anxiety, nervousness, postpartum depression, and post-traumatic stress disorder by providing family-centered resources that encourage parents to participate in their infant's occupations, such as

bathing and feeding, while also providing parents with education and social support regarding stress management to alleviate post-traumatic stress disorder symptoms (American Occupational Therapy Association, 2020; Sabnis et al., 2019). One evidence-based program that addresses this is the Parent Education Empowerment Program, or PEEP (Adams et al., 2022). PEEP is a one-on-one educational program that incorporates educational sessions, resources, and follow-ups throughout and after discharge. PEEP educates on feeding, bathing, sleeping, massage, the timing of milestones they should observe in their infant, establishing routines, and various aspects of mental health (Adams et al., 2022).

Another intervention occupational therapy practitioners can administer is the Supporting and Enhancing NICU Sensory Experiences, or SENSE program (Whitehill et al., 2021). The SENSE program is an evidence-based program that encourages parental presence and engagement by providing education for parents to deliver sensory interventions to their infants in the NICU. This program has been shown to increase parental confidence in their roles (Whitehill et al., 2021). The SENSE program educates parents on how to incorporate sensory activities each day of their infant's stay to maximize the sensory environment. The SENSE program includes specific times parents should incorporate auditory, visual, tactile, kinesthetic, and olfactory activities each day with their infant. When the infant reaches term equivalent age, it is recommended that there should be at least 3 hours of tactile and auditory, 16 minutes of kinesthetic, 7 minutes of vestibular, and individualized amounts of visual and olfactory activities each day (Whitehill et al., 2021).

An intervention occupational therapy practitioners can utilize to facilitate trust between the NICU healthcare team and parents is the Supportive Therapeutic Excursion Program, or STEP (McGuire-Brown et al., 2022). STEP involves parents walking their infant in a stroller

each day to build self-efficacy in their new roles while also passing trust from the staff onto the parents. This intervention helps parents build confidence in their roles and increase connectedness with their infants (McGuire-Brown et al., 2022).

Lastly, Smith et al. (2013) determined discharge preparation programs should be led by a professional with extensive knowledge of childhood development, such as an occupational therapy practitioner, and be implemented starting at admission to allow parents enough time to develop the skills and confidence of what will be expected post-discharge. The authors of this study discovered that preparation programs reduced hospital readmissions and increased the rate of follow-up care, which decreased costs. A discharge preparation program should be broken into two sections: (a) educating the family regarding infant care and (b) transferring care to those who will be working with the family post-discharge. Results from this study determined that the structure of the education portion must include incorporating family-centered care, using teaching strategies such as a checklist, practicing the skills needed to care for their infant post-discharge, and utilization of both written and recorded materials.

The research conducted by Smith et al. (2013) identified that using a checklist assists with the gradual progression of the content being learned while also communicating to the interdisciplinary team regarding the education the family still needs. The authors discussed that parents should practice their new skills throughout the education process as repetition increases the recall of the skill. The educational content for discharge should include skills for basic care, what they need in their home environment, car seat use, typical and nontypical infant behaviors, guidance on what to expect at home, components regarding mental health, and how to cope with stressors (Smith et al., 2013).

Throughout this literature review, two aspects to include in occupational therapy interventions in the NICU were increased education and emotional support from the NICU care team. These aspects must be evidence-based and user-friendly for it to be effective with this population.

**Evidence-Based Recommendations for Education and Emotional Support**

Kessler et al., (2020) determined that occupational therapy-led educational sessions should involve continued care and active participation while in the NICU, which in turn increases knowledge and maternal mental health. This review identified that education should incorporate relaxation techniques, information on caregiver-infant communication, and fundamental knowledge regarding caring for a medically complex infant. Integrating these aspects into education increases parental mental health and confidence in their abilities for their roles (Kessler et al., 2020).

Similarly, a guideline published by the Journal of Perinatology states that education should include preparing parents for their transition home by mentoring them on how to complete their daily occupations (Purdy et al., 2015). This guideline recommended that the mentorship should consist of feeding, providing medications, managing tubes, correctly ordering equipment, and performing CPR if necessary.

NICU settings should have designated health professionals, such as an occupational therapy practitioner, observe the family before transitioning to analyze their interactions and give feedback to equip parents with the skills needed to respond to their infant's cues, which assists in building the parent-infant relationship (Purdy et al., 2015). These authors also recommend that emotional support should be addressed through mental health screening paired with giving parents resources, educational handouts, and support groups in their area. Overall, coordinating

care across the healthcare team while focusing on the psychosocial factors that affect the development of the parent-infant relationship is essential in supporting these families and their infants (Purdy et al., 2015). With evidence-based interventions, there must be outcome measures to ensure efficiency over time.

**Measuring Outcomes**

One way that outcomes are measured is before discharge, parents must be able to distinguish between normal and abnormal behaviors and demonstrate basic care skills (Purdy et al., 2015; Smith et al., 2013). These are skills regarding feeding, bathing, safe sleeping, giving medications, managing tubes, correctly ordering and using equipment that will be in the home, performing CPR, safely utilizing a car seat, and maintaining healthy coping skills (Purdy et al., 2015; Smith et al., 2013). These studies identified most, if not all, skills that parents should be able to complete to increase their competency and personal causation before discharge, which can be educated by an occupational therapy practitioner.

**Introduction to the Product**

Parents are under extreme stress and due to this stress and overall environment, are experiencing anxiety, depression, and post-traumatic stress disorder. This can lead to an altered occupational identity, decreased occupational competence, a lack of personal causation, and a delayed parent-infant relationship, which can cause long-lasting physical and emotional deficits in the infant. The literature identified the need for additional education and support for parents to address the concerns stated above.

The evidence supports the increased need for parental support, which can be facilitated by occupational therapy practitioners. This is done by educating parents on how to care for their infant during their stay and post-discharge, while also coaching the parents on how to

communicate with the interdisciplinary team. The creation of an educational resource would increase parents' confidence in caring for their medically complex infant during their stay and post-discharge. This resource will decrease stress and anxiety for parents while enhancing their identity, competency, personal causation, and the parent-infant relationship. Chapter III will discuss the methodology used to identify relevant evidence, best practice for this population, theories that were used, and the creation of this scholarly project.

# Chapter III

# Methodology

## Product Development Idea

This product aimed to develop an accessible educational resource for parents with information and demonstration on how to safely engage in various occupations with their infant during their stay in the NICU and post-discharge. The author is interested in working with infants in the NICU as she learned about occupational therapy working with this population during her time in the program. The author was very passionate about creating a product that would benefit not only this population and their families but also the occupational therapy profession. A literature review and needs assessment were completed to identify gaps in services in this setting and the facility's specific needs. The author determined the idea for the project by collaborating with the NICU occupational therapy practitioner at the facility where the author was completing her 14-week doctor experiential placement.

## Literature Review

PubMed, CINAHL, and Embase were searched with various compilations of Boolean phrases including parents, neonatal intensive care unit (NICU), education, anxiety, stress, parental roles, parent-infant relationship, and occupational therapy. The American Journal of Occupational Therapy was also searched with the search terms parent-infant relationship, anxiety, and education. Lastly, Google Scholar was searched with the question "What is best practice for occupational therapists to reduce stress for parents with an infant in the neonatal intensive care unit to improve the parent-infant relationship?"

One OT Practice article from The American Occupational Therapy Association in March of 2022 was utilized during the literature review to identify best practices for educational

components for parents in the NICU. Inclusion criteria included articles from 2012-2022, use of preterm infants, and NICU based. Exclusion criteria include articles published before 2012 and not in a NICU setting. The total number of studies included in the literature review was 23. Of the 23 studies, 11 were published between 2020 and 2022, nine were published between 2015 and 2019, and three were published in 2013. This literature combined with directly stated needs from the NICU occupational therapy practitioners, pediatric occupational therapy practitioner, nursing team, speech-language pathologist, and lactation specialist concluded the needs assessment dedicated to this project.

**Need for Education**

Within the literature review, it was found that parents with infants in the NICU were experiencing extreme stress, anxiety, and post-traumatic stress disorder with symptoms lasting 3-6 months after discharge (Cook et al., 2018; Garfield et al., 2018; Harris et al., 2018; Purdy et al., 2015). These emotions affected parents' ability to confidently move into their new parenting roles with a medically complex infant, decreased their beliefs regarding their ability to complete various caregiving occupations, and delayed the parent-infant relationship (Garfield et al., 2018; Matricardi et al., 2013; Sabnis et al., 2019). The literature review revealed a need in providing increased education and emotional support for parents to increase their confidence in caring for their infant, which increased the bond, or the parent-infant relationship. This included education during bedside cares and teaching parents how to decipher their infant's communication (Kessler et al., 2020; Purdy et al., 2015; Sabnis et al., 2019; Smith et al., 2013).

