2016

A Resource Manual for Occupational Therapists to Use with Parents of Infants Transitioning Home from the NICU

Alyssa N. Briggs
University of North Dakota

Nicholle R. Clouse
University of North Dakota

A RESOURCE MANUAL FOR OCCUPATIONAL THERAPISTS TO USE WITH PARENTS OF INFANTS TRANSITIONING HOME FROM THE NICU

by

Alyssa N. Briggs & Nicholle R. Clouse

Advisor: Sclinda Janssen, PhD, OTR/L

A Scholarly Project

Submitted to the Occupational Therapy Department

of the

University of North Dakota

In partial fulfillment of the requirements

for the degree of

Master's of Occupational Therapy

Grand Forks, North Dakota
May, 2016

This Scholarly Project, submitted by Alyssa Briggs, OTS and Nicholle Clouse, OTS in partial fulfillment of the requirement for the Degree of Master of Occupational Therapy from the University of North Dakota, has been read by the faculty Advisor under whom the work has been done and is hereby approved.

Selinda Janssen, PhD, OTR/L
Signature of Faculty Advisor

April 18, 2016
Date

PERMISSION

Title: A Resource Manual for Occupational Therapists to Use with Parents of Infants Transitioning Home from the NICU

Department: Occupational Therapy

Degree: Master's of Occupational Therapy

In presenting this Scholarly Project in partial fulfillment of the requirements for a graduate degree from the University of North Dakota, we agree that the Department of Occupational Therapy shall make it freely available for inspection. We further agree that permission for copying for scholarly purposes may be granted by the professor who supervised our work, or in her absence, by the Chairperson of the Department. It is understood that any copying, publication, or other use of this Scholarly Project or part thereof for financial gain shall not be allowed without our written permission. It is understood that due recognition shall be given to us and the University of North Dakota in any scholarly use which may be made of any material in our Scholarly Project.

Signature Nichalle Clouse Date 4/18/16

Signature Alyssa Briggs Date 4/18/16

TABLE OF CONTENTS

ACKNOWLEDGEMENT

The authors would especially like to thank their advisor, Cindy Janssen, for her guidance throughout the development of this Scholarly Project. A special thank you is also extended to their friends, family, and classmates for their overall support and encouragement.

ABSTRACT

One of the many challenges facing health care professionals practicing in the neonatal intensive care unit (NICU) is providing appropriate care and support for parents throughout the transition process from hospital to home. Because the families are often the ultimate advocates and caregivers for infants it is important that they are well equipped with the skills and knowledge needed to take part in their infant's care. Therefore, by providing clear and easy to use resources that address parental confidence, skills, knowledge, roles, routines, and the environment, professionals can help alleviate parental stress and uncertainty throughout the transition process.

An extensive review of literature was completed in order to determine the unmet needs of parents and their infants' as they transition home from the NICU. During this review of literature, programs that address this population were reviewed; however, the programs in place only address the unmet needs of the infants. There is a lack of programs that address the unmet needs of parents whose infants are transitioning home from the NICU. We also visited with a local occupational therapist who works with this population in order to find out more about the unmet needs of parents. It was concluded that parents may benefit from the provision of a user friendly resource manual that can be utilized by occupational therapists when working with parents as their infant transitions home.

A resource manual was developed to provide occupational therapists with an easy to understand guide to help address the unmet needs of parents. The manual starts out by

providing a brochure that can be given to parents to describe the role of occupational therapy. Initial and discharge evaluations are then included for the occupational therapist to measure the parents needs before and after use of the manual. The remainder of the manual is divided into sections and includes information about: developing confidence and self-efficacy, adjusting to new roles and routines, developing caregiving skills and knowledge, as well as tips to address the environment. Each section provides easy to use handouts and worksheets for occupational therapists to use in order to address the unique unmet needs of parents.

CHAPTER I

INTRODUCTION

We initially developed an interest in the neonatal intensive care unit (NICU) through our pediatric course work. We further explored this area of practice through Level I Fieldwork experience, and contact with local professionals who have worked with this population. Our interest was also heightened by personal experiences with individuals who have spent time in the NICU setting. Our interest in this area led us to seek out additional information on common practices in the NICU.

One of the many challenges facing health care professionals practicing in the NICU is providing appropriate care and support for parents throughout the transition process from hospital to home. This transition is often a stressful and confusing time for parents and their infants. In addition to coping with a child who has unique medical needs, families must also learn to embrace the increased skill and knowledge required of them in order to properly care for their infant. It is necessary for occupational therapists and healthcare professionals to provide education and support to parents in order to build skill and knowledge so that they can deliver the best care for their infant.

The primary role of an occupational therapist working with parents and their infants during the transition process is to provide skilled services in relation to the following: (1) stress and anxiety management, (2) self-efficacy, (3) adequate information about the caregiver role, and (4) education about child development (Plomgaard, Hansen, & Greisen, 2006; Potijk, Kerstjens, Bos, Reijneveld, & Winter, 2013). These areas may

have been included in past programs; however, there has been a lack of holistic, individualized, and client-centered programing, which is the central focus of occupational therapy. Ultimately, the goal of the occupational therapist is to help the parents increase their occupational performance to fulfill their occupation of caregiving.

The Model of Human Occupation (MOHO) provides a framework for conceptualizing the role occupational engagement has in promoting a successful transition from hospital to home for parents and their infants (Kielhofner, 2009). The MOHO was developed with participation in occupation at the core. Kielhofner (2009) postulated that occupational engagement affects and reveals interrelated internal (personal) and external (environmental) characteristics. There are four core constructs of this model: volition, habituation, performance capacity, and environment (Kielhofner, 2009).

The three attributes of the person, which are volition, habituation, and performance have a dynamic and interactive relationship (Kielhofner, 2009). Volition includes the thoughts and feelings that motivate an individual to participate in an occupation. For this population, volition is evident as parents are motivated to successfully raise their child and fulfil their caregiving role. Habituation is the way occupations are organized into patterns of doing (Kielhofner, 2009). Habituation needs to be addressed for this population as the occupational therapist will work with the parents to develop new habits in regards to their role serving as a caregiver to their infant. The third attribute of performance capacity, or the individual's underlying ability, impacts the experience a person has when performing occupations (Kielhofner, 2009). Parents need to increase their performance capacity related to skills needed to successfully care for

their infant. Finally, the environment, or the physical, cultural, social, economic, and political contexts influence the personal characteristics formally described. Environmental aspects such as objects, spaces, people, and expectations that may alter parents' occupational performance in their caregiving role need to be addressed. These four main constructs of the MOHO were used to organize this scholarly project.

This scholarly project is divided into six color-coded sections; referral, evaluation, volition, habituation, performance capacity, and environment. In the referral a brochure is provided that can be given to parents to describe the role of occupational therapy. Initial and discharge assessments are located in the evaluation sections that the occupational therapist can use to measure the parent's needs before and after use of the manual. The remaining four sections of the manual are divided based on the constructs of the MOHO. Each section contains different worksheets or handouts that are specific to the different constructs. In the volition section, resources address developing confidence, self-efficacy, and motivation. Resources that help parents to adjust to new roles and routines, as well as develop healthy coping habits, are found in the habituation section. Under the performance capacity section, there are resources related to increasing parental skill and knowledge related to caregiving. Lastly, unmet parental needs related to the environment are addressed in the last section of the resource manual.

A literature review was conducted on the needs of infants and their parents as they transition home from the NICU. The following chapter contains the literature review.

CHAPTER II

LITERATURE REVIEW

The University of Iowa Children's Hospital (2015) indicated that 12% of all births in the US are premature. Premature infants often have extensive medical care for their special needs, which costs an estimated 18 billion dollars annually (University of Iowa Children's Hospital, 2015). While healthcare services and technologies have advanced well in the ability to care for these premature babies in the neonatal intensive care unit (NICU), the transition from NICU to home is challenging, often resulting in readmission to the hospital due to complications (The University of Iowa Children's Hospital, 2015). Many of these complications are due to limited education of the parents about specialized caregiving. Parents report limited involvement with their infants' cares in the NICU, which in turn affects their confidence and leads to hospital readmission soon after discharge (Bastani, Abadi, & Haghani, 2015). Researchers in multiple studies concluded that parents of infants who were in the NICU expressed significant frustration regarding a lack of knowledge to properly care for their infants, as well as feelings of insecurity, instability, decreased confidence, depression, anxiety, and detachment from their newborns (Broedsgaard & Wagner, 2005; Callery, 2002; Fenwick, Barclay, & Schmied, 2001). This literature review will further explore the issues associated with the transition from NICU to home environments and any supportive programs that are helpful with the transition. Because there is limited research in this area, older studies are included. The lack of literature also suggests a need to target this topic in order to develop more

supportive resources for parents of infants transitioning from the NICU to the home environment.

Challenges in Transitioning to Home

The challenges associated with the transition from NICU to home play a critical role in the quality of care and the appropriate development of infants that were in the NICU as well as the overall well-being of parents. These premature infants are at an increased risk for learning and behavioral deficits, developmental issues, and other medical complications (The University of Iowa Children's Hospital, 2015). These complications lead to high rates of hospital readmission, and further delay the continued development and progress of the infants in the NICU and at home (The University of Iowa Children's Hospital, 2015). Parents of infants who were in the NICU also experience challenges that affect their overall well-being such as depression, anxiety, and lack of confidence to name a few (Broedsgaard & Wagner, 2005; Callery, 2002; Fenwick, Barclay, & Schmied, 2001).

Parents' Mental Health

Multiple researchers have found that parents' mental well-being is frequently compromised when transitioning from the NICU to the home environment. Singer et al. (2010) noted that with the advancing technology in the world of healthcare, there is increased survival rate of very low birth weight infants (VLBW) infants. However, there is currently minimal information that explores how parents of VLBW infants cope with their stress, and if stress levels fluctuate based on specific personal factors. Additionally, Singer et al. (2010) studied how "social support, maternal intelligence, education, coping

strategies, and family socioeconomic status" (p. 523) affected a mother's stress and depression levels through the years of raising a child born extremely premature.

To further examine the impact of maternal depression, Silverstein, Feinberg, Young, and Sauder (2010) conducted a study that sought to assess how mothers' perceptions of their child's social abilities and participation in age-appropriate activities are impacted by the mother's depression. From the results, researchers concluded that depressed mothers perceived their children's social abilities more negatively than non-depressed mothers. In addition, depressed mothers found their children less likely to make friends, share with others, and play independently. The significance of these results demonstrate that children continue to be impacted by their mother's maternal health far beyond the infant stage of development.

Pizur-Barnekow (2010) completed a study in order to examine the psychological characteristics of women who have given birth to high-risk infants. Because the experience of postnatal stress after birth of a high-risk infant has symptoms that are consistent with posttraumatic stress disorder (PTSD), the author also chose to examine PTSD in mothers as well. From the results, the researcher found that half of the mothers experienced upsetting memories of giving birth as well as lost interest in doing activities they previously enjoyed. Additionally, a significant amount of participants identified difficulty falling asleep, staying asleep, and concentrating compared to before they gave birth. Finally, 90% of participants experienced significant symptoms of PTSD following the birth of their infant.

In order to explore and understand mothers' state of anxiety after their infant was released from the NICU, Zanardo, Freato, and Zachello (2003) studied 100 new mothers

of high-risk infants being discharged from the NICU and 100 new mothers of healthy infants four days after being discharged from the hospital. Investigation was done to see how mothers possessing high anxiety responded to the emotional challenges, in addition to the high levels of anxiety from the NICU experience. The authors concluded that when comparing the state of anxiety for mothers of high-risk infants and the anxiety levels of mothers to healthy newborns, there was a significance difference just four days after hospital discharge. Mothers of high-risk infants experienced much higher anxiety levels than mothers of healthy newborns.

When parents experience impairment with stress and coping skills, self-efficacy is challenged. In connection with inadequate stress and coping skills, self-efficacy may be challenged. Researchers have studied parents' levels of self-efficacy in regards to caring for their premature infants during the transition from the NICU to home. According to Bandura (1994), "self-efficacy is defined as people's beliefs about their capabilities to produce designated levels of performance that exercise influence over events that affect their lives" (p. 71). A parent's level of self-efficacy can significantly influence the care the child receives during the vital transition period from hospital to home (Spielman & Taubman-Ben-Ari, 2009; Hess, Teti, & Hussey-Gardnerc, 2004).

Hess, Teti, and Hussey-Gardnerc (2004) aimed to discover if the amount of knowledge regarding child development of mothers with high-risk infants affected the level of self-efficacy and behavioral competence of these mothers. Spielman and Taubman-Ben-Ari (2009) also examined the topic of self-efficacy in regards to parents with premature infants, but these researchers studied how stress-related growth affected these adults as well. Through a 1-year longitudinal study, Hess, Teti, and Hussey-

Gardnerc (2004) examined 65 mothers and their infants; each infant was cared for in the NICU. Spielman and Taubman-Ben-Ari (2009) examined 49 married couples who had a premature infant and 50 married couples who did not have a premature infant; these two groups of couples were compared to each other throughout the study.