**Guiding Occupational Therapy Theory**

The model that guided the literature review and needs assessment was the Model of Human Occupation (MOHO; Kielhofner, 2008). MOHO asserts that alterations in one's volition,

habituation, performance capacity, or environment can cause an inhibited performance pattern. Kielhofner (2008) also explains that to keep an equilibrium between these systems, repetition in an environment that is supportive is required. Lastly, occupational therapy practitioners address the client's thoughts and feelings regarding their occupational performance to create change.

The concept of repetition corresponds with this product as it offers various forms of materials to access information and demonstrations of various occupations while also encouraging parents with each handout. This allows parents to learn and review through repetition in a supportive environment, which also helps parents with maintaining equilibrium with their motivation, roles, and ability to complete caregiving occupations while in the NICU and post-discharge.

**Adult Learning Theory**

The author determined principles of andragogy teaching and learning theory must be incorporated throughout the project as the target audience is adults with infants in the NICU. The author utilized multidimensional learning by creating educational material using written, auditory, and visual components to adhere to various learning styles. The author also followed health literacy guidelines by ensuring that the materials were written at a 5$^{th}$-grade reading level. Embedding these components throughout the project ensures that adult learners can comprehend and retain the materials to apply them during their infant's NICU stay and after discharge. The following chapter describes the product, goals and objectives of the product, how theory is incorporated into the product, and implementation of the product.

# Chapter IV

# Product

## The Problem

Parents with infants in the NICU experience a heightened level of stress and anxiety in addition to an inhibited state of occupational identity and occupational competence due to stressors in this setting (Berns & Drake, 2021; Gibbs et al., 2016; Jiménez-Palomares et al., 2021). These stressors include an infant in the NICU's communication style, the equipment being used in this setting, medical jargon being used by the NICU team, and the overall concern regarding the infant's safety (Berns & Drake, 2021; Harris et al., 2018; Purdy et al., 2015). Parents in this setting are also experiencing a delayed parent-infant relationship, which has long-lasting effects on the infant, including the development of their brain, inhibited development of motor skills, and potential behavioral difficulties (Pineda et al., 2018).

The author used themes found in the literature review and needs assessment and incorporated principles from MOHO and andragogy teaching and learning theory for the creation of an evidence-based product (Bastable et al., 2020; Kielhofner, 2008). The following information discusses the product, whom the product is utilized by, and how to implement the product into practice. Overall, the product is a program to educate parents to assist them with moving into their new role and increase their understanding and competence with caregiving occupations.

## Goal

The goal of this program, entitled *"How to" Activities for Positive Parent Engagement and Empowerment Program*, or the *HAPPEE Program*, is to increase parents' confidence and involvement with their infant in the NICU and after discharge.

## Objectives

By discharge, 25% of parents with infants in the NICU will report

- A decrease in stress and anxiety (volition)
- An increase in the bond between them and their infant (volition)
- An increase in confidence when engaging with their infant (personal causation)
- An increase in competency in their new parenting roles (habituation, occupational identity, and occupational competence)

The stated goal and objectives are accomplished by providing education and emotional support for parents to participate in caregiving occupations with their infant. The goal and objectives can be measured by the parent satisfaction survey at the end of Appendix A.

## The Product

The *HAPPEE Program* uses handouts and QR codes to access videos for parents to view during their infant's NICU stay and post-discharge regarding caregiving occupations with their infant. These occupations include the progression of feeding stages, diaper changes, neonatal massage, skin-to-skin, and swaddle bathing. The handouts discuss signs that an infant may be in distress and how to help the infant return to a calmer state. There are also handouts describing occupational therapy equipment they may see while in the NICU, developmental milestones for one to four months, and early intervention services that are available post-discharge. The *HAPPEE Program* uses strategies from andragogy teaching and learning theory by incorporating visual, auditory, and written material, known as multidimensional learning styles. This program also targets health literacy, ensuring that the materials meet the standards of a 5th-grade reading level. These strategies facilitate comprehension for an adult learner (Bastable et al., 2020). This

program increases parents' confidence in completing these occupations and includes information relevant to both the infant's stay in the NICU and post-discharge.

The *HAPPEE Program's* educational handouts discuss how a parent can safely engage with their infant while completing various occupations. This program empowers parents by increasing their personal causation, or belief in their abilities, when completing caregiving occupations with their infant, and therefore, decreases their stress and anxiety while facilitating the development of their occupational identity, occupational competence, and the parent-infant relationship. Below is a color-coded chart discussing the incorporation of MOHO.

| Concepts of MOHO | |
|---|---|
| Volition | Parents' lack of confidence in taking care of their medically complex infant |
| Habituation | Alteration of roles, disruption in previously set expectations |
| Performance Capacity | Parents needing knowledge of NICU infant communication style, how to engage with their infant |
| Environment | The stressful environment of the NICU, no medical team for parents to rely on while at home |

## Implementation of Product

The *HAPPEE Program* is a resource for parents of infants who are admitted to the NICU. Once an occupational therapy practitioner has evaluated the infant, the infant's medical team can guide parents to this resource. The occupational therapy practitioner and other team members on the infant's team can guide parents on which activities are developmentally appropriate for their infant's current medical status and as they grow and develop through their stay in the NICU and at home. Since occupational therapy practitioners are with infants and their families for a brief period of their time, this program is beneficial as parents can reference information from their occupational therapy practitioner at any given time.

Additionally, the *HAPPEE Program* can be used for transferring care to early intervention services. The occupational therapy practitioner working with the infant can inform parents of what early intervention is and who can send in a referral for early intervention services before discharge. Informing families about early intervention services in the area and how to start with these programs will help in a smoother transition of services needed for the infant and their families. The full implementation plan can be found in Appendix C.

## Summary

Concepts of MOHO and andragogy teaching and learning theory were used to influence the creation of the *HAPPEE Program* and were incorporated throughout the program itself. The *HAPPEE Program* gives visual, auditory, and written educational materials, which are components of how adults learn best (Bastable et al., 2020). The *HAPPEE Program* also addresses parents' personal causation by having information to reference and safely practice caring for their infant while in the NICU and at home. Having this information readily accessible to parents with infants in the NICU helps facilitate the skills needed to safely engage in

caregiving occupations, which increases their occupational identity and occupational competence.

The *HAPPEE Program* should be utilized by parents with infants in the NICU as a reference tool to facilitate their newly formed occupational identity, occupational competence, and personal causation when interacting with their infant. Since the *HAPPEE Program* targets parent education, it is important to recognize adult learning styles to ensure parents' comprehension of the materials and confidence to carry out the various caregiving occupations with their medically complex infant while in the NICU and post-discharge. Please refer to Appendix A to view the *HAPPEE Program.*

# Chapter V

## Summary

The literature review identified that parents with infants in the NICU were experiencing an alteration in their roles along with high levels of stress and anxiety leading to an inhibited occupational identity and occupational competence. The literature review paired with the needs assessment for the facility influenced the creation of the *HAPPEE Program*.

This program was created for parents with infants in the NICU to have an occupation-based and evidence-driven resource to access at any point during their infant's stay in the NICU and after discharge. The *HAPPEE Program* is used to support parents' caregiving roles and the development of the parent-infant relationship. This program uses concepts from MOHO and andragogy teaching and learning theory. This program utilizes MOHO by including repetition, such as providing encouragement throughout each handout and demonstrating how to give hand hugs during multiple occupations. This program includes foundations from andragogy teaching and learning theory by incorporating multidimensional learning, such as written, auditory, and visual material, and following health literacy guidelines, ensuring that all materials are at a 5th-grade reading level. These aspects support parents with infants in the NICU in building their occupational identity, occupational competence, personal causation, and parent-infant relationship while decreasing their stress and anxiety.

### Strengths

One strength of the *HAPPEE Program* includes the utilization of written, auditory, and visual learning. Multidimensional learning targets different learning styles to assist with comprehension of the material. Another strength of this program is providing increased access to the materials for parents to review as needed. Parents can review the material multiple times at

various locations for repetition of knowledge and practice. A strength of this program also includes incorporating evidence-based interventions paired with simple demonstrations of various occupations to engage with their infant.

Foundations of MOHO were utilized within each video by giving information repetitively in a supportive environment to facilitate the parents' caregiving roles, occupational identity, occupational competence, and parent-infant relationship. Supporting parents in completing occupations with these new roles increased their personal causation and performance capacity in caregiving for a medically complex infant.

**Limitations**

While this program will benefit the targeted audience, there are a few limitations. One limitation of the *HAPPEE Program* is that it has not yet been implemented into clinical practice due to the time needed for the facility's marketing approval. Therefore, there has not been an opportunity to gather comments or feedback from parents regarding the program's effectiveness. While this program can be used by other occupational therapy practitioners, the resources in the early intervention handout are based locally and may not apply to other communities. Finally, the *HAPPEE Program* is not all-encompassing and therefore should be utilized as supplemental education to the standard level of education and care normally provided.

**Further Recommendations and Development**

The *HAPPEE Program* is intended to be administered by occupational therapy practitioners at the neonatal intensive care unit facility the program was designed for. If warranted, the *HAPPEE Program* can be implemented at both local and non-local NICU facilities, noting that the early intervention handout may not apply to non-local NICUs. Occupational therapy practitioners can modify and change aspects within the program to reflect

best-practice recommendations and updates to services. As stated earlier, it is recommended to use this program as supplemental material for in-person education and care.

## Implications for Practice

Occupational therapy in the NICU setting is an emerging practice that supports not only infants but their parents as well. The *HAPPEE Program* includes occupation-based and evidence-driven educational materials to facilitate the repetition of skills in a supportive environment to empower parents with their abilities in their new roles. This program was influenced and developed from the literature within the last ten years and can be used by other occupational therapy practitioners in the NICU.

The *HAPPEE Program* supports parents with infants in the NICU, occupational therapy students, and occupational therapy practitioners. This program incorporates multidimensional learning, is easily accessible, and includes best practices for this setting, all of which are essential for assisting parents with building the skills and confidence needed to empower them in their new roles.

## Conclusion

When an infant is admitted to the NICU, parents' expectations related to caregiving change. The infant may need a variety of medical devices and the collaboration of a medical team to keep the infant safe and ensure they are stable. This potentially overwhelming experience can negatively affect parents, causing increased stress, anxiety, depression, and post-traumatic stress disorder even months after their infant has been discharged.

A literature review was conducted to identify themes and gaps in services for parents in this setting. Within this review, it was found that some causes of psychological stress in parents included the fear of their infant's health status, the medical terminology used, and a premature

NICU infant's communication style. The disruption in expectations prompted parents to experience altered occupational identities of being new parents, a decrease in their beliefs about their ability to care for their medically complex infant, and a delayed parent-infant relationship. These all can lead to continued difficulties for parents after discharge and can cause life-long impacts on the infant.

To address this heightened level of psychological stress, the literature review identified that parents in this setting need increased education and emotional support which can be facilitated by an occupational therapy practitioner. Thus, the *"How to" Activities for Positive Parent Engagement and Empowerment Program*, or the *HAPPEE Program*, was created. This program incorporates concepts from MOHO to change the perceptions of parents regarding their capabilities in caring for a medically complex infant. The *HAPPEE Program* uses repetition and encouragement throughout each educational piece to increase parent confidence and involvement. The program was also influenced by the andragogy teaching and learning theory. This theory includes multidimensional learning and health literacy to ensure adult comprehension of the educational material. The author utilized auditory, visual, and written material at a 5$^{th}$-grade reading level to facilitate the understanding of materials with various learning styles within the targeted audience.

The *HAPPEE Program* is designed for parents with infants in the NICU and can be used as the infant is in the NICU, progressing to discharge, and while at home. Implementing the *HAPPEE Program* supports parents in increasing their confidence, adjusting to this new role, and developing the parent-infant relationship which supports both the infant and parents for positive outcomes later in life.

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Appendix A

# *The "How to" Activities for Positive Parent Engagement and Empowerment Program*

## *The HAPPEE Program*

By Megan Berginski

# *The "How to" Activities for Positive Parent Engagement and Empowerment Program (The HAPPEE Program)*

This program was influenced by the incorporation of the Model of Human Occupation (MOHO) and andragogy teaching and learning theory during the research process and creation of the program (Bastable et al., 2020; Kielhofner, 2008). The author incorporated MOHO by including repetition of various activities within each occupation, such as providing hand hugs and talking softly to their baby, while also providing support and encouragement to parents to engage with their medically complex infant. The author also utilized multidimensional learning and health literacy with the use of auditory, visual, and written material at a 5$^{th}$-grade reading level. Integrating both theories within the program facilitates an increase in parent confidence and involvement with their infant while in the NICU and at home.

## **Volition** and **Habituation**

Throughout the entire program, volition and habituation are indirectly addressed by the **increase in knowledge and practice of skills, increasing the parent's confidence** in their **new roles** and abilities when interacting with their infant. Volition is also addressed by providing **encouragement within each educational piece.**

| Concepts of MOHO | |
|---|---|
| Volition | Parents' lack of confidence in taking care of their medically complex infant |
| Habituation | Alteration of roles, disruption in previously set expectations |

**Performance Capacity** and **Environment**

MOHO was incorporated within this section by providing information about the **NICU environment and services for after discharge**, **and activities to promote developmental milestones**, which involves both environment and performance capacity. The following handouts were created to increase knowledge regarding these subjects

- Developmental Milestones with activities (1-4 months)
- Occupational Therapy Positioners
- Early Intervention Services

| Concepts of MOHO | |
|---|---|
| Performance Capacity | Parents needing knowledge of NICU infant communication style, how to engage with their infant |
| Environment | The stressful environment of the NICU, no medical team for parents to rely on while at home |

# Developmental Milestones

1 Month

## What can you expect from baby?

- Turns their head side-to-side while on their back
- Starts to briefly lift their head while in tummy time
- Follows your face
- Gets startled by sudden noises
- Makes throaty noises such as grunts, gurgles, and growls

## What is helpful at this age?

Give baby toys with different textures and sounds. Encourage baby to grab toys. You can help do this by wrapping baby's fingers around the object.



Babies this age sleep about **16 hours a day**! Promote safe sleeping in the home. Have baby on their back, on a firm mattress, with no blankets. Sleep sacks and Velcro swaddles are safe to sleep with.

When they are awake, place baby in tummy time for short periods of time as baby allows. Get face-to-face or add toys to keep them interested. Other positions include holding baby in a "football hold." This also helps stretch out their neck.

The football hold is when you place your baby over your forearm. Support their head in the natural bend of your elbow. Rest your opposite arm between baby's legs supporting them with your hand at their tummy or shoulder.

Place a mobile with black and white contrast for baby to look at. You can also move the crib to different locations in the room. This gives baby new things to look at.

For the first 2 years, you will correct your preterm baby's age for their development. Calculate your baby's age corrected age from your due date. This will give you a better idea when they may reach common developmental goals.

Keep in mind that premature milestones may differ from the milestones of a full-term baby. If baby is not meeting the same milestones at the rate of another baby that was born at term, don't worry! Keep doing age-appropriate activities for baby, use services that target developmental milestones, such as early intervention, and celebrate the small wins with baby.

# Developmental Milestones

2 Months

## What can you expect from baby?

- Starts to lift their chest off the floor while on their stomach
- Their head starts to bob back and forth when in an unsupported seated position
- Holds rattle if you place it in their hand
- Starts to hold their hands together
- Follows large, black and white high-contrast items or toys
- Recognizes parents
- Social smiles
- Coos, “oooh,” “aaaah,” “eeeh” noises

## What is helpful at this age?

Continue to give baby toys with different textures and sounds (O-ball, rattles, light up, or noise-making toys). Babble back and forth with baby. Imitate sounds they are making.

Do not overuse of bouncers, jumpers, bamboo seats, or the like. It can cause container baby syndrome. This is when a baby spends most of their day within some sort of device. It limits their freedom to move and explore their environment on their own. This can affect their motor and language abilities.

We like to see babies in a C position. This engages their core muscles. When your baby is in your lap, you can encourage baby to hunch over. Rather than arch their back.

Babies this age sleep about **14-17 hours a day!** When they are awake, place baby in tummy time and side-lying as baby tolerates. Get face-to-face, add toys, or use a play mat to keep them interested. Encourage baby to reach for toys.