Hess, Teti, and Hussey-Gardnerc (2004) discovered a notable relationship in the data. When the mother rated herself with a higher level of knowledge regarding her infant's development, she also rated a higher level of self-efficacy, which increased the mother's behavioral competence. Similarly, when the mother rated herself with a lower level of knowledge regarding her infant's development, she also rated a lower level of self-efficacy, which decreased the mother's behavioral competence. In addition, these authors found that mothers who rated themselves with a higher level of self-efficacy, but possessed a lower level of knowledge, showed a decrease in their behavioral competence when interacting with their infants; this correlation signified that these mothers were overconfident with their self-efficacy judgments regarding their ability to appropriately interact with their infants (Hess, Teti, & Hussey-Gardnerc, 2004).

Likewise, Spielman and Taubman-Ben-Ari (2009) discovered that the parents' perception of their baby impacted the rated level of self-efficacy; for example, parents who rated their infants as less tempered rated themselves as more confident when caring for the child, whereas parents who rated their infants as more tempered rated themselves less confident when caring for their child. Furthermore, Spielman and Taubman-Ben-Ari (2009) realized that parents who rated themselves as more anxious with their infants had a more difficult time appropriately bonding with the infant as well as rated themselves lower in regards to their self-efficacy caring for their child. Lastly, these authors reported

that parents who possessed a higher level of self-esteem also possessed a higher level of self-efficacy (Spielman & Taubman-Ben-Ari, 2009).

The implication of the results of these research studies demonstrates the need to address parents' mental health. Specifically, healthcare professionals should address depression, anxiety, lack of self-efficacy, and lack of motivation when working with parents and their infants as they transition home from the NICU.

Lack of Caregiving Skills

Previous literature has illustrated that self-efficacy of caregiving is significantly impacted by the amount of education the parents possess in regards to their new role of parenting, particularly with premature infants transitioning from the NICU to home. According to Spicer et al. (2008), optimal quality of care for preterm infants was compromised by a lack of information and support for parents, inadequate caregiver education, and poor communication between the healthcare team members and family. Benasich and Brooks-Dunn (1996) noted quality of care was reflected in the competence levels of parents based on their knowledge level of how to respond to a child's needs. When the parent had adequate knowledge of developmental milestones and influential factors on child development, positive child development occurred (Benasich & Brooks-Dunn, 1996).

Similarly, Hutchinson, Spillett, and Cronin (2012) found that not only does parental knowledge influence positive child development, but parents' feelings, perceptions, and experience can influence the parent-child interaction as well. Specifically, these factors influence how receptive parents are to participating in the care of their infant.

One educational area that parents seem to be lacking knowledge in involves information addressing the unique developmental stages and common developmental delays of premature infants (Plomgaard, Hansen, & Greisen, 2006). Plomgaard, Hansen, and Greisen (2006) completed a study to assess developmental deficits in infants born at a gestational age of less than 26 weeks compared to infants born at full-term. The researchers indicated that higher gestational age was associated with higher scores in categories such as communication, gross motor skills, fine motor skills, problem solving, and personal-social skills. Overall, Plomgaard, Hansen, and Greisen (2006) found that infants born significantly premature were found to have developmental delays, which can lead to cognitive deficits.

In a similar study conducted by Potijk, Kerstjens, Bos, Reijneveld, and Winter (2013), the aim was to assess the growth, development, and general health of premature infants. While using the same questionnaire as Plomgaard, Hansen, and Greisen (2006), Potijk et al. (2013) discovered that a lower gestational age increased the occurrence of developmental delays such as fine motor, communication, problem-solving, and personal-social skills in children.

Garfield, Lee, and Kim, (2014) examined the concerns of mothers and fathers of VLBW infants as they transitioned home from the NICU. Through interviews, the researchers found that parents questioned their abilities to care for their infant despite training and discharge planning from the NICU staff. Another concern that emerged was the medical issues that are common to VLBW NICU infants. These concerns were in regards to feeding issues such as spitting up, not gaining weight, or poor feeding in general, as well as breathing issues (apnea, bradycardia, and desaturation in oxygen).

Other findings that arose during this study were that parents expressed concerns regarding 1) balancing work and family, 2) sleep deprivation and the round the clock care of the infant, and 3) their knowledge regarding care for the infant.

As lack of parental knowledge creates challenges for parents as they transition to home with their infant, Brazy, Anderson, Becker, and Becker (2001), sought to examine how parents learn and take in information. From this research, the authors found that parents go from being passive recipients of information before the birth of their child to active recipients of information after the birth of their child, specifically during the transition from NICU to home. Study participants expressed that they felt unable to retain information being provided by healthcare professionals throughout the duration of their infants NICU stay. Failure to retain information was thought to be a result of parents' lack of opportunity to care for their infant while in the NICU setting on a consistent basis. This lack of opportunity was due to healthcare professionals needing to provide the specialized and immediate care the high-risk infants required. From these findings, researchers suggest that parents do not receive enough support from healthcare professionals during the transition from NICU to home (Brazy, Anderson, Becker & Becker, 2001).

Challenges in Establishing New Roles and Routines

According to Boykova and Kenner (2012), many factors increase the likelihood of an unsuccessful transition from hospital to home for new parents of premature infants in the NICU. Two major transitions identified for this population include the shift from hospital to home as well as the transition to parenthood (Boykova & Kenner, 2012). Boykova and Kenner (2012) expressed the initial period after discharge may be life

changing and challenging, based on the demands of new caregiving roles, especially for parents of premature infants. This new caregiving role included all the responsibilities and activities necessary to care for a premature infant.

When examining the perceptions of motherhood, Lupton and Fenwick (2002) found that first-time mothers faced challenges with their new role including feelings of alienation, despair, grief, and the possibility of their infant not surviving. Additionally, researchers found that mothers commonly felt detached from their child. When examining the feelings of detachment, mothers expressed they felt they needed to be supervised by the nursery staff in order to interact with their infant. This constant need for supervision left mothers feeling inadequate as though they were lacking the skills required to be a good mother. In order to help mothers, feel more competent caring for their child, services that carry over into the home environment that provide support to the mother would be beneficial.

Transition from NICU to Home

Even though the authors did not specifically separate out the environment, it did emerge as a concern within the literature. The incongruence between the hospital setting and the home can cause fear for parents (Zanardo et al. 2003). In the hospital, there are many supportive systems, medical staff who are highly trained in extensive medical interventions, and state of the art medical equipment to care for infants' specific needs. In contrast, in a typical home environment parents do not have access to skilled healthcare professionals or advanced technologies. This incongruence between the two settings can cause fear in the parents as they adjust to caring for their infants in the home

environment. Therefore, the home environment needs to be addressed when facilitating a successful transition to the home after being in the NICU.

Recommendations for a Successful Transition

From the previously discussed research studies, it is evident that a significant problem currently exists in today's healthcare system. Amongst a high prevalence of premature infants receiving care in the NICU, many parents lack coping skills, self-efficacy, confidence, and knowledge, which limits an effective transition from the NICU to home. As a result of these parental challenges, premature infants are at an increased risk for learning and behavior deficits, developmental issues, and other medical complications (The University of Iowa Children's Hospital, 2015). This transition experience also heightens the possibility of readmission rates for premature infants, which doubled when compared to infants born at full-term (Spicer et al., 2008). The challenges presented in the research, provide a need for a program that addresses the areas of mental and emotional support, parental education and knowledge, as well as the environment.

As a result of their findings, Pizur-Barnekow (2010), Singer et al. (2010), and Zanardo et al. (2003) all emphasized that future implications must be taken to provide effective interventions for emotional support that will prevent increased stress and anxiety for parents after NICU discharge. Additionally, authors highlighted the need to address symptoms of depression as this was a common challenge that emerged in the literature for parents (Pizur-Barnekow, 2010). Ultimately, the psychological health of parents should be addressed during the transition home following their infants' stay in the NICU.

Benasich and Brooks-Gunn (1996) and Hutchinson, Spillett, and Cronin (2012) all found the importance in the need for healthcare providers to understand parents' level of education, knowledge and their feelings regarding their infant's NICU stay and transition home. From the results of their study, researchers found that parents who lacked education and knowledge regarding their infant, felt unprepared and did not know what to expect next developmentally for their child. To build off of these results, Plomgaard, Hansen, and Greisen (2006) and Potijk et al. (2013) signified through their study that parents need to be further educated on the possible occurrence and signs of developmental delays unique to premature infants. As parents transition home from the NICU setting with their infants, it is imperative that healthcare professionals make sure that parents are equipped with the knowledge and education they need to appropriately and successfully care for their infant.

Past Programs

A way in which parents can gain further education and understanding in regards to caregiving for a premature infant is through programs designed by healthcare providers. The literature revealed five different programs that have been created in the past for parents and their infants who have experienced time in the NICU setting (Katz, 1993; Landsem, Handegard, Tunby, Ulvund, & Ronning, 2014; MeInyk et al., 2006; Willis, 2008). Willis (2008) described that the Parenting Preemies program focuses on premature infants as well as infants with special needs, providing parents with education and social support. According to Willis (2008), the goals of Parenting Preemies include building confidence and competence, addressing low birth weight and special needs, promoting positive relationships, and providing early access to resources. The program

primarily functions through support groups and individualized home visits. A multidisciplinary team provides all interventions, and a nurse practitioner is the primary provider (Willis, 2008). However, other team members may include a clinical social worker, occupational therapist, dietitian, lactation educator, early childhood educator, personal trainer, and licensed massage therapist. Members of the multidisciplinary team take turns lecturing each week, during the 90-minute group sessions (Willis, 2008). Common parent feedback was associated with a positive view of the educational sessions, support groups, and occupational therapy visits (Willis, 2008).

Landsem, Handegard, Tunby, Ulvund, and Ronning (2014) described the Mother-Infant Transaction Program (MITP) as a 13-week program that works to strengthen not only parents' perceptions of their preterm infant but also to prevent the increased levels of stress that are commonly reported after giving birth to a preterm infant. This program was designed to facilitate interactions between the parent and infant in order to instill parental enthusiasm, pleasure, and empowerment. The MITP intervention for this study was solely facilitated by the nursing staff from a neonatal nursery and included seven one-hour long sessions that were conducted throughout the program's duration. The goal of this program was that parents who participated in MITP would report less stress as their child aged.

According to MeInyk et al., (2006), the focus of the Creating Opportunities for Parent Empowerment (COPE) program is to strengthen parents' understanding and beliefs about their preterm infants. Additionally, the program aims to strengthen parents' knowledge regarding their new role as parents and remove barriers that would inhibit them from participating in their infant's care as well as interacting with their infant

appropriately. After completing the program, it is anticipated that parents will experience less stress and negative mental health outcomes such as depression and anxiety not only during the NICU stay, but after discharge as well. The COPE program is an educational-behavioral intervention program that consists of four phases that occur from right after the infant enters the NICU up until one week after the infant is discharged. Throughout the four phases, parents were provided with written and audiotaped information regarding different strategies to meet their infants' needs, enhance quality of interaction with their infant, and facilitate their infant's development. Additionally, activities were provided to assist parents with implementing this new information. The hope of the program was that having the intervention in audio and written format would allow for the program to be easily reproduced and accessible to many parents of preterm infants at a low cost.

Project Headed Home, as stated by Katz (1993), stands as another transitional program that was designed intentionally to address the early intervention transition from the NICU to community-based services. Project Headed Home is a collaborative, family-centered intervention program, meant for infants who were continually re-hospitalized and unable to receive early intervention services due to chronic illness (Katz, 1993). Katz (1993) described that this interdisciplinary team primarily consisted of a physical therapist, infant specialist, pediatric psychologist, nurse, and occasionally a speech pathologist. The author mentioned the psychologists and speech pathologists are the primary members providing education and information to the family. Activities in this program address parental competence, family resources and concerns, developmental activities, and advocacy (Katz, 1993). Intervention sessions are provided two to three times weekly, and group session is held once a week for infants and family members.

Katz (1993) said the program utilizes a communication book that is available to all team and family members to comment on the progress of the child. The major emphasis on Project Headed Home was to address family emotional support and that one specific disciplinary member may not be necessarily important.

Although the previously discussed research focused on specific programs that could be implemented for parents and their premature infants, other studies have been conducted to look more broadly at the various intervention topics that should be included in a program. Meyer, Lester, Boukydis, and Bigsby (1998) discovered the need to address behaviors, developmental gains, and facilitate the parent-child interaction in the development of future transitional programs. Also of importance, researchers concluded that having the ability to individualize a unique plan for each infant would be most beneficial over a broad predesigned plan because each infant and their family are different. Research by Meyer et al. (1994) supported this idea of having individualized family-based intervention with preterm infants and their families. When comparing families who received standard care with families who received an individualized family-based intervention, results indicate better outcomes for the intervention group. Specifically, mothers in the intervention group reported less stress regarding the nursery environment, characteristics of their infants, less overall stress, and fewer signs of depression. Additionally, mothers from the intervention group reported higher levels of self-esteem than mothers who received standard care. Overall, the study demonstrates that an individualized family-based intervention for preterm infants and their families have beneficial effects at the time of discharge when transitioning home from the NICU.