Get baby’s attention with a toy or your face. Slowly move it side to side and up and down to help baby track it with their eyes.

Watch to see if baby has a head turn preference. This is when your baby turns their head to one side every time they sleep or during tummy time. See if one of baby’s shoulders looks like it is closer to their ear than the other shoulder.

Some ways to help prevent this is by changing the side you stand when you change baby’s diaper, place toys on the opposite side of baby when in tummy time, and change the direction of the head of the crib when baby sleeps.

For the first 2 years, you will correct your preterm baby’s age for their development. Calculate your baby’s age corrected age from your due date. This will give you a better idea when they may reach common developmental goals.

Keep in mind that premature milestones may differ from the milestones of a full-term baby. If baby is not meeting the same milestones at the rate of another baby that was born at term, don’t worry! Keep providing age-appropriate activities for baby, use services that target developmental milestones, such as early intervention, and celebrate the small wins with baby.

# Developmental Milestones

3 Months

## What can you expect from baby?

- Starts to put weight on their forearms while on their belly
- Rolls from their back to their side
- Swings arms and hands at items
- Looks at toys for longer periods of time
- Follows toys with their eyes while on their back
- Follows a person with their eyes as they move through the room
- Laughs
- Makes sounds when they are talked to

## What is helpful at this age?

Read books with colorful pages. Let baby interact with the pages. Sing lullabies to baby.

Encourage baby to reach and grab toys. To help with this you can grab baby's hand and help them to reach for toys. A play mat helps encourage baby to reach and bat at toys.

Do tummy time when baby is awake. You can place a mirror in front of baby to keep them interested.

While baby is on their back, help them grab their feet. This helps prepare them to start rolling.

Do not overuse of bouncers, jumpers, bamboo seats, or the like. It can cause container baby syndrome. This is when baby spends most of their day within some sort of device. This can affect their motor and language abilities.

Continue to promote safe sleeping. Once baby starts to roll, swaddle them with their arms free.

For the first 2 years, you will correct your preterm baby's age for their development. Calculate your baby's age corrected age from your due date. This will give you a better idea when they may reach common developmental goals.

Keep in mind that premature milestones may differ from the milestones of a full-term baby. If baby is not meeting the same milestones at the rate of another baby that was born at term, don't worry! Keeping doing age-appropriate activities for baby, use services that target developmental milestones, such as early intervention, and celebrate the small wins with baby.

# Developmental Milestones

4 Months

## What can you expect from baby?

- Sits with support
- Rolls from belly to back
- Reaches for items consistently
- Shakes and explores rattles
- Starts to hold breast or bottle
- Mouths toys and objects
- Stops crying at the sound of your voice
- Head turns in the direction of a voice

## What are helpful at this age?

Support baby to sit while they are sitting in your lap.

Keep imitating baby's sounds and reading books with baby.

Give baby teethers.

Place toys that interest baby slightly out of reach during tummy time. Encourage baby to reach out on their own.

Place a toy in baby's line of sight. Move it to encourage baby to roll. A baby's vision directs their movement. Place your hand on baby's hips to help them roll.



For the first 2 years, you will correct your preterm baby's age for their development. Calculate your baby's age corrected age from your due date. This will give you a better idea when they may reach common developmental goals.

Keep in mind that premature milestones may differ from the milestones of a full-term baby. If baby is not meeting the same milestones at the rate of another baby that was born at term, don't worry! Keep doing age-appropriate activities for baby, use services that target developmental milestones, such as early intervention, and celebrate the small wins with baby.

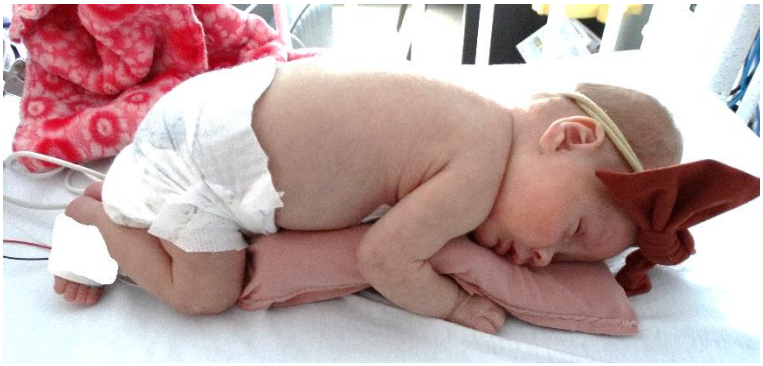
# Occupational Therapy Positioners You May See While in the NICU

## Positioners (boundaries)

Positioners help baby stay flexed and supported, which helps baby's musculoskeletal development.

These boundaries are used to keep baby's knees and hips tucked into their body, their arms/hands close together near the face and middle of their body, and their head in line with their spine.

These boundaries can help position baby on their back, side, and tummy. They also help baby feel safe and secure.



# Early Intervention

*For Care After Discharge from the NICU*

## What is Early Intervention?

Early Intervention (EI) is a program for children from birth to age 3 to help your child meet their developmental milestones.

After you agree to a referral, a team will come into your home to see your child. If your child qualifies, a plan would be created to support you and your child in your home as needed. The plan helps your child make progress with their development.

Your child's team would be led by an early intervention service coordinator, an occupational therapist (OT), a physical therapist (PT), a speech-language pathologist (SLP), an early childhood special educator, or a social worker.

All are specialties that could answer any questions you may have about your child's development.

## Why Might My Child Need Early Intervention?

NICU babies are more likely to have a delay in meeting childhood milestones. It's okay as early intervention can help.

This program gives you and your child tools and skills early on. It helps children meet the same milestones as their peers faster than if a child does not receive services. Your child is also less likely to need occupational or physical therapy services later in childhood.

## How Much Does EI Cost?

EI is a free program for all families.

## How Can I Get My Child Referred?

1. Call to refer your child to the early intervention program through your local county health and human services or school district
2. Talk with your child's doctor about a referral
3. Go to
    a. righttrack5.org (for North Dakota)
    b. helpmegrowmn.org (for Minnesota)
    c. actearly.wisc.edu/ (for Wisconsin)

## Performance Capacity

The utilization of MOHO within this section includes **demonstrating the skills needed to safely engage with their infant**, or to increase their performance capacity. The following videos were completed for demonstration of occupations including

- Progression of feeding stages (pre-feeder and early feeder)
- Swaddle bathing
- Diaper changes
- Skin-skin
- Neonatal Massage

**The early feeder, skin-skin, and neonatal massage handouts come with a QR code

| Concept of MOHO | |
|---|---|
| Performance Capacity | Parents needing knowledge of NICU infant communication style, how to engage with their infant |

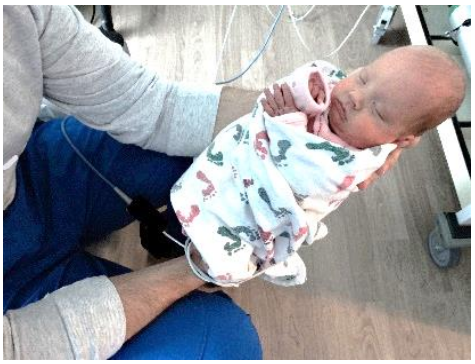
# Feeding Activities for the Pre-Feeder

Babies are not always born ready to eat safely. Once baby starts to show hunger cues, we will assess your baby to see if they are ready to each by bottle or breast.

We will give your baby a feeding tube until they are ready to eat. This tube travels to their stomach either through their nose or their mouth to provide nutrition.

## What you can do during this time to help your baby

- Swaddle your baby and hold them in an upright position
- Skin-to-skin
- Talk softly to your baby



Keep in mind, feeding skills do not become ready with practice. Rather when your baby's brain is more developed to learn these skills. For now, enjoy this time to bond with your baby.

# The Early Feeder

While baby is developing the skills to eat, your healthcare team will assess your baby for feeding cues. The timing of this depends on baby's readiness.

## Feeding cues include:

- Opening their mouth and turning their head for food, also called rooting
- Bringing their hands to mouth
- Sucking on their hands and fingers
- Staying awake during feeding times
- Nestling at the breast
- Smacking lips
- Sucking on their pacifier for a few minutes at a time

## Pre-feeding activities we can do before your baby is ready for bottle feeding:

1. Your baby can do **non-nutritive sucking**. This is when your baby sucks on
    a. A pacifier
    b. Mom's breast after pumping
    c. A clean gloved finger
2. Your baby can also do **tethered tasting**. This is when you
    a. Place a drop of breast milk or formula on a pacifier or gloved finger
    b. Let your baby start sucking

This gives the baby rewards for showing feeding cues. It lets them taste the breast milk or formula to help their coordination.