Of the programs discussed, they all have commonalities. They all presented programs developed for infants and their parents while they were in the NICU setting. Additionally, these programs lacked involvement from occupational therapists. None of the programs found throughout the literature review address the unmet needs of parents as their infant transitions home from the NICU. Therefore, the proposed product will be different in that it will be focused on strictly the parents' unmet needs, which includes not only physical needs, but mental and emotional needs as well. In addition, the product is intended to be used in the home setting rather than in the NICU. It is proposed than an occupational therapist utilize our product because it is all about increasing the parents' occupational performance so that they can successfully fulfill their occupation of a caregiver.

Summary

Each year 10-15% of infants born in the United States spend time in the NICU (Underwood, Danielsen, & Gilbert, 2007). Of these infants, 15% experience at least 1 hospital readmission within their first year of life (Underwood, Danielsen, & Gilbert, 2007). With lack of parental skill and knowledge being one contributing factor to these readmission statistics, the transition from the NICU to home is a vital period that needs to be addressed. Due to the lack of literature addressing the parents during this transition, the following product was designed to address the unmet needs of parents. It is suggested that occupational therapists use this manual with parents of infants transitioning home from the NICU in order to help increase occupational performance of the parents while they engage in the occupation of caregiving.

CHAPTER III

METHODOLOGY

When we began creating this product, we went into the process thinking we were going to address the unmet needs of infants transitioning home from the NICU setting. However, after completing a thorough literature review, it was clear that it was actually the parents who had the unmet needs. Therefore, the product of this scholarly project is a user-friendly resource manual for occupational therapists to use with parents as they transition home from the NICU with their infant. This chapter describes the application of research to the product and justifies the process and decisions made.

Literature Review

A literature review was conducted on the needs of infants and their parents as they transition home from the NICU using search engines such as *PubMed, OT search, CINAHL, AJOT, Academic Search Premier, EBSCOhost databases, ODIN catalog, Google scholar,* and course textbooks. During the literature review, topics were searched that addressed needs of infants and parents, NICU-based programs, the transition process from NICU to home, and common challenges for NICU infants. Specifically, key search words utilized in the online literature search are as follows: *occupational therapy, caregivers, parents, infants, premature infants, quality of life, neonatal intensive care unit, home health care, transition, parental mental health, health promotion,* and *concerns.* A local occupational therapist who works with this population was also visited in order to find out more about the unmet needs of parents. The unmet needs

identified through the literature review are: 1) lack of self-efficacy, confidence, and motivation, 2) difficulty developing new roles, routines, and coping habits, 3) lack of caregiving skills and knowledge, and 4) difficulty transitioning from NICU to home. The information gathered was used to supplement the literature findings and guide the development of the product.

Model Application

Following the literature review, the next step was to choose a model to guide the creation of our product. As we further examined the unmet needs of the parents, it was clear that these needs fell perfectly into the four main constructs of the Model of Human Occupation (MOHO) which are volition, habituation, performance capacity, and environment. When organizing our data, the needs naturally aligned with the main constructs of MOHO. The table below was created to serve as a visual representation of the unmet needs revealed from the literature and how they organically fit into the four main constructs of MOHO.

Unmet Needs	**MOHO**
Lack of self efficacy, confidence, and motivation (Zanardo, Freato, & Zachello, 2013)	Volition
Difficulty developing new roles, routines, and coping habits (Boykova & Kenner, 2012)	Habituation
Lack of caregiving skills and knowledge (Benasich & Brooks-Dunn, 1996)	Performance Capacity
Difficulty transitioning from NICU to home (Zanardo, Freato, & Zachello, 2013)	Environment

Product Development

The research gathered in the literature review was utilized as both a means to identify the unmet needs of parents as their infant transitions home from the NICU, as well as to provide a strong foundational basis for the product. Resources to address the unmet needs for parents are disbursed continuously throughout the product. Our product is organized into six main sections; referral, evaluation, volition, habituation, performance capacity, and environment.

The first section is the referral process. It is assumed that there is already a referral process in place that the hospital would use to refer parents and their infants to occupational therapy services. To supplement the process that is already in place, a brochure was created for occupational therapy practitioners and healthcare providers to share with parents. The brochure describes the role of occupational therapists with parents, where occupational therapy services can be received, and areas of expertise occupational therapists can help with.

Next is an evaluation section containing an initial and discharge evaluation. The initial evaluation was created to determine the exact needs of the parents. When creating the questions for the evaluation, each concept of MOHO was color coded and used accordingly. The discharge evaluation asks similar questions and is organized the same in order to compare results and then measure progress. The discharge assessment also contains space to get feedback from parents which can be used to make modifications and improvements to the manual.

The next four sections are divided based on the constructs of MOHO. Each section contains different worksheets or handouts that are specific to the different

constructs; however, all sections do contain a few similar resources. They all begin with a true and false questionnaire and answer guide that the occupational therapist can use to facilitate important talking points with the parents regarding each specific construct. Each section ends with a table that provides information regarding different assessments that can be used with parents to address each specific construct if needed.

The volition section directly addresses the concepts of self-efficacy, confidence, and motivation. Following the true and false questionnaire there is a handout on motivation which describes the importance of motivation and how it is impacted for some parents. Other than this handout, there is not one particular resource that addresses motivation. Rather, the entire manual provides resources that are aimed at helping to increase parental motivation in order to help them feel more inclined and equipped to care for their infant. In order to address confidence, there is a worksheet that helps parents build confidence by having them reflect on things they are good at or accomplishments they have achieved. The final resource included in the volition section is a handout on self-efficacy. The handout describes what self-efficacy is, why its important, things that lower self-efficacy, and how parents can work to improve self-efficacy.

Throughout the habituation section of our resource manual, there are resources related to helping parents adjust to new roles and routines and develop healthy coping habits. Following the true and false questionnaire there is a handout on engaging in new roles and routines. This worksheet requires the parents to identify how their roles and routines have changed since having their infant. In addition, parents are asked to discuss any new roles and routines that they feel hesitant about as well as what they feel they

need more help with while adjusting to their new roles and routines. Following completion of this handout, it can be used to facilitate discussion between the occupational therapist and parents in order to further determine resources that might be beneficial to the parents. In order to help promote healthy coping habits, a handout is provided that lists a variety of strategies parents can use when feeling stressed or overwhelmed. The healthy coping habits handout is followed by a progressive muscle relaxation script that can be used to practice healthy coping habits for parents who are interested in that specific strategy.

The next section in the manual is performance capacity. In this section there are resources that address parental needs related to caregiving skills and caregiving knowledge. Following the true and false questionnaire, this section starts out with a handout providing tips for effectively feeding an infant. Next, two handouts are provided that give general information about positioning as well as the physiological effects of positioning. In order to further promote caregiver knowledge, a handout is provided regarding developmental milestones. A developmental milestones chart is then provided that contains common motor, language, and social emotional skills that parents can expect to see from their infant as they age. Because infants who were in the NICU often require special medical equipment, three handouts are provided that disuses the need for medical equipment and important things to remember when using it.

The final section of our manual addresses parental needs related to the environment. Following the true and false questionnaire, there is a handout on overall home safety. This handout includes tips regarding medication, CPR, nursery safety, and bathroom safety to help ensure the infants overall safety when returning home. Next a

temperature control handout is provided that lists tips on how to adjust the environment in order to ensure the baby remains at an adequate temperature. Following the temperature handout, there is a handout which provides a plan of action for any medical concerns that may arise in the home environment. This handout lists possible scenarios that may occur and what strategies parents can use that are present in their own environment. At the end of the environment section, multiple brochures and handouts from safe kids of grand forks are provided. These resources were used with permission from Carma Hanson and discuss topics such as temperature, car seat safety and positioning, sudden infant death syndrome, and safe sleeping.

Summary

The process for creating this scholarly project began first with a literature review before determining the direction of the product. With the literature review providing solid evidence of need for parental interventions that address 1) lack of self-efficacy, confidence, and motivation, 2) difficulty developing new roles, routines, and coping habits, 3) lack of caregiving skills and knowledge, and 4) difficulty transitioning from NICU to home, a product was created to fulfill these needs. Application of the evidence gathered through careful review of the literature and incorporation of the model and treatment interventions provides a strong framework for the product. The following chapter includes a copy of our finished product, which is a resource for occupational therapists to use to identify the unmet needs of parents as they transition home from the NICU with their infant.

CHAPTER IV

PRODUCT

The manual developed for this scholarly project is a resource manual for the occupational therapist to use with parents throughout the transition process from the hospital NICU to the home environment. The resource manual was designed to be a user-friendly resource that occupational therapists working with this population can use in order to address the unmet needs of parents. The role of occupational therapists with parents could be introduced during the infants stay in the NICU and could could start during discharge planning; however, this resource manual would primarily be used in the home setting.

Resources to address the unmet needs for parents are disbursed continuously throughout the product. This manual is organized into six main sections; referral, evaluation, volition, habituation, performance capacity, and environment. In each section, there are handouts and worksheets to address the multiple unmet needs of parents. Under the volition section, resources address lack of confidence, self-efficacy, and motivation. In the habituation section, resources address difficulty adjusting to new roles and routines, as well as developing healthy coping habits. The section on performance capacity provides resources aimed at increasing parental skill and knowledge. Finally, the environment section includes handouts related to adjusting the environment.

A Resource Manual for Occupational Therapists to use with Parents of Infants Transitioning Home from the NICU

Picture used with permission

Table of Contents

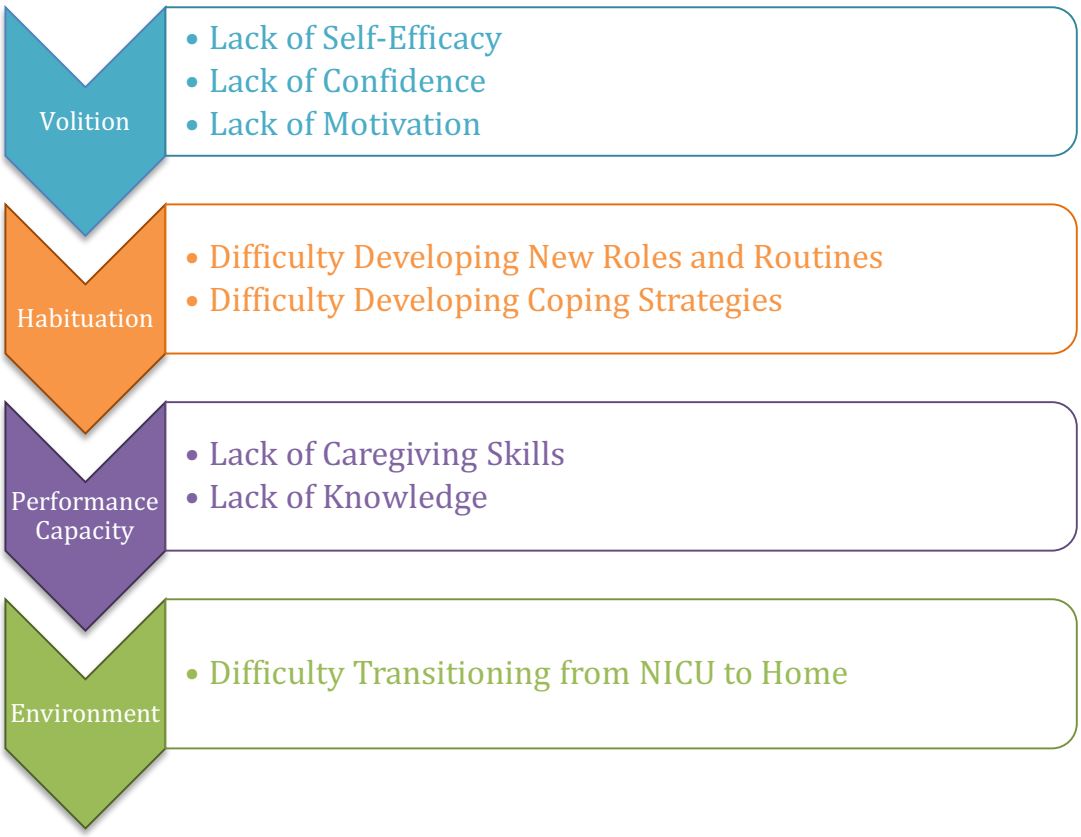
Introduction

Introduction

The University of Iowa Children's Hospital (2015) indicated that 12% of all births in the US are premature. Premature infants as well as other infants who spend time in the neonatal intensive care unit (NICU) often have extensive medical care for their special needs, which costs an estimated 18 billion dollars annually (University of Iowa Children's Hospital, 2015). While healthcare services and technologies have advanced well in the ability to care for these premature infants in the NICU, the transition home is challenging, often resulting in readmission to the hospital due to complications.

Many of these complications are due to limited knowledge of the parents about specialized caregiving, as well as decreased parental confidence, self-efficacy, and motivation (Broedsgaard & Wagner, 2005; Callery, 2002). Additionally, parents experience difficulty adapting to new routines and roles in their home environment (Boykova & Kenner, 2012). Through an extensive literature review, these complications were further explored. This resource manual presents resources for occupational therapists to use with parents of infants as they transition home from the NICU. The format of this resource manual follows the four main constructs of the Model of Human Occupation (MOHO) including volition, habituation, performance capacity, and the environment (Kielhofner, 2009).

Use of MOHO to Address Parents' Unmet Needs



The chart shown above was created to demonstrate how the Model of Human Occupation (MOHO) main constructs fit with the needs of the target population. When identifying which model to use, the needs of the population naturally fell into the main constructs of the MOHO including volition, habituation, performance capacity, and the environment (Kielhofner, 2009).

The following resource manual is organized into six sections (referral, evaluation, volition, habituation, performance capacity, and environment). In each section you will find resources that can be photocopied and used with parents based on their needs.

Referral

Introduction to Referral Process

After families are referred from the hospital to receive occupational therapy (OT) services, it is up to the OT practitioner to advocate for the profession. This involves educating new parents on the role of OT and how it can assist parents as well as their infants as they transition home from the NICU. The following pages contain a brochure that describes the role of OT while working with parents of infants as they transition home from the NICU. OT practitioners and healthcare providers are encouraged to share this brochure with parents as indicated by needs.

What is Occupational Therapy (OT)?

An OT is a therapist who can help babies or their parents successfully complete every day activities from the time they wake up until the time they go to sleep at night. OT's address physical changes as well as mental and emotional changes.

Contact Altru To Set Up An Appointment With An OT Today!

Address:
1000 South Columbia Road
Grand Forks, ND 58201

Phone:
701.780.5000
800.732.4277

Kayla Oates, MOTS
218-780-3958
kayla.oates@my.und.edu

Nicholle Clouse, MOTS
218-205-0992
nicholle.clouse@my.und.edu

Occupational Therapy: Helping Parents of Infants Transitioning Home from the NICU

Pictures used with permission

Where Can OT Help You?

- Hospital/Clinic
- Outpatient Therapy
- Home

"1 of every 8 infants born in the United States is premature."
-Center for Disease Control and Prevention (2015)

What Can OT Do For You?

- Stress Relaxation Tips
- Tips on incorporating your new preemie into your everyday life
- Education on what to expect with your new baby
- Tips on feeding your baby
- Help with your feelings
- Getting your home ready for baby
- How to increase your confidence as a parent
- How to position your new baby

Depression affects up to 53% of parents who have a premature baby. (Leonard, 1998)

Leonard, L. (1998). Depression and anxiety disorders during multiple pregnancy and parenthood. *Journal of Obstetric, Gynecologic & Neonatal Nursing,* 27(3), 329-337.

Pictures used with permission

Evaluation

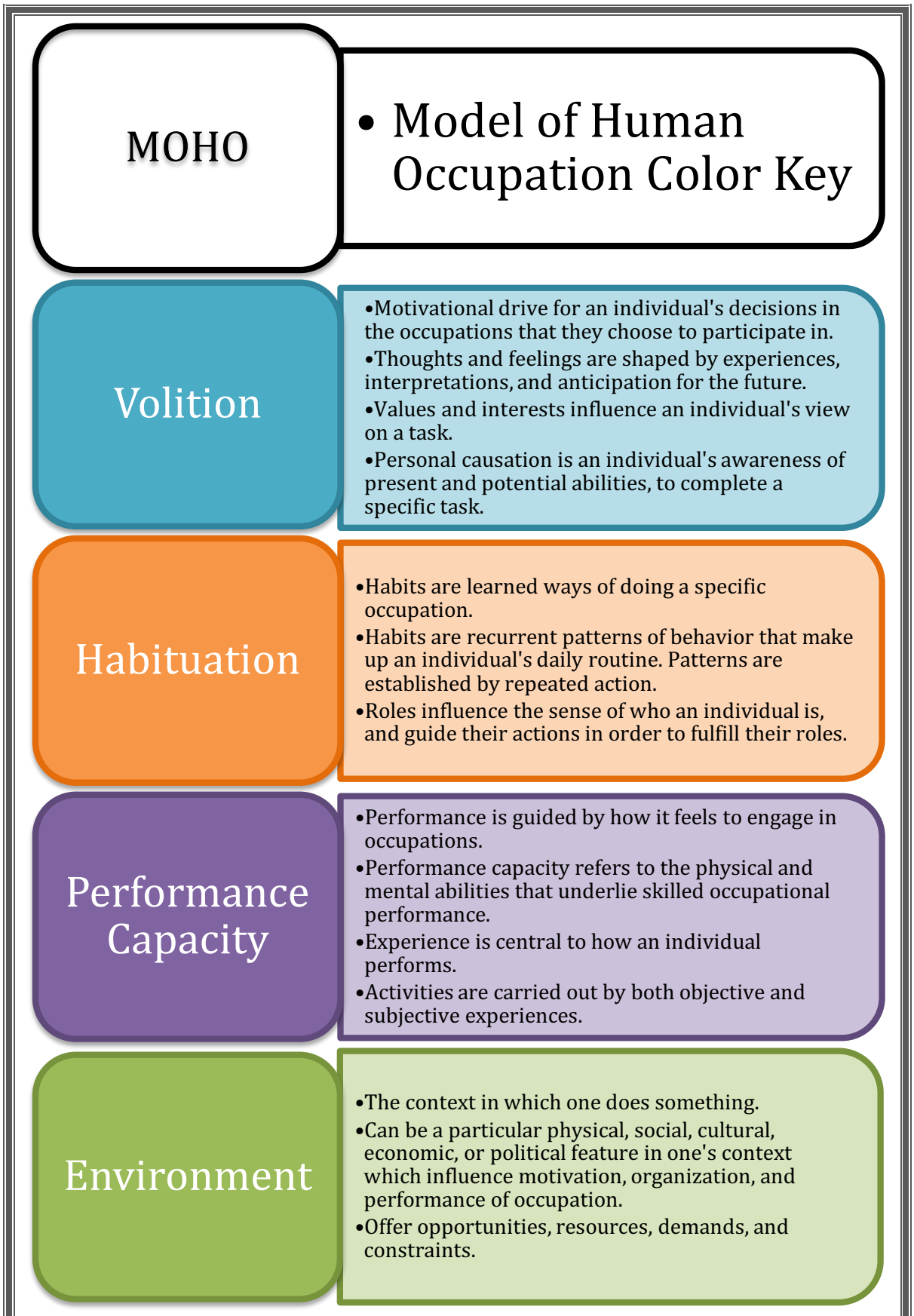
Introduction to Evaluation Tools

Throughout the literature, many needs were identified by parents when transitioning home from the NICU with their infant. Several researchers concluded that parents of high risk infants experienced lack of self-efficacy, lack of confidence, and lack of motivation when compared to parents of full-term infants (Hess, Teti, & Hussey-Gardnerc, 2004; Spielman & Taubman-Ben-Ari, 2009; Zanardo, Freato, & Zachello, 2013).

Additional areas of concern that authors identified, were that parents lack healthy coping habits and experience challenges with the demands of new caregiving roles (Boykova & Kenner, 2012; The University of Iowa Children's Hospital, 2015). Furthermore, researchers found that optimal quality of care for preterm infants is compromised by a lack of information and support for parents, lack of caregiving skills, and inadequate caregiver knowledge (Benasich & Brooks-Dunn, 1996; Spicer et al., 2008). Plomgaard, Hansen, and Greisen (2006) also found that parents seem to be lacking knowledge when it comes to addressing the unique developmental stages and common developmental delays of premature infants.

A final concern that was not specified, but rather implied from the literature was the environment. The incongruence between the hospital setting and the home can cause fear for parents (Zanardo et al., 2003) as the hospital has many supportive systems, medical staff who are highly trained, and state of the art medical equipment to care for infants' specific needs; whereas, the home environment does not.

*** These needs were threaded into both initial and discharge assessments for each individual parent to complete in order to verify if they have identified similar needs. The needs that are typically seen among parents that were identified in the literature organically fit with MOHO constructs, which are categorized by color on the assessment tools. The following page contains a diagram displaying the constructs according to their assigned color.**


MOHO
• Model of Human Occupation Color Key
Volition
•Motivational drive for an individual's decisions in the occupations that they choose to participate in.
•Thoughts and feelings are shaped by experiences, interpretations, and anticipation for the future.
•Values and interests influence an individual's view on a task.
•Personal causation is an individual's awareness of present and potential abilities, to complete a specific task.
Habituation
•Habits are learned ways of doing a specific occupation.
•Habits are recurrent patterns of behavior that make up an individual's daily routine. Patterns are established by repeated action.
•Roles influence the sense of who an individual is, and guide their actions in order to fulfill their roles.
Performance Capacity
•Performance is guided by how it feels to engage in occupations.
•Performance capacity refers to the physical and mental abilities that underlie skilled occupational performance.
•Experience is central to how an individual performs.
•Activities are carried out by both objective and subjective experiences.
Environment
•The context in which one does something.
•Can be a particular physical, social, cultural, economic, or political feature in one's context which influence motivation, organization, and performance of occupation.
•Offer opportunities, resources, demands, and constraints.

Initial Assessment of Parental Needs

Parents: Please complete the initial assessment to the best of your abilities.

Question	Poor	Fine	Average	Good	Excellent
How would you rate your understanding of appropriate feeding and eating techniques for your infant?					
How would you rate your confidence level of providing care for your child?					
How would you rate your knowledge on the use and management of your infant's medical equipment?					
How would you rate your ability to manage your stress while caring for your infant?					
How would you rate your understanding of appropriate positioning techniques for your infant?					
How would you rate your confidence in recognizing developmental milestones in your infant?					

What kinds of concerns do you have about going to your home environment?

_____

_____

_____

Additional Comments:

_____

_____

_____

Discharge Assessment

Parents: Please complete the initial assessment to the best of your abilities.

Question	Poor	Fine	Average	Good	Excellent
How would you rate your understanding of appropriate feeding and eating techniques for your infant?					
How would you rate your confidence level of providing care for your child?					
How would you rate your knowledge on the use and management of your infant's medical equipment?					
How would you rate your ability to manage your stress while caring for your infant?					
How would you rate your understanding of appropriate positioning techniques for your infant?					
How would you rate your confidence in recognizing developmental milestones in your infant?					
Overall, how satisfied with the program are you?					

What kinds of concerns remain (if any) about being in your home environment?

_____

_____

_____

Additional Comments Regarding the Program:

_____

_____

_____

Volition

To address parental needs related to:

Motivation

Self-Efficacy

Confidence

Introduction to Parental Needs Related to Volition

The parents of infants who are transitioning home from the NICU setting have been shown to experience difficulty in many areas related to volition. Many researchers concluded that parents of high risk infants experienced lack of self-efficacy, lack of confidence, and lack of motivation when compared to parents of full-term infants (Hess, Teti, & Hussey-Gardnerc, 2004; Spielman & Taubman-Ben-Ari, 2009; Zanardo, Freato, & Zachello, 2013). Lack of these volitional aspects can significantly influence the care the infant receives during the vital transition period from hospital to home.

How Volitional Aspects of MOHO Address These Parental Needs

Volition includes the thoughts and feelings that motivate an individual to participate in an occupation. In this program, volition is evident as parents are motivated to successfully raise their child and fulfil their caregiving role. While fulfilling their caregiving role, parents' success is based on their self-efficacy and confidence, which also fall under the volitional construct of the MOHO. The OT practitioner is encouraged to use the True/False questionnaire as a warm-up activity to facilitate important *talking points* regarding volition

True or False???

T or F	All parents feel 100% confident and comfortable bringing their infant home from the hospital.
T or F	Parents who have more confidence in their parenting skills and abilities are usually able to provide better care for their infant.
T or F	Having motivation to care for your infant is extremely important.

True or False Answer Guide

1. **All parents feel 100% confident and comfortable bringing their infant home from the hospital.**
   False: It is normal for most parents to not feel 100% confident bringing their new infant home from the hospital as it is a new & sometimes overwhelming experience.

2. **Parents who have more confidence in their parenting skills and abilities are able to provide better care for their infant.**
   True: Parents who have more confidence in their parenting skills second guess themselves less & can learn & better respond to their infants' cues.

3. **Having motivation to care for your infant is extremely important.**
   True: Having the motivation to care for your infant is important because if someone is not motivated, there can be serious consequences for the infant's health and development. Having motivation will help you want to care for your infant in the best way possible.

Motivation

Research indicated parents of infants who have spent time in the NICU setting sometimes lack motivation to care for their infants because they are afraid. They feel that their caregiving skills are limited compared to that of the skilled NICU staff because they do not have an extensive medical background. This whole resource manual is intended to build skills that give them confidence in their ability to care for their infants. Therefore, there is not one particular resource or activity that addresses motivation. Rather, the entire manual provides resources that are aimed at helping to increase parental motivation in order to help parents feel more inclined and equipped to care for their infant.