The first position we encourage once your baby is ready to bottle feed is: **Upright Side Lying**

1. Swaddle your baby (pictures show not swaddled and swaddled baby for educational purposes. See the position of hip, shoulders, neck)
2. Support their head and neck. Place the bottom of your baby on your legs or a pillow

What are the benefits of this position?

- Slows the milk down. This makes it easier for your baby to manage
- Keeps your baby awake
- Helps to see and feel your baby's breaths, positioning, and latch

## Cues to watch for

1. Watch your baby's color:
    a. If baby does change color, take the nipple out. Press your call nurse button.
    b. If baby does not naturally recover, start by rubbing their head or chest.
2. If baby starts to cough while eating:
    a. Stop feeding your baby and take the nipple out of baby's mouth.
    b. Position baby upright and forward and pat baby's back.
3. Gulping noises:
    a. Tip the bottle down. This stops the milk from entering the nipple.
4. Gagging or not wanting to take the bottle anymore:
    a. Stop feeding and take the nipple out of baby's mouth.
    b. Give baby a rest break.
    c. Try burping or gently reintroducing the nipple around their lips and tongue to get them interested again.
    d. If your baby still is to not be interested, do not force-feed them.

Let them rest and we can try again at another time. It is okay if they want to be done!

Quality over Quantity – At this time, sleep is more important than the volume of milk your baby takes.

- We want to teach good eating habits and let baby know that feeding time is fun and enjoyable
    - If we push babies to eat, this teaches them poor eating behaviors, which can cause difficulty later.

The most important thing for your baby right now is to sleep. Babies' brains develop the most while they are sleeping.

Let your baby sleep. This will help with feeding down the road.

## What are some helpful tips?

- Use pillows to position yourself and your baby.
- Point the bottle towards baby's ears. Align it with their nose.
    - Place the nipple at the roof of their mouth. This will help them to latch easier.
- Gently massage baby's lips or gums to stimulate interest.
- Try not to twist the bottle or take it out of baby's mouth too much.
- Give your baby breaks when they stop sucking, need to burp, or cough.
- For burping, sit baby on your lap. Cup their face using your hand to support their neck.
- Your therapist or nurse can help you pace your baby so they can maintain their breathing.
- Keep lights dim and keep it quiet so baby can focus.

**Important** - watch your baby for cues rather than watching the monitor. Baby will let you know that they are having a tough time faster than the monitor can.

This part of the NICU stay can be frustrating. It can take time. Every baby develops differently and at their own pace. Be patient. Try not to push them to eat more. Let them lead you to when they want to eat. For now, enjoy this time to bond with your baby.

(S. Ludwig & K. A. Waitzman, personal communication, November 4, 2013)

# Swaddle Bathing

There are several factors for when baby can have their first bath in the NICU. It depends on their age and level of health. It is recommended to wait 24 hours before bathing baby.

For babies born less than 32 weeks, a sponge-bath with no soap is preferred. Babies born after 32 weeks can be bathed every 2-3 days with baby-friendly soaps. Once your baby's umbilical stump has healed, you can submerge baby in water.

Bathing is normally a night shift activity done by your nurse. You can always let your nurse know you want to be present. Bathing can be very calming for baby if done correctly. Your nurse and doctor will help determine when your baby is safe to swaddle bathe.

There are 3 types of bathing in the NICU

1. Sponge bathing
2. Swaddle bathing
3. Tub bathing

## What are the benefits of swaddle bathing?

Swaddle bathing helps :

- Maintain baby's temperature.
- Lessen baby's stress and time crying.
- Support baby's development. It keeps them flexed and contained.

Ask your nurse if you can help with swaddle bathing your baby when you are ready.

## Supplies you will need:

- Neonatal tub
- Small thin blanket
- Baby-friendly soap (from the hospital)
- Washcloth
- Cup
- Warm towel to dry
- Clean diapers and maybe clothes

## Steps in Swaddle Bathing your Baby While in the NICU

### Test water temperature

- It should just feel warm, not hot
- Ideal temperature is 100 degrees

### Swaddle your baby

- Remove baby's clothes and monitors with help from your nurse
- Use a thin blanket

### Place baby in the tub

- Always keep your hands on your baby
- Make sure their head is supported

### Wash your baby's head and neck

- Wipe eyes and then their face with no soap
- Shampoo and rinse baby's hair
- Wash in neck creases and down to belly

**Important to note**: Special areas that need cleaning are creases around the

- Neck.
- Armpit.
- Groin.

### Wash baby's arms and legs

- Take 1 arm out at a time to wash, cleaning armpits too
- Take 1 leg out at a time, cleaning groin areas

### Dry baby

- Use a warm dry towel to hold and dry baby
- Put on diaper and check with your nurse to see what baby's next activity should be

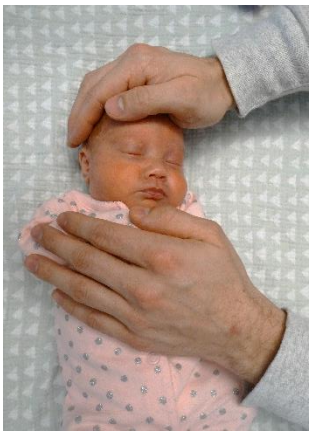
If your baby is not wearing clothes, you can place them back in the warmer with their diaper. This could also be a good time for skin-to-skin time or feeding your baby.

Keep calm and enjoy this time to bond with your baby.

# Diaper Changes

Diapers are usually changed every 3 hours in the NICU. This is a great way to get involved in baby's care.

When you are ready, ask your nurse if you can help with changing baby's diaper. Most parents may feel like they are "in the way" of baby's medical team. Rest assured, we are here to help you interact with and safely care for your baby.



You can give hand hugs if you are not ready to change baby's diaper. Hand hugs are a great way to make your baby feel more comfortable.

Place your hand on your baby's head and across their arms. It's like you are giving a hug. Give constant and light pressure. Try not to stroke baby. Stroking is harder for babies to adjust to.

You can leave your hands on your baby throughout the nursing care. Keep your hands on baby when the nurse is done. Slowly take 1 hand off at a time. This will help keep your baby calm.

## What are some helpful tips for diaper changes?

Check with your nurse if your baby has a skincare protocol. When you are ready, follow these tips.

Wash your hands before and after diaper changes. Use **warm** soapy water. Warm hands are calming to a baby.

There are 2 ways to change your baby's diaper while you keep them calm:

1. Place a new, proper-fitting diaper under the unopened dirty diaper. This helps to avoid soiling the bedding. Try not to raise your baby's hips so high that their back comes off the bed. Try to keep baby's lower back on the bed. Turn baby side to side if you need to wipe their lower back.

2. Roll baby's hips to 1 side. Place a clean diaper under baby. Roll baby's hips towards the other side to center the diaper under baby. Keep rolling baby's hips from side to side to remove the dirty diaper and clean baby's skin.

Fold the top half of the diaper down. This will keep the diaper from irritating your baby's healing umbilical stump. Make sure the diaper sticky strips are not stuck to baby's skin. Their skin is very sensitive.

**How to keep your baby calm when you do diaper changes by yourself:**

1. Try to change baby's diaper right as they wake up or right before feedings. If your baby becomes very upset or inconsolable, feed them a little to satisfy them, then change their diaper.
2. Offer a pacifier.
3. Keep your hands warm. Use warm wipes. You can warm them up in your hands if you do not have a warmer.
4. Provide a half-swaddle. Swaddling only your baby's upper half.

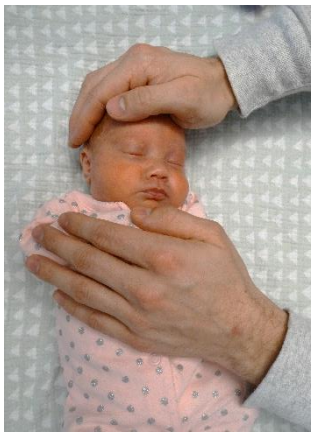
Most importantly, keep breathing and stay calm. You can do this!

# Skin-to-Skin

Skin-to-skin is when you hold your baby chest-to-chest. Your skin is touching your baby's skin. This is also called Kangaroo care. Your baby is naked except for a diaper and a blanket. Or you can put part of your clothing over your baby's back.