Picture used with permission

When It Comes To Being A Parent…

Picture used with permission

Things I am good at

Things that make me happy

5 things that make me a good parent

Accomplishments I am proud of

Things that inspire me

My favorite memories

Building Your Parental Self-Efficacy

What is self-efficacy?

Self-efficacy is an individual's belief in his or her ability to succeed in specific situations or accomplish a specific task.

Why is it important to have self-efficacy in my role as a parent?

Having self-efficacy is important because it can greatly impact how you feel, think, and behave when it comes to your role as a parent. Parents who have higher self-efficacy are more willing to learn and more committed to their personal caregiving goals. Parents that have greater self-efficacy feel more confident and are more driven when facing challenges.

Things that can lower my self-efficacy

- Dwelling on personal failures
- Avoiding difficult or intimidating tasks
- Lack of knowledge
- Lack of confidence

How can I improve my self-efficacy?

The following are steps one can use to increase/improve their self-efficacy:

- Pay attention to things you succeed at
- Select activities you can reasonably expect to be able to do
- Keep written records of your performance
- When feeling overwhelmed, make a list of tasks you need to accomplish and tackle the least difficult things first

Assessments to Address Volition

The following table provides a list of assessments that address volitional aspects. On the chart you will find a description of each assessment, a reference where it can be found, and the cost of the assessment. These assessments can be used to address parental needs related to the volitional aspects. The assessment that is free of charge was indicated *public domain* and is provided following the table.

Title	Description	Reference	Cost
Beck's Depression Inventory	The Beck Depression Inventory is a 21-item self-report rating inventory that measures characteristic attitudes and symptoms of depression.	Beck, A., Steer, R., & Brown, G. (1996) Link: http://mhinnovation.net/sites/default/files/downloads/innovation/research/BDI%20with%20interpretation.pdf	$
Model of Human Occupation Screening Tool	The Model of Human Occupation Screening Tool addresses volition, habituation, skills, and environment to gain an overview of the person's functioning.	Parkinson, Forsyth, & Kielhofner (2006) Link: http://www.cade.uic.edu/moho/productDetails.aspx?aid=4	$
Volition Questionnaire	The Volition Questionnaire is made up of 14 items addressing motivation, personal causation, and values/interests.	Heras, Geist, Kielhofner, & Li (2007) Link: http://www.cade.uic.edu/moho/productDetails.aspx?aid=8	$
Zung Self-Rating Anxiety Scale	The Zung Self-Rating Anxiety Scale is a 20-item self-report assessment used to measure anxiety based on cognitive, autonomic, motor, and central nervous system symptoms.	Zung (1971) Link: https://psychology-tools.com/zung-anxiety-scale/	Free

Zung Self-Rating Anxiety Scale (SAS)

For each item below, please place a check mark (✓) in the column which best describes how often you felt or behaved this way during the past several days. Bring the completed form with you to the office for scoring and assessment during your office visit.

Place check mark (✓) in correct column.	A little of the time	Some of the time	Good part of the time	Most of the time
1 I feel more nervous and anxious than usual.				
2 I feel afraid for no reason at all.				
3 I get upset easily or feel panicky.				
4 I feel like I'm falling apart and going to pieces.				
5 I feel that everything is all right and nothing bad will happen.				
6 My arms and legs shake and tremble.				
7 I am bothered by headaches neck and back pain.				
8 I feel weak and get tired easily.				
9 I feel calm and can sit still easily.				
10 I can feel my heart beating fast.				
11 I am bothered by dizzy spells.				
12 I have fainting spells or feel like it.				
13 I can breathe in and out easily.				
14 I get feelings of numbness and tingling in my fingers & toes.				
15 I am bothered by stomach aches or indigestion.				
16 I have to empty my bladder often.				
17 My hands are usually dry and warm.				
18 My face gets hot and blushes.				
19 I fall asleep easily and get a good night's rest.				
20 I have nightmares.				

Source: William W.K. Zung. A rating instrument for anxiety disorders. Psychosomatics. 1971

Habituation

To address parental needs related to:
New Roles and Routines
Coping Habits

Introduction to Parental Needs Related to Habituation

The parents of infants who are transitioning home from the NICU setting, have been shown to experience difficulty in many areas related to habituation. Authors from The University of Iowa Children's Hospital (2015) found that parents lack healthy coping habits, which limits an effective transition from the NICU to home. Additionally, Boykova and Kenner (2012) expressed that the initial period after discharge may be life changing and challenging, based on the demands of new caregiving roles, especially for parents of premature infants. Poor habituation patterns and behaviors can significantly influence the care the infant receives during the vital transition period from hospital to home.

How Habituation Aspects of MOHO Address These Parental Needs

Habituation is the way occupations are organized into patterns of doing (Kielhofner, 2009). Habituation is addressed in this program as the OT practitioner will work with the parents to develop new habits in regards to their role serving as a caregiver to their infant. Additionally, the therapist will work with parents to develop new coping habits to deal with the various emotions and challenges that arise. The OT practitioner is encouraged to use the True/False questionnaire as a warm-up activity to facilitate important *talking points* regarding habituation.

True or False???

T or F	Forming healthy caregiving habits is important when caring for your infant.
T or F	Habits have the ability to both support and hinder your performance when caring for your infant.
T or F	Being a parent/caregiver is not considered one of your roles.

True or False Answer Guide

1. **Forming healthy caregiving habits is important when caring for your infant.**

   True: Forming healthy habits is important when caring for your infant because it can help you better organize your time as well as decrease stress.

2. **Habits have the ability to both support and hinder your performance when caring for your infant.**

   True: Forming healthy habits helps you be more efficient & effective when caring for your infant. Forming unhealthy habits can result in accidents & less effective care.

3. **Being a parent/caregiver is not considered one of your roles.**

   False: Being a parent/caregiver is considered one of your roles because it is a duty/responsibility that you have taken ownership to fulfill. It is your role to make sure that your infant's physical & emotional needs are met.

Engaging in New Roles and Routines

Bringing your infant home from the NICU is a challenging and life changing process. Therefore, it is important to establish as much routine as possible to help the transition go more smoothly and help relieve unnecessary stress. This worksheet, along with other resources from your occupational therapist will help you feel more equipped to adjust to the new roles and routines that are associated with parenting an infant that was in the NICU.

Please answer and discuss the following questions with your occupational therapist:

What did your roles and routines look like before having your infant?

_____

_____

_____

How have your roles and routines changed since having your infant?

_____

_____

_____

What new roles and routines do you feel hesitant about and why?

_____

_____

_____

What do you feel you could use more help with in regards to adjusting to your new roles and routines?

_____

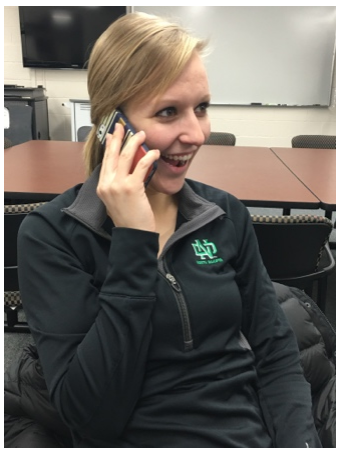
_____

_____

Ask your occupational therapist to provide you with the resources you need to address these concerns

Positive Coping Strategies

- Below is a list of positive coping strategies that can be used when you are feeling overwhelmed or in need of a break. This list provides only a few suggestions, so by no means is it conclusive.



- Do a Meaningful Activity
- Join a Support Group
- Call a Friend or Loved One
- Make Yourself Laugh
- Engage in Physical Activity
- Participate in Meditation or Relaxation Techniques

- Take Time for Yourself
- Listen to Music You Enjoy
- Progressive Muscle Relaxation
- Deep Breathing Exercises

Progressive Muscle Relaxation Script

Progressive muscle relaxation is an exercise that relaxes your mind and body by progressively tensing and relaxation muscle groups throughout your entire body. Throughout this exercise you will tense each muscle group forcefully, but without straining, and then suddenly release the tension and feel the muscles relax. Tense each muscle for about 5 seconds. If you have any pain or discomfort at any of the targeted muscle groups feel free to repeat that step. Throughout this exercise you may visualize the muscles tensing and a wave of relaxation flowing over them as you release that tension. It is important that you keep breathing throughout the exercise. Now let's begin.

- Begin by finding a comfortable position either sitting or lying down in a location where you will not be interrupted (lying down is the ideal position).
- Allow your attention to focus only on your body and your breathing. If you begin to notice your mind wandering, bring it back to the muscle you are working on.
- Take a deep breath through your abdomen, hold for a few second, and exhale slowly. Again, as you breathe notice your stomach rising and your lungs filling with air.
- As you exhale, imagine the tension in your body being released and flowing out of your body. And again inhale.....and exhale. Feel your body already relaxing.
- Tighten the muscles in your forehead by raising your eyebrows as high as you can. Hold for about 5 seconds. And abruptly release feeling that tension fall away.
- Now smile widely, feeling your mouth and cheeks tense. Hold for about 5 seconds, and release, appreciating the softness in your face.
- Next, tighten your eye muscles by squinting your eyelids tightly shut. Hold for about 5 seconds, and release.
- Gently pull your head back as if to look at the ceiling. Hold for about 5 seconds, and release, feeling the tension melting away.
- Now feel the weight of your relaxed head and neck sink. Breath in...and out. In...and out. Let go of all the stress In...and out.
- Now, tightly, but without straining, clench your fists and hold this position until I say stop. Hold for about 5 seconds, and release.
- Now, flex your biceps. Feel that buildup of tension. Hold for about 5 seconds, and release, enjoying that feeling of limpness. Breath in...and out.

- Now tighten your triceps by extending your arms out and locking your elbows (like a mummy). Hold for about 5 seconds, and release.
- Now lift your shoulders up as if they could touch your ears. Hold for about 5 seconds, and quickly release, feeling their heaviness.
- Tense your upper back by pulling your shoulders back trying to make your shoulder blades touch. Hold for about 5 seconds, and release.
- Tighten your chest by taking a deep breath in, hold for about 5 seconds, and exhale, blowing out all the tension.
- Now tighten the muscles in your stomach by sucking in. Hold for about 5 seconds, and release.
- Tighten your back muscles by gently arching your lower back. Hold for about 5 seconds, relax.
- Feel the limpness in your upper body letting go of the tension and stress, hold for about 5 seconds, and relax.
- Tighten your buttocks. Hold for about 5 seconds..., release, imagine your hips falling loose.
- Tighten your thighs by pressing your knees together, as if you were holding a penny between them. Hold for about 5 seconds...and release.
- Now flex your feet, pulling your toes towards you and feeling the tension in your calves. Hold for about 5 seconds, and relax, feel the weight of your legs sinking down.
- Tense the muscles in your feet by curling your toes downward. Hold for about 5 seconds, release.
- Now imagine a wave of relaxation slowly spreading through your body beginning at your head and going all the way down to your feet.
- Feel the weight of your relaxed body. Breathe in...and out...in...out....in...out.

Assessments to Address Habituation

The following table provides a list of assessments that address habituation aspects. On the chart you will find a description of each assessment, a reference where it can be found, and the cost of the assessment. These assessments can be used to address parental needs related to the habituation aspects that may need improvement. The assessment that is free of charge was indicated as *public domain* and is provided following the table.

Title	Description	Reference	Cost
Arnett Caregiver Interaction Scale	The Arnett Caregiver Interaction Scale comprised of 26 questions to measures the quality of caregiver interactions.	Arnett (1989) Link: http://fpg.unc.edu/sites/fpg.unc.edu/files/resources/assessments-and-instruments/SmartStart_Tool6_CIS.pdf	Free
Model of Human Occupation Screening Tool	The Model of Human Occupation Screening Tool addresses volition, habituation, skills, and environment to gain an overview of the person's functioning.	Parkinson, Forsyth, & Kielhofner (2006) Link: http://www.cade.uic.edu/moho/productDetails.aspx?aid=4	$

Caregiver Interaction Scale
Arnett, 1989

Evaluation Tool
Smart Start Evaluation Team

FPG Child Development Institute
UNC-Chapel Hill

General:

- Be sure to note examples of behaviors on your score sheet as you see them during the observation to make rating more accurate
- When scoring, it may help to think of the word "true" at the end of each rating descriptor (e.g., not at all **true**, somewhat **true**).
- Because the words "somewhat" and "quite a bit" may sound very similar to some people, here's some help. Think of "not at all" and "very much" as representing the 2 endpoints of a continuum, with "somewhat" and "quite a bit" as points equidistant between the 2 ends.

Item 4. Interpret this item to mean that the teacher places an **overly** strong focus on obedience. If the teacher values obedience a normal amount or less, the score is "1." If you believe she values obedience more than normal, then you must decide whether it's somewhat high, quite a bit high, or very much high.

Item 7. Interpret "misbehavior" very broadly; for example, a rule can be explained if children want to take off their shoes and the caregiver says no. If there are absolutely no such incidences during the observation, you may score this item as "Not Applicable."

Item 8. To credit the teacher for this, you must hear the teacher say something to encourage children to try something new. Just placing new, interesting materials in the classroom is not enough. "New experiences" should be interpreted broadly to include things like reading a new book, playing a new game, etc.

Item 9. (everyone's favorite) It may help to remember that this item is measuring whether the teacher is **too** permissive. If you believe the teacher uses a normal amount of control (or even uses too much control), then the score is "1." If you believe the teacher is too permissive, then you must decide whether it's "somewhat" "quite a bit" or "very much" too permissive.

Item 15. It may help to remember that this item measures the teacher's permissiveness. Although the word "reprimand" may have negative connotations, do not interpret it negatively. If the teacher intervenes when children misbehave, then the score is "1." If you do not observe any misbehavior (broadly interpreted, see clarifications to Item 7), score this item "1." If you see children misbehaving without any intervention from the teacher, then you need to decide whether she "sometimes" "quite a bit" or "very much" doesn't reprimand children when they misbehave.

Item 17. If you do not observe any punishment during the observation, you should score this item as a 1

Item 19. Pro-social behavior includes behavior toward adults and other children.

Item 23. If the teacher provides the "right amount" of supervision (or even supervises them too closely), the score is "1." If the teacher does **not** supervise children close enough, then you must decide to what degree she does not supervise closely.

Caregiver Interaction Scale (CIS) Subscale Items

Sensitivity: 1, 3, 6, 7, 8, 11, 14, 16, 19, 25

Harshness: 2, 4, 10, 12, 17, 20, 22, 24, 26

Detachment: 5, 13, 21, 23

Permissiveness: 9, 15, 18 (R)

/98/ ___ ___ /C/ ___ ___ ___ ___
sample **county** setting **center**

Caregiver Interaction Scale (Arnett, 1989)

Center name _____ **Date of observation** _____

Teacher name _____ **Data collector initials** _____

	not at all true	somewhat true	quite a bit true	very much true
1. Speaks warmly to the children	1	2	3	4
2. Seems critical of the children	1	2	3	4
3. Listens attentively when children speak to her	1	2	3	4
4. Places high value on obedience	1	2	3	4
5. Seems distant or detached from the children	1	2	3	4
6. Seems to enjoy the children	1	2	3	4
7. When the children misbehave, explains the reason for the rule they are breaking	1	2	3	4
8. Encourages the children to try new experiences	1	2	3	4
9. Doesn't try to exercise much control over the children	1	2	3	4
10. Speaks with irritation or hostility to the children	1	2	3	4
11. Seems enthusiastic about the children's activities and efforts	1	2	3	4
12. Threatens children in trying to control them	1	2	3	4
13. Spends considerable time in activity not involving interaction with the children	1	2	3	4
14. Pays positive attention to the children as individuals	1	2	3	4
15. Doesn't reprimand children when they misbehave	1	2	3	4
16. Talks to children on a level they can understand	1	2	3	4
17. Punishes the children without explanation	1	2	3	4
18. Exercises firmness when necessary	1	2	3	4
19. Encourages children to exhibit prosocial behavior, e.g. sharing, helping	1	2	3	4
20. Finds fault easily with children	1	2	3	4
21. Doesn't seem interested in the children's activities	1	2	3	4
22. Seems to prohibit many of the things that children want to do	1	2	3	4
23. Doesn't supervise the children very closely	1	2	3	4
24. Expects the children to exercise self control; e.g., to be undisruptive for group, provider-led activities, to be able to stand in line calmly	1	2	3	4
25. When talking to children, kneels, bends, or sits at their level to establish better eye contact	1	2	3	4
26. Seems unnecessarily harsh when scolding or prohibiting children	1	2	3	4

Performance Capacity

To address parental needs related to:
Caregiving Skills
Caregiving Knowledge

Introduction to Parental Needs Related to Performance Capacity

The parents of infants who are transitioning home from the NICU setting, have been shown to experience difficulty in many areas related to performance capacity. Multiple researchers have found that optimal quality of care for preterm infants is compromised by a lack of information and support for parents, lack of caregiving skills, and inadequate caregiver knowledge (Benasich & Brooks-Dunn, 1996; Spicer et al., 2008).

Additionally, Plomgaard, Hansen, and Greisen (2006) found that parents seem to be lacking knowledge when it comes to addressing the unique developmental stages and common developmental delays of premature infants. Ultimately, decreased caregiving skills and poor parental education can significantly influence the care the infant receives during the vital transition period from hospital to home.

How Performance Capacity Aspects of MOHO Address These Parental Needs

Performance capacity, or the individual's underlying ability, impacts the experience a person has when performing occupations (Kielhofner, 2009). Throughout this manual, the OT practitioner will work with the parent in order to increase their performance capacity related to education and skills needed to successfully care for their infant. The OT practitioner is encouraged to use the True/False questionnaire as a warm-up activity to facilitate important *talking points* regarding performance capacity.

True or False???

T or F	The skills and abilities you have at the time of your infants' birth cannot be built upon or enhanced.
T or F	Your infant is safest when being cared for by medical professionals.
T or F	Caring for an infant who spent time in the NICU is a challenging and rewarding process.
T or F	The more experience you gain the better you will be able to care for your infant.

True or False Answer Guide

1. **The skills and abilities you have at the time of your infants' birth cannot be built upon or enhanced.**
   False: Skills and abilities can easily be enhanced through proper education & experiences.

2. **Your infant is safest when being cared for by medical professionals.**
   False: Caregivers can easily be trained to provide safe & effective care to their infants.

3. **Caring for an infant who spent time in the NICU is a challenging and rewarding process.**
   True: Caregivers can expect challenges while caring for their infant, but there are also many rewards that can be expected throughout the transitioning period.

4. **The more experience you gain the better you will be able to care for your infant.**
   True: As caregivers gain experience, their ability to provide effective care to their infants' increases. Over time, parents learn about their infant & their specific needs.

Picture used with permission

Tips for Effectively Feeding Your Infant

S – Swaddle your baby during feedings. This will give your baby postural control and support while they eat so they can focus on the "workout" of eating rather than how to stabilize or control his/her body.

T – Touch your baby. Some people call this Kangaroo Care. Make sure you spend as much time as you can in skin-to-skin contact with your baby. This goes for both parents!

E – Evaluate the flow of milk from the nipple or your breast. Avoid using high flow nipples and if the natural flow of your breast milk is fast, try pumping a few minutes prior to beginning the feeding.

P – Pace your baby. Recognize signs of stress, such as increased work of breath, furrowed eyebrows, coughing, red/watery eyes, and loss of liquid around the mouth. Be sure you give your baby the breaks he/she needs to breathe.

S – Position your baby in an elevated sidelying position. This feeding position will decrease breathing effort, improve head and trunk alignment and allow for the liquid to collect in the cheek prior to the swallow.

Adapted from: http://handtohold.org/resources/helpful-articles/nicu-to-home-a-perspective-on-feeding-difficulties/

Positioning Protocol

General Information

- When positioning your infant, it is important to provide an environment that developmentally supports the infant's physical and neurobehavioral growth.
- The following are instructions for positioning your infant in a variety of positions:

Prone

- Turn head to the side but alternate to the other side regularly to prevent head deformity.
- Use positioning aids to prevent total hip abduction.
- Tuck arms and legs under the infant with hands close to the face for self-comforting.
- Use a blanket or other object to support the infant's chest.

Side-Lying

- Encourage hip and knee flexion.
- Keep the head in midline.
- Provide support so the back is slightly rounded.
- Positioning aids may be used to maintain appropriate position.

Supine

- Provide support to keep shoulders slightly forward.
- Provide foot support.
- Encourage midline position.
- Encourage hip and knee flexion.

Picture used with permission

Adapted from: http://www.archildrens.org/documents/Services/IPC/NICU_positioning_guidelines_revised2013.pdf

Physiological Effects of Positioning

Picture used with permission

Heart Rate

- When your infant is positioned on their stomach, it can lower their heart rate
- If the head is elevated it facilitates a more normal heart rate and lower blood pressure

Respiration

- Placing your infant on their stomach while sleeping helps them breathe better and decrease the chance of them stopping breathing during sleep

Oxygen Saturation

- Placing your infant on their stomach can increase oxygen saturation
- Making sure your infant is not in their car seat for prolonged periods of time will ensure they have adequate oxygen saturation

Sleep

- Positioning your infant on their stomach during sleep can result in fewer awakenings
- Infants have also been shown to sleep better when positioned on their stomach

Pain

- Positioning your infant on their side with a rolled blanket for support, it can significantly decrease pain

Lung Function

- If your infant requires an oxygen machine, placing your infant on their stomach will increase their lung function and volume of oxygen in their lungs

Muscular Outcomes

- Placing your infant on their back helps their muscles mature and promote neck movement

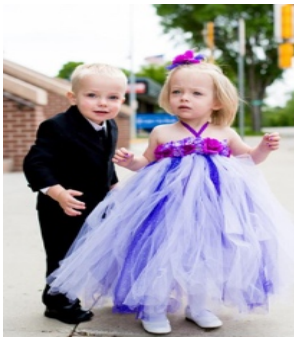
Stomach Health

- Placing your infant on their left side can reduce acid reflux and help settle an upset stomach

Adapted from: http://connect.jbiconnectplus.org/viewsourcefile.aspx?0=5391

Developmental Milestones

Pictures used with permission



What's Normal Development for your Premature Infant?

Many infants grow in a fairly predictable pattern; however, for infants who were born premature or spent time in the NICU following birth, this pattern may vary (March of Dimes, 2015). Developmental milestones are meant to serve as a guideline to monitor your infant's development. However, when considering these milestones for infants born prematurely, you must look at the milestone guidelines a little differently. Rather than looking at your infants chronological age, you'll need to look at the infants adjusted age. Below, you will find definitions comparing chronological age to adjusted age.

Chronological Age: The age of your infant from their day of birth. For example, this is the number of days, weeks, or years old the baby is.

Adjusted Age: The age of your infant based on his or her due date. For example, if your infant is 6 months old but was born two months early, their adjusted age is 4 months.

When Will Your Baby Catch Up Developmentally?

Although there is not a set period of time it will take your infant to catch up to his or her peers, many sources report that the infant will reach the expected developmental stage within two to three years depending on how prematurely they were born (March of Dimes, 2015). After this period of time, differences in development or size are likely due to individual differences that are not associated with premature birth.

*Ask your occupational therapist for more information and resources on this topic!

Adapted from: http://www.babycenter.com/0_whats-normal-development-for-your-premature-baby_10300025.bc

Developmental Milestones Chart

Age	Motor Skills	Language Skills	Social/Emotional Skills
2 Months (8 Weeks)	• Moves hands and legs actively • Lifts head and chest while lying on stomach • Holds objects in hands • Still needs some head support but is able to control head a little bit	• Makes cooing noises • Cries when needs something • Responds to sounds and turns head when hears noises.	• Recognizes primary caregivers • Smiles • Makes eye contact
4 Months (16 Weeks)	• Reaches for objects • Lifts head and pushes on arms when on stomach • Brings hands together or to mouth • Makes crawling movement	• Turns head to follow familiar voices • Laughs and squeals • Combines sounds more often	• Shows interest in preferred objects • Increasingly interactive • Able to comfort him/herself
6 Months (24 Weeks)	• Sits by him/herself • Bangs and shakes objects • Puts weight on feet when held in standing position • Transfers objects from one hand to the other • Holds 2 objects at a time • Rolls over from stomach to back	• Responds to name, turns and looks • Babbles	• Notices if caregivers are present or not • Reacts differently to strangers • Expresses excitement, happiness, and unhappiness

Adapted from: HealthyChildren.org.html

9 Months (36 Weeks)	• Pulls self up to stand • Crawls, moves along furniture • Walks when hands are held • Picks up smaller objects with thumb and finger	• Imitates sounds and movements • Babbles with combination of vowel and consonant sounds • Recognizes familiar words and short phrases	• Starts to show signs of "stranger danger" • Plays peek-a-boo Claps hands
12 Months (1 Year)	• Takes first steps • Stands alone • Puts small objects in container • Turns a few pages of a book at a time	• Hands over object when asked • Combines movements with sounds • Associates "mama" or "dada" with parents	• Plays with others • Prefers to be with familiar people
18 Months (1 ½ Years)	• Walks without help • Can sometimes run • Kicks ball forward • Scribbles • Pulls toy along the ground • Climbs on furniture	• Follows simple directions • Points to nose, mouth, eyes, ears, hands, and feet • Says increasing number of simple words • Shows what he or she wants by pointing	• Can separate from parent more often (less "stranger danger") • Gives kisses • Listens to stories • Greets people with "hi" • Sometimes says "no"
24 Months (2 Years)	• Walks up and down stairs • Turns single pages in a book • Scribbles in circular motion and can draw vertical lines • Stands on one foot without support • Feeds self with little mess	• Follows 2-part instructions • Talks in 2-3 word sentences • Uses at least 20 words	• Helps with simple household tasks • Responds to correction by stopping

Adapted from: HealthyChildren.org.html

Home Medical Equipment: Feeding Pump

- After graduation from the NICU, your infant will need special home medical equipment to help keep him or her well.

Why does my infant need this equipment?