Hold your baby for at least 1 hour. This is a normal sleep cycle for your baby. Place your baby back in their bed if you are falling asleep. Don't have your baby sleep with you. Push your call light if you need help.

If you are not yet ready to do skin-to-skin, providing hand hugs is a great activity to participate in!



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You can leave your hands on your baby throughout the nursing care. Keep your hands on your baby when the nurse is done. Slowly take one hand off at a time. This will help keep your baby calm.

## What are the benefits of skin-to-skin for babies?

- Staying warmer.
- Staying calmer.
- Heart and breathing rates become regular.
- Improves sleep.
- Improves feeding and digestion.
- Healthy weight gain.
- Lessens pain.

## What are the benefits of skin-to-skin for parents?

- Less stress.
- Promotes bonding with your baby.
- Gives you more confidence to hold and interact with your baby.
- Improves your milk supply.

## Helpful tips for skin-to-skin

Ask your therapist or nurse if you can do skin-to-skin with your baby. This is a great first step!

Even if your baby is on a breathing device, your baby's therapist or nurse can help you do skin-to-skin.

Wear clothes that allow you to easily do skin-to-skin with your baby.

Ask your therapist how to use blankets or a wrap to help you be more hands-free.

Stand at the crib with your baby's feet towards you. Bring your chest to your baby as you are able. Keep your baby's arms and legs tucked against you. This will help prevent flailing and stress.

As you hold your baby skin-to-skin, feel for their breath on their back. Ask your therapist or nurse for a mirror so you can look at your baby's face.

It's best to not be on your phone during this time. Enjoy this bonding time. Baby is listening for your voice, breathing sounds, and heartbeat.

Lower the lights and sounds. Have less movements in your baby's room. This will help to not disrupt your baby's sleep.

You can do this! Keep breathing and stay calm.

Enjoy this bonding time with your baby.

# Neonatal Massage

While in the NICU, your occupational therapist can help you give neonatal massage. Be sure to also get approval from your nurse.

## What are the benefits of neonatal massage?

- Helps digestion.
  Lowers stress and pain.
- Improves circulation.
- Improves parent-infant bonding.
- Helps with the sleep-wake rhythm.
- Helps with weight gain.
- Helps with brain development.
- Improves breathing and heart rate.
- Helps maintain temperature.

## Back Massage

1. Place your baby on their stomach.
2. Lightly hold your hands on your baby's back until they have adjusted to your touch.
3. At a snail's pace, move your hands down your baby's back. Keep your hands and fingers together.
4. Once your hand reaches baby's bottom, gradually release it. Cross over to place it just below their neck.

Important - it is not about how many strokes you do or how long you do it. It's about getting a relaxed response from your baby.

## Arm Massage

1. Place your baby on their side.
2. Hold your hands still on your baby's shoulder blade until they have adjusted to your touch.
    a. With your other hand, hold your baby's wrist to support their arm off their bed.
3. Once baby is ready, very slowly move your baby's shoulder blade down and out.
4. Next move your fingers down to your baby's shoulder and upper arm.
    a. Cup your hand around baby's arm.
    b. Place your thumb on the front of your baby's arm, and your fingers on the back of their arm.
    c. Try not to go over your baby's armpit as this can be ticklish.

5. Slowly move down their arm. Let your baby straighten their arm rather than pulling it straight.
6. When baby relaxes and straightens their arms, move slowly down their forearm, wrist, hand, and fingers. Try not to let their arm drop. Hold their wrist as you let go with your stroking arm.
7. Repeat to baby's other arm

Again, this process should be very slow. It is more important how baby responds than how many strokes you did.

## Leg Massage

1. Place baby on their back.
2. Un-swaddle 1 leg.
3. Undo 1 side of baby's diaper
4. Stand at the foot of baby's bed. Hold 1 hand on baby's upper thigh. Hold baby's foot with your other hand. Do this until your baby has adjusted to your touch.
5. When baby is ready, cup your hand around your baby's leg. Thumb on the inside of their thigh. Slowly glide your hand down baby's leg.
6. Re-swaddle that leg when you are done. Un-swaddle the other leg for a massage.

Again, it is more important in how baby responds than how many strokes you do. Keep all massages very slow.

### Do **not** do neonatal massage if your baby has

An infection.
A bleeding disorder.
Phototherapy.
A skin disorder.

### Signs your baby is **not** tolerating massage

Heart rate will go up.
Fidget.
Cry.
Drop in oxygen (lower than 90%).

### Massage Oil

Oil lessens friction. This makes massage more comfortable for your baby. Use natural, unscented oils such as grapeseed, sunflower, or coconut. Natural oils are easily absorbed by the body. Stay away peanut and tree nut oils. These could be an allergen. You should also not use mineral oils or lotions. These are not easily absorbed by the body and can disrupt the intestinal tract.

Enjoy this time to bond with your baby.

(Waitzman, personal communication; Usher, personal communication)

# HAPPEE Program Satisfaction Survey

"How to" Activities for Positive Parent Engagement and Empowerment Program

| **During your infant's stay in the NICU:** | **Strongly disagree** | **Somewhat disagree** | **Neither agree nor disagree** | **Somewhat agree** | **Strongly agree** |
|---|---|---|---|---|---|
| **1.** This program decreased my stress and/or anxiety. | 1 | 2 | 3 | 4 | 5 |
| **2.** This program made me feel more confident when interacting with my baby. | 1 | 2 | 3 | 4 | 5 |
| **3.** This program helped me bond with my infant. | 1 | 2 | 3 | 4 | 5 |
| **4.** This program helped me develop into my role as a parent with an infant in the NICU. | 1 | 2 | 3 | 4 | 5 |
| **5.** This program increased my knowledge of how to interact with my baby. | 1 | 2 | 3 | 4 | 5 |
| **6.** This program was helpful for me while in the NICU and/or at home. | 1 | 2 | 3 | 4 | 5 |
| **7.** This program helped me discharge to home. | 1 | 2 | 3 | 4 | 5 |
| Are there any improvements that you feel we could make that would benefit this program? | Comments: | | | | |

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Appendix B

## Permission Statements

*Written parent permission for taking infant photos and verbal permission from the NICU nursing supervisor for taking photos of the equipment utilized in the neonatal intensive care unit were obtained prior to the creation of the product. The facility's marketing team has all written parent consent and photos used on record. Permission statements are also included below. Images and videos used within the "How to" Activities for Positive Parent Engagement and Empowerment Program are subject to copyright.*

**Photo and Video Release Form**

I grant permission for Megan Berginski and the Occupational Therapy Department at the University of North Dakota School of Medicine and Health Services to use photographs and/or videos of me for her scholarly project entitled *Increasing Parent Confidence and Involvement in the NICU: An Occupational Therapy Educational Guide*. I understand that these may be published in scholarly work through Scholarly Commons, a repository service of the University of North Dakota libraries, which may be accessed around the world.

Signature Skylar Bailey

Printed Name Skylar Bailey

Date 2/20/23

☒ I give permission to use photos and/or videos of my child/children who are under 18 years of age.

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Signature Mark Durham OTR/L

Printed Name Mark Durham

Date 2/20/23

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Appendix C

## Implementation Plan

### Purpose

The *"How to" Activities for Positive Parent Engagement and Empowerment,* or the *HAPPEE Program* aimed to create occupation-based and evidence-based educational materials for parents with infants in the neonatal intensive care unit that apply to their infant's NICU stay and after discharge. This program intends to decrease parent stress, assist parents with developing into their new roles, and facilitate the bond with their infant.

### Materials

- Handouts found in Appendix A
    - Developmental Milestones with activities (1-4 Months)
    - Progression of feeding stages (pre-feeder and early feeder)
    - Swaddle bathing
    - Diaper changes
    - Skin-skin
    - Neonatal Massage
    - Occupational Therapy Positioners
    - Early Intervention Services
- QR codes on
    - Skin-skin
    - Neonatal Massage
    - Early feeder

**Guidelines**

There will be a binder containing this information in the debrief room at the nurse's station and within the occupational therapy department. These binders are strictly for informational purposes for therapy and nursing. The handouts will be printed by therapy and/or nursing for parents on an as-needed basis. It is important that these handouts are not given to parents all at once.