- Some babies who need extra nutrition or cannot swallow require special feeding tubes. A nasogastric tube (NG tube) is inserted into the nose and goes directly down into the stomach. A gastrostomy tube (G-tube) goes directly into the stomach. A jejunosto- my tube (J-tube) goes past the stomach and directly into the top part of the small intestine (called the *jejunum*). Proper nutrition helps your baby to have the best health and healing abilities.
- A *feeding pump* is a small electric or battery-powered machine that sends formula or breast milk (liquid food) through a tube that connects to your baby's feeding tube.
- The feeding pump controls how much of the food is given, how fast, and for how long.

Company Information

- A company will bring the equipment to your home and teach you how to use and manage any problems with the equipment that may arise.

Name: _____

Phone Number: _____

Address: _____

_____

Other Emergency Numbers: _____

Important Things to Remember

- Always follow the directions for mixing your infant's formula or breast milk.
- Always follow the directions given by the vendor of the feeding pump.
- Always follow the schedule for your infant's feedings. Some infants who need a feeding pump are also able to eat by mouth. Be sure to talk with your infant's provider to check if it is safe for your baby to take any food or liquid by mouth.
- Call your emergency medical services, telephone, and electric companies to let them know your infant uses a feeding pump. This is important because if there is a power outage, you will be on a priority list for help.
- You may be nervous at first, but with practice, you will become more comfortable using the equipment. It's always OK to ask for help! Make sure you ask your baby's healthcare provider who you can call for help, questions, and concerns.

* *The above information is to help you better understand your baby's care. Always follow the instructions given by your baby's provider and ask questions if you have concerns about your baby.*

Adapted from: http://www.feedingtubeawareness.com/index.html

Home Medical Equipment: Pulse Oximeter (Pulse Ox, Oxygen Saturation Monitor)

- After graduation from the NICU, your infant might need special home medical equipment to help keep him or her well.

Why does my infant need this equipment?

- Your baby needs a pulse oximeter to monitor the amount of oxygen in his or her blood (oxygen saturation).
- A small, lighted probe attached to your baby's foot or hand will measure the amount of oxygen in his or her blood.
- An alarm will sound if the amount of oxygen in your baby's blood becomes too low.

Company Information

- A company will bring the equipment to your home and teach you how to use and manage any problems with the equipment that may arise.

Name: _____

Phone Number: _____

Address: _____

_____

Other Emergency Numbers: _____

Important Things to Remember

- Always use the pulse oximeter when your baby is asleep, takes a nap, while he or she is riding in the car, or when you are busy.
- Make sure the monitor is hooked up the right way to decrease false alarms.
- Always check on your baby when you hear the pulse oximeter alarm. If needed, tap your baby's foot or rub your baby's chest to help remind your baby to breathe or help raise the heartbeat.
- If the alarm goes off and your baby is not breathing, shout for help, start cardiopulmonary resuscitation (CPR), and 911 right away.
- Call your telephone and electric companies if your baby also uses oxygen. This is important so that if there is a power outage
- or emergency, you will be on a priority list for help.
- Do not stop using the pulse oximeter until your baby's provider tells you it is safe to do so.

** The above information is to help you better understand your baby's care. Always follow the instructions given by your baby's healthcare provider and ask questions if you have concerns about your baby.*

Adapted from: https://www.aap.org/en-us/about-the-aap/aap-press-room/Pages/Pulse-Oximetry-a-Viable,-Readily-Available-Screening-Tool-for-Infants-with-Suspected--Critical-Congenital-Heart-Disease.aspx

Home Medical Equipment: Oxygen

- After graduation from the NICU, your infant might need special home medical equipment to help keep him or her well.

Why does my infant need this equipment?

- Oxygen is a gas that provides energy for every organ in the body.
- Oxygen is also a drug and must be ordered by a doctor or nurse practitioner.
- Extra oxygen from the nasal cannula will help your infant breathe easier, feed better, and grow.
- You will be going home with a pulse oximeter (pulse or oxygen saturation monitor)

Company Information

- A company will bring the equipment to your home and teach you how to use and manage any problems with the equipment that may arise.

Name: _____

Phone Number: _____

Address: _____

_____

Other Emergency Numbers: _____

Important Things to Remember

- Complete cardiopulmonary resuscitation (CPR) teaching, as well as monitor and equipment training.
- Stay overnight with your baby—use the equipment you will be going home with and care for your baby for at least 24 to 48 hours before going home.
- Do not let anyone smoke in the house or around your baby or the oxygen tanks.
- Oxygen burns easily. Keep the oxygen tanks and tubing at least 6 to 10 feet away from open flame such as candles, fire or burners, radiators, fireplaces, or heaters.
- Do not use grease, oil, rubbing alcohol, powders, petroleum jelly, or spray cans near your baby on oxygen or the equipment.
- Call your telephone, and electric companies to let them know your baby uses a pulse oximeter. This is important so if there is a power outage, you will a priority for help.
- If your baby is blue or having breathing problems, be sure the oxygen tank is on, that oxygen is flowing out of the cannula, and that prongs are in your baby's nose. If your baby is not breathing, shout for help, start CPR, and call emergency medical services (EMS) or 911 right away.

* *The above information is to help you better understand your baby's care. Always follow the instructions given by your baby's healthcare provider and ask questions if you have concerns about your baby.*

Adapted from: https://www.healthychildren.org/English/ages-stages/baby/preemie/Pages/When-Baby-Needs-Oxygen-At-Home.aspx

Assessments to Address Performance Capacity

The following table provides a list of assessments that address performance capacity aspects. On the chart you will find a description of each assessment, a reference where it can be found, and the cost of the assessment. These assessments can be used to address parental needs related to the performance capacity aspects that may need improvement.

Title	Description	Reference	Cost
Model of Human Occupation Screening Tool	The Model of Human Occupation Screening Tool addresses volition, habituation, skills, and environment to gain an overview of the person's functioning.	Parkinson, Forsyth, & Kielhofner (2006) Link: http://www.cade.uic.edu/moho/productDetails.aspx?aid=4	$
Occupational Self-Assessment	The Occupational Self-Assessment is a self-report used to assist the person in establishing priorities for change and identifying goals for occupational therapy.	Baron, Kielhofner, Iyenger, Goldhammer, & Wolenski (2006) Link: http://www.cade.uic.edu/moho/productDetails.aspx?aid=2	$

Environment

To address parental needs related to:
Environment

Introduction to Parental Needs Related to Environment

The parents of infants who are transitioning home from the NICU setting, have been shown to experience difficulty in many areas related to the environment. Although authors did not specifically separate out the environment, it did emerge as a concern within the literature. The incongruence between the hospital setting and the home can cause fear for parents (Zanardo et al., 2003).

In the hospital, there are many supportive systems, medical staff who are highly trained, and state of the art medical equipment to care for infants' specific needs. In contrast, a typical home environment does not provide access to skilled healthcare professionals or advanced technologies. Ultimately, this incongruence between the two settings can cause fear in the parents as they adjust to caring for their infants at home and can significantly influence the care the infant receives during the vital transition period from hospital to home.

How Environmental Aspects of MOHO Address These Parental Needs

In this section, the OT practitioner will evaluate environmental aspects such as objects, spaces, people, and expectations that may alter parents' occupational performance in their caregiving role. The OT practitioner is encouraged to use the True/False questionnaire as a warm-up activity to facilitate important *talking points* regarding the environment.

True or False???

T or F	The home is usually not a very safe place for your infant to be cared for.
T or F	It is not necessary to have a professional assess your home environment and whether or not it is a safe place for you to provide care for your infant.
T or F	The home can easily be modified to meet the needs of you and your infant.

True or False Answer Guide

1. **The home is usually not a safe place for your infant to be cared for.**
   False: As long as your infant's health is stable & you are properly educated on the needs of your infant, the home is a perfectly safe environment.

2. **It is not necessary to have a professional assess your home environment and whether or not it is a safe place for you to provide care for your infant.**
   False: It is important to have a professional like an occupational therapist assess your home environment before bringing your infant home from the NICU. This will help make sure transitioning home is a smooth process and your home is equipped with necessary tools to properly care for your infant.

3. **The home can easily be modified to meet the needs of you and your infant.**
   True: An occupational therapist is trained to look at your environment and find ways to make things like feeding & caring for your infant easier. The therapist will assess the environment, make recommendations, & give you other helpful resources.

Home Safety

- Below are some tips to help ensure your infant's safety when you return home.

Medications

- Keep the infant's medicine bottles away from other small children.
- Discuss medications with other caregivers and share instructions that you received.

CPR

- Enroll all caregivers in cardiopulmonary resuscitation(CPR) class in case of emergencies.

Nursery Safety

- Your infant should sleep in a crib, not in your bed.
- The infant's crib should hold a firm mattress with tight-fitting sheets.
- The crib should not have any excessively soft surfaces such as comforters or fluffy quilts.
- Remove any loose blankets, toys, pillows, or stuffed animals from the crib.
- Never leave your baby unattended on a changing table due to risk of falling.

Bathtub Safety

- Always have adult supervision; do not rely on baby bathtubs, bathtub rings, or other air-filled devices to keep your infant above water.
- Before bathing begins, have all supplies within arm's reach.
- Test bath water temperature with your inner wrist or a bath thermometer. The water should be luke warm or no warmer than (37.7 °C to 40 °C [100 °F to 104 °F]).
- Move your hand through water to minimize hot spots before placing infant in tub.
- Wash the infant's face with clean water – do not use soap until they are older.

Adapted from: www.healthychildren.org/English/tips-tools/Pages/Safety- for-Your-Child-Birth-to-6-Months.aspx

Temperature Control for Your Infant

- Your infant can have a hard time keeping their temperature in the normal range. Full-term infants have a layer of fat under their skin that helps them stay warm, which preterm infants lack.
- When your infant is bigger, he or she can be dressed in clothes or a t-shirt, wrapped in a blanket, and put in an open crib or bassinet. This is one of the milestones along the journey to go home.
- Your infant can get cold really fast. The best way to keep your infant warm is to dry your infant; give your infant a warm, dry bed; and place a hat on his or her head.
- Make sure your infant doesn't get too warm. Dressing your infant in too many clothes, covering your infant in too many blankets, or covering your infant's face can make him or her too warm.

Things to Remember when going home:

- If your infant's body temperature is lower than 97 °F (36 °C), undress your infant, place him or her skin to skin on your chest, wrap yourselves in blankets, and call your infant's provider.
- Keep the crib away from drafts, windows, and outside walls by placing your infant's crib on the inner wall of the room.
- If your infant's temperature is higher than 100.4 °F (38 °C), call your infant's provider.
- If your infant's hands or feet are cool or look pale or blue, warm them with a blanket. You can also add a layer of clothing. If the color of your infant's hands and feet does not improve, call your infant's provider.
- Dress your infant in layers. Add or take away layers depending on your infant's needs. Use sleepers when you can.
- Remove clothes when they are wet or dirty.

Plan of Action for Medical Concerns

- When transitioning home from the hospital environment, it is common for parents to be fearful due to lack of medical support such as equipment, staff, and medications. The following suggestions are provided to help parents feel more confident in their abilities to manage minor events your infant may experience.

Concern	Strategy	Picture of Strategy
Infant has excessive nasal congestion making it hard to breath.	Suction bulb	
Your infant is having difficulty breathing.	Call 911	
Infant feels warmer than normal (and possibly clammy).	Thermometer / Call doctor if needed	
Your infant's lips are tinted blue.	Call your doctor	
Your baby experiences diaper rash and has redness and irritation around his or her buttocks.	Frequently change your babies diaper. Clean area with wipes. Apply special cream.	
Your baby has very loose or watery stools and/or forceful vomiting.	Call your doctor.	

Assessments to Address Environment

The following table provides a list of assessments that address environmental aspects. On the chart you will find a description of each assessment, a reference where it can be found, and the cost of the assessment. These assessments can be used to address parental needs related to the environment that may need improvement.

Title	Description	Reference	Cost
Model of Human Occupation Screening Tool	The Model of Human Occupation Screening Tool addresses how the environment affects volition, habituation, skills, and environment to gain an overview of the person's functioning.	Parkinson, Forsyth, & Kielhofner (2006) Link: http://www.cade.uic.edu/moho/productDetails.aspx?aid=4	$

The Untold Dangers Of Cars & Heatstroke In Small Children

A child dying in a hot vehicle seems like the least of your worries as a new parent. But the danger is very real. Child fatalities have occured in the United States due to heatstroke where children have been left in hot cars, trucks, vans and SUV's. Some of these even occurred on days with relatively mild (i.e., 70 degrees F) temperatures. Since 1998, there have been over 600 of these needless tragedies.

Due to current air bag regulations, all young children are being placed in back seats instead of front seats. There have been, on average, 38 fatalities from heatstroke each year, an almost 900% increase from the rate of the early 1990s. Although airbags are an essential vehicle safety measure and children should not be placed in front of them, putting children in the back seat increases the chance of "forgetting" the child is there as you drive from place to place.

On average summer day, the temperature in a car can rise 34 degrees in 30 minutes - even with the windows "cracked".