Parents can be informed of the *HAPPEE Program* after an infant is admitted to the neonatal intensive care unit and evaluated by the occupational therapist. This ensures that parents are made aware of handouts that are developmentally appropriate for their infant at that time. As the infant progresses throughout their NICU stay, therapy and nursing can guide parents to more advanced activities that the infant can tolerate. Once the infant is preparing for discharge, the early intervention handout should be made aware to parents to assist with the transition to at-home care.

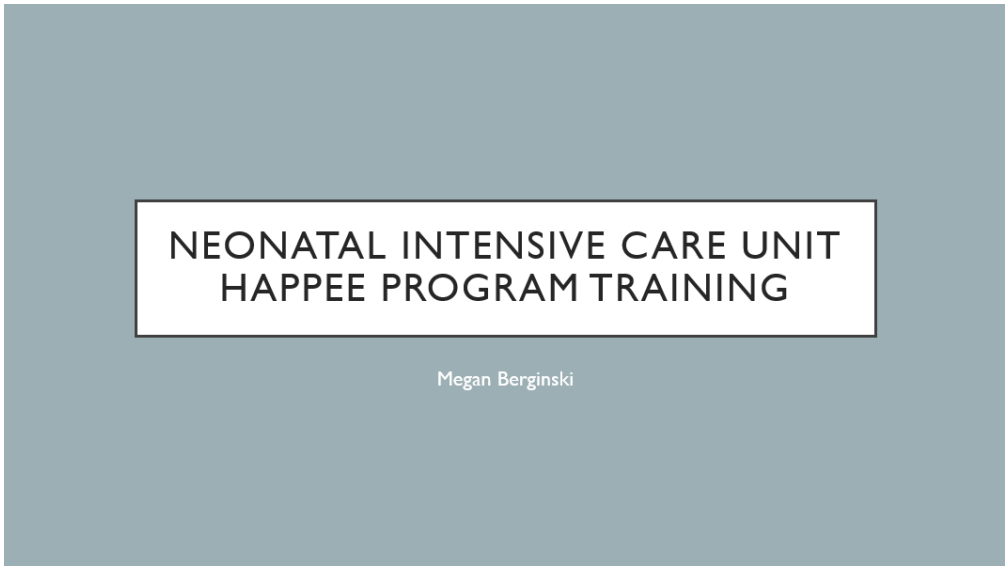
If the facility wants to measure the effectiveness of the program, a survey is available and included in this plan. The survey was created to give to parents prior to discharge if the parents utilized the program during their infant's NICU stay. The survey measures parents' stress and anxiety levels, confidence in interacting with their infant, ability to bond with their infant, beliefs in their parenting roles and abilities, helpfulness of the program, and preparation for discharge.

It is important to note that the *HAPPEE Program* is not all-encompassing, and therefore should be utilized as supplemental education to the standard level of education and care normally provided.

**The HAPPEE Program Training In-Service**

The creator of the program will lead an in-service to the facility's NICU occupational therapist, NICU nurse supervisor, and any nursing staff that is available during that time. The binder will be available for staff to look through during the presentation. The presentation that will be given is titled "Neonatal Intensive Care Unit HAPPEE Program Training" and is included below.

***Slide 1***

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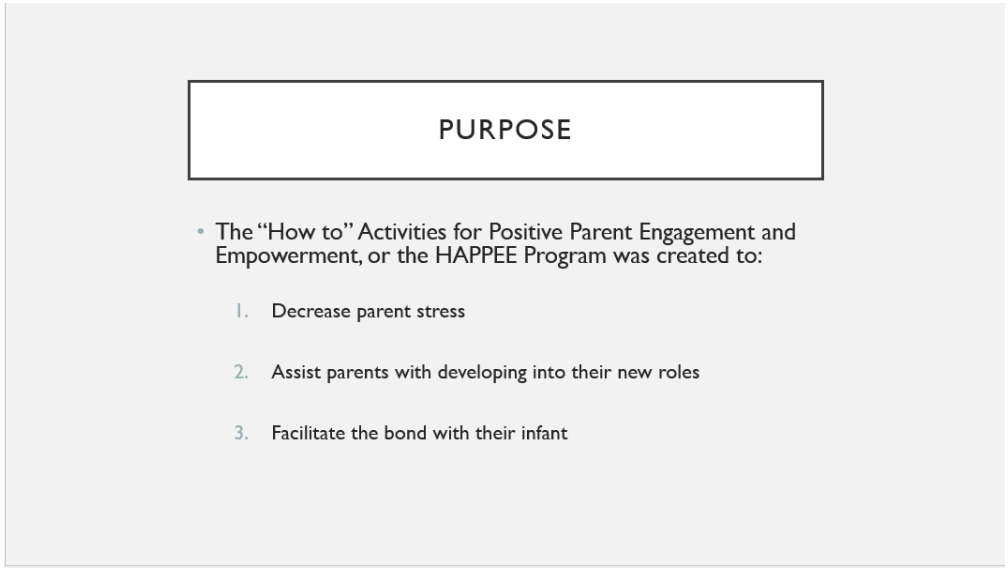

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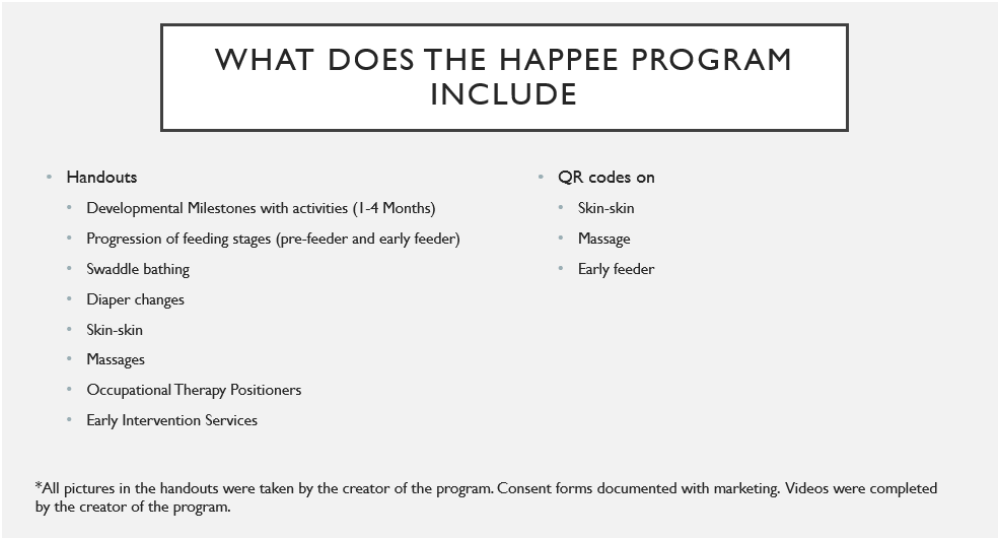


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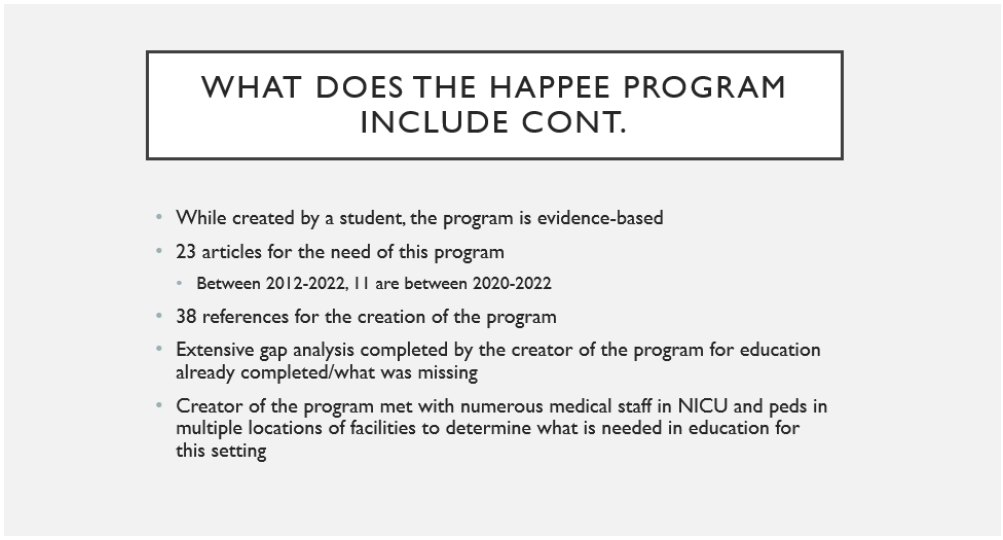
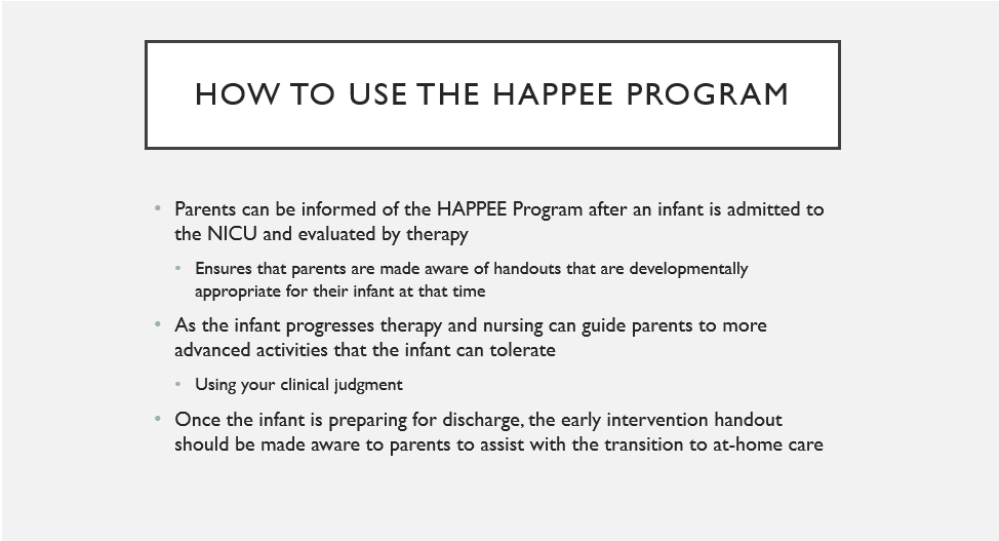
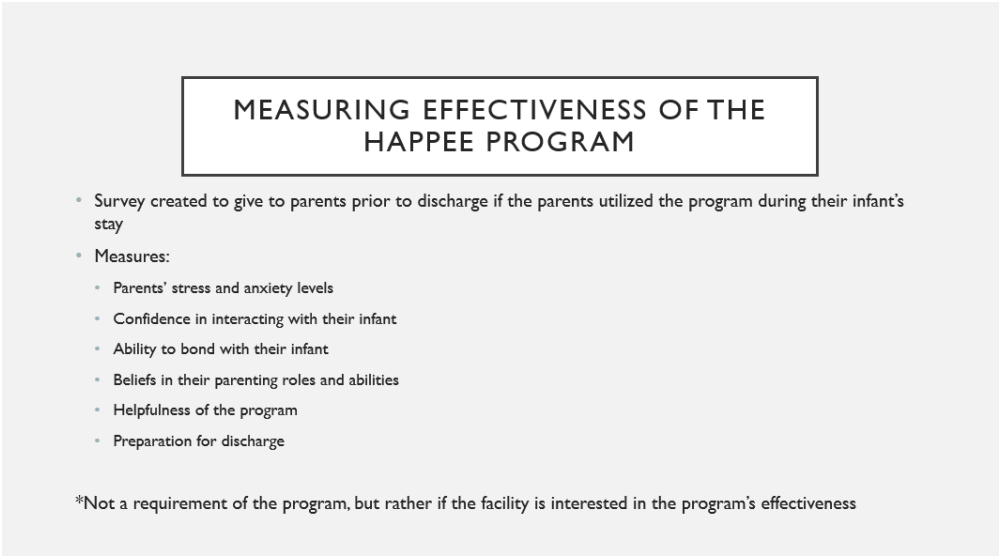


***Slide 5***




***Slide 6***



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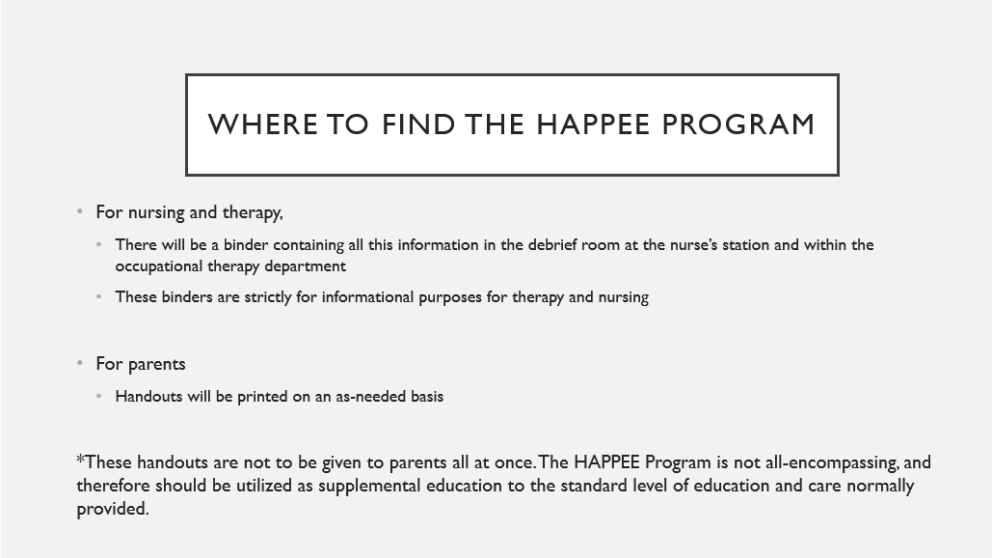
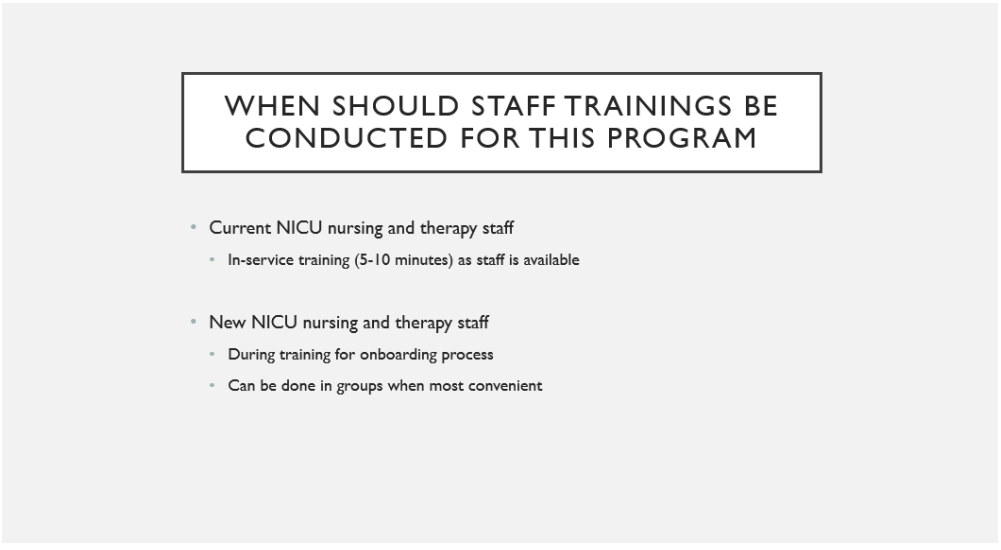



***Slide 8***



***Slide 9***


**Script for Presentation**

***Slide 1:*** Introduce program and presenter

***Slide 2:*** Explain that the program is a "how to" activity guide for parents to review as supplemental material to what they are learning while they are in the NICU. Also read purpose of program mentioned on slide.

***Slide 3:*** Read what is on slide. Important to note: the Early Intervention Services handout should be made aware to parents as they are in the discharge process. This helps facilitate a smooth transition to care post-discharge.

***Slide 4:*** Read what is on slide. References available upon request.

***Slide 5:*** Read what is on the slides. Emphasize providing information as infant becomes developmentally appropriate/relevant time for infant. (For example: don't provide information on swaddle-bathing if parents are not interested/infant is not ready for swaddle bathing).

***Slide 6:*** Read what is on slide, note that it is at the end of the program in the binder.

***Slide 7:*** Read what is on slide. Show exactly where mutually agreed upon spot in debrief room that everyone wants binder.

***Slide 8:*** Read what is on slide/make changes as when to provide training as needed.

***Slide 9:*** Answer any questions. Feel free to contact creator of program if need be.