Forgetting your child seems like an impossibility to most. However, if you have ever driven from point A to point B and not really remembered how you got there, i.e. drove on "autopilot", you can see how this may happen.

Sometimes parents leave children in the car intentionally while they run into a store, etc. Although this may seem like an easy solution when you just need to "run in for 5 minutes", the outcome could be disastrous. In addition, it is illegal to do this in some states. Never use your vehicle as a babysitter.

In addition to parents accidentally or intentionally leaving children in vehicles, parents also need to be aware of the dangers of children playing in or around vehicles. Children are naturally curious and can easily become locked inside the car or trunk and not able to let themselves out in time.

Please follow the safety instructions and tips on the back side of this handout to prevent a tragedy from occuring.

Kate's Story

by Andrea Boe
Grand Forks, ND

Our second child, Kate Lola, was born January 30, 2006, a beautiful and healthy baby girl. We are the typical American family. Both my husband and I worked full-time, and with two small children, we were busy with everyday life. That all changed on June 28, 2006, just five short months after Kate was born.

It was our usual busy morning. Our oldest daughter didn't have daycare and my husband was going to stay home with her. Kate went to a different daycare so I was going to drop her off before I went to work. Normally, I dropped both girls off, but that day was different and so I took a different route to work.

I had fed Kate, dressed her in a new cute pink dress, and then my husband placed her in her car seat. As soon as I put her in the backseat of my van, she was sound asleep. Driving to work, I started thinking about all the things I had to get done at work and home. I somehow got on "autopilot" and arrived at work without dropping Kate off at daycare.

I worked the entire day without ever going back out to my van. In my mind, I had dropped Kate off. After work, I went to her daycare to pick her up; only then did I realize she was still in my van. I don't remember much after that, just people trying to resuscitate her and my agonizing disbelief that I had "forgotten" my own beautiful baby girl.

Nothing has been the same since that day. Our family is slowly trying to heal and I am still trying to understand how and why this happened. The truth is, it happens more than people realize. The reason we are sharing our story is to raise awareness so that this will never happen to another family. Please carefully read the safety recommendations and take them to heart.

Altru HEALTH SYSTEM

SAFE KIDS GRAND FORKS

6053-0095 AUG 14

Used with permission

Tehya's Story

by Dan Carlson
Sisseton, SD

The pain, the loss, the guilt. How could this happen? How could I have made such a mistake? These are the thoughts and feelings that have been going through my mind constantly since August 17, 2005.

My two daughters had just returned from the summer with their mom on August 14. The morning of August 17, 2005, was just like any other morning. I woke up and started getting the girls ready for the day. I was bringing my oldest daughter to spend the day with my mother and my 15-month old daughter, Tehya, to daycare in Browns Valley, MN where I work.

I put Tehya in her car seat and gave her a kiss. I then went and dropped my oldest daughter off with my mom. My mom met me outside, walked over to talk to Tehya, and gave her a kiss. Then, I drove to Browns Valley to drop Tehya off at daycare and go to work. The drive is about a fifteen minute commute. As I drove into Browns Valley, there is a turn that I would always take to bring Tehya to daycare. I didn't turn. Instead, I drove to work, parked my car and went in, the whole time thinking that my precious little baby was at daycare. I was so happy at work that day. I was telling everyone that would listen that my girls were back for the summer and how excited I was. I was thinking about them all day long, but I didn't realize that I had forgot to bring Tehya to daycare until it was too late.

I don't have any answers as to how I could make this kind of mistake, but it is very important for me to tell my painful story in the hopes that this can prevent another tragedy like this from happening again. It is the unthinkable, the unimaginable, but if it can happen to me it can happen to anybody.

It is the absolute worst thing in this world to have to live with.
Please don't let this happen to you!

The Untold Dangers Of Heatstroke In Small Children

To avoid the possible mistake of unintentionally leaving your child in your car, please review the recommended safety tips listed below.

SAFETY RECOMMENDATIONS:

- Do not leave a child in an unattended car, even with the windows down.
- Keep a stuffed animal in the carseat and when the child is put in the seat, place the animal in the front with the driver.
- Place your purse, briefcase or your left shoe in the back seat as a reminder that you have your child in the car.
- Make "look before you leave" a routine whenever you get out of the car.
- Put a sticker (such as the one shown/provided) or your own sticker on your car window to remind you to look before you leave.

- Have a plan that your childcare provider will call you if your child does not show up.
- Always lock your car and keep the keys out of older children's reach. If a child is missing, check the car first, including the trunk.
- Teach your children that vehicles are never to be used as a play area.

For additional information about hyperthermia and kids and car safety, visit these websites:
www.safekidsgf.com
www.safekids.org
www.kidsandcars.org
www.ggweather.com/heat

Used with permission

Winter Coats & Car Seats

How to stay warm AND safe

Bulky winter coats and snow suits should not be worn in a car seat as it makes the harness straps too loose to be effective in a crash.

No coat. Use a blanket for warmth.

Lightweight coat.

No coat and use a car seat cover that goes around (but not under) the car seat. This does not affect the tightness of the harness straps.

The fluff of a bulky winter coat or snow suit can compress in a car crash making harness straps loose, which can cause injury or ejection.

Car seat liners that go under a child can bunch up and makes extra padding that can compress in a car crash.

Remember to "Strap Before You Wrap"

Warm your car ahead of time when possible.

www.safekidsgf.com

SAFE KIDS GRAND FORKS

Altru HEALTH SYSTEM

Used with permission

Special Needs Car Seat Evaluation

There is a lot to think about prior to discharge. An early consultation with a special needs car seat technician is important to assure that the proper resources are available. Starting early with this process will ease the transition to home. We may have rental seats and special needs technicians available to assit with car seat installation. They are here to provide consults on positioning seats or casted patients in the vehicles, assistance with securing seats (short term and long term) and training caregivers on how to safely transport children. Altru staff can assist you with contacting a certified technician.

Special Considerations

There are many considerations that need to be taken into account when transporting a child with special needs or securing medical equipment.

- Some vehicles better accommodate large medical seats. Often times, vehicle seats need to be removed or placed in the collapsed position in order to accommodate the child.
- Additional passengers in the vehicle may be restricted due to the space needed for medical restraints.
- Transportation of additional medical equipment such as monitors, oxygen tanks, or wheel chairs will be addressed prior to discharge. You may also need to bring pillows or blankets to help with proper/comfortable positioning.
- Special anchors (top tethers and/or heavy duty top tethers) are often required due to the size and weight of the car seat. Arrangements can be made at your local car dealership to have hardware installed.

Renting Special Needs Seats

There is a cost associated with providing special needs seats, but thanks to the support of generous donors, Altru is equipped with several of these expensive seats that are available to rent for a minimal charge to families. The staff assisting you will discuss the cost and payment options.

For more information call 701.780.1660 or e-mail safekids@altru.org.

SAFE KIDS GRAND FORKS

Altru HEALTH SYSTEM

P.O. Box 6002 | Grand Forks, ND 58206-6002
altru.org

6050-0107JUN 14

Improving Health, Enriching Life altru.org

Special Needs Car Seat Program

Altru HEALTH SYSTEM

What is this program about?

At Altru Health System, keeping your child safe is important to us. Upon discharge, some children are unable to use a traditional car seat for transportation. Altru has developed a car seat program that assesses a child's car seat needs and rents specialized seats if necessary.

Who needs specialty seats?

- **Children with leg casts or a hip spica cast:** These children often have casts that put their legs in a position that is too wide to fit a car seat or an angle that prevents them from sitting correctly in a car seat. The child often needs a Hope car bed, Hippo seat, Traveler Plus, or an E-Z On vest.
- **Premature infants:** Traditional infant seats typically have a 4-5 pound minimum weight. Premature infants are often discharged prior to reaching that weight or may not be able to tolerate sitting upright in a traditional car seat. These infants may be discharged laying flat in a car bed that allows them to lay on a vehicle seat. Altru offers three options including the Angel Guard, Dreamride, or Hope car bed, depending on the size and weight of the infant.
- **Other medical diagnoses:** There are a variety of other reasons why a child may need a specialty seat or a consult on how to best transport them in the vehicle.

Casted Patient Special Needs Seats

Hippo Rear Facing

Hippo Foward Facing

Traveler Plus

E-Z On Vest

Infant Special Needs Seats

Angel Guard

DreamRide

Hope Car Bed

A car seat consultation will assess the vehicle options, seating positions and limitations of additional passengers in the car.

It is important that these considerations be made prior to discharge.

Don'ts

- Babies/children should never ride or be held in a front seat where there is a passenger side airbag.
- Avoid using blankets, heavy snowsuits or a bunting under the harness straps. These make it impossible to get the harness straps tight enough to hold the baby in a crash.
- Don't remove your baby from the car seat in a moving vehicle. Pull off the road and stop the car first.
- Avoid using vehicles that have no back seats.
- If your child is using a car bed because they did not tolerate the upright angle of an infant carrier, there are other things you must consider. You should not use an infant swing, an infant chair, an upright stroller, or be left in an upright position when unattended.
- Minimize travel when possible. It is best to have someone ride in the back seat with the infant.
- Never leave infant unattended in a car seat in a vehicle.

As your baby grows

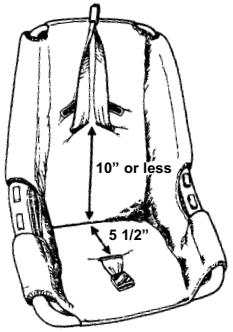
- Keep shoulder straps in the lowest slots until your baby's shoulders reach the higher set of slots.
- If your baby rides in an infant-only car seat, move the baby into a larger car seat, generally rear-facing, before the baby's head gets to the top of the car seat shell. It should be no closer than 1" from the top of the seat.
- Your baby should always ride rear-facing in the back seat until the baby reaches at least 1 year of age AND at least 20 pounds. It is best to keep them rear facing as long as the convertible seat will allow (usually to 30 or 35 pounds).

6053-0263 DEC 14

Car seat positioning for premature or small newborns

Altru HEALTH SYSTEM

When your baby is ready to go home from Altru Health System, you will need to be prepared to take the baby home in a government-approved car seat. The car seat you choose is especially important if your baby weighs less than 7 pounds.



Infant safety seat showing maximum recommended harness dimensions for correct fit on a very small baby. Even with a small harness, a baby may need padding beside their body at first.

PICTURE A

The "best" seat for your baby is one that fits your baby and fits into your vehicle, and one that you will find easy to use correctly every time.

A car seat given to you as a gift may not be the best fit for your baby. You may want to exchange it for one that fits your baby's needs and your vehicle more appropriately.

Choosing a car seat to fit your premature or small baby

- Car seats with a space of 5 1/2 inches or less between the crotch strap and the seat back will keep your baby from slouching too much (Picture A).
- Seat harnesses with shoulder strap slots located 10 inches or less above the seat bottom will work best to hold your baby in place in a crash (Picture A).
- The lowest harness strap slots need to be at or below shoulder level. If there's room for the baby to move, there's room for the baby to get hurt.
- Car seats with shields or trays in front should not be used when the baby is small, because the baby's face or chest could hit the shield in a crash.
- It is recommended that seats not be used if they are over 6 years old.
- If the seat has been in a crash, it may not be safe to use. Please talk to the baby's nurse about his.
- The car seat must meet current federal motor vehicle safety standards. This information can be found with the car seat instruction manual and stamped on the seat itself.
- Read your vehicle owner's manual regarding car seats and their usage in your particular make and model vehicle.
- Once a car seat is obtained, read the car seat manufacturer's instruction manual. Over 90% of car seats are misused and much of the misuse can be prevented if the parents read the instructions and are familiar with their car seat's use.

Infant placement in car seat

- Dress your baby in clothes with legs so the crotch strap can go between the baby's legs.
- Do not buy an additional infant head support. Extra padding can make the harness too loose in a crash, allowing the baby to be thrown out. It is best to purchase and use receiving blankets that are rolled up around the baby but not put behind the body. (Picture B)
- The baby's back and buttocks should be flat against the back of the car seat.
- Shoulder straps must be in the lowest slots. They should fit at or below the level of the shoulders. If they are above the shoulder level, the seat and harness system is too large for the baby as it does not provide a proper fit.
- Position the harness retainer clip at armpit level and NOT under the chin. This places it across the hard chest bone rather than soft tummy tissue. It also holds the straps together so the baby won't fly out of the seat in a crash.
- Rolled up receiving blankets along side the baby's body, around the baby's head, and between the baby's legs behind the crotch strap can make the car seat fit better (Picture B).
- Buckle your baby in the rear-facing position in the back seat and secure the seat belt so the seat does not move more than 1" side-to-side.
- Make sure the car seat reclines at approximately a 45 degree angle in the vehicle. This angle keeps the baby's head from flopping forward. If the vehicle seat slopes, put tightly rolled towels under the car seat below the baby's feet to obtain the correct degree angle. The base of the seat, or seat bottom, if there is no base, should sit level with the ground.

Securing a monitor or other medical equipment

Equipment, such as monitors or oxygen tanks should be wedged under the vehicle seat or on the floor to prevent it from becoming a dangerous projectile in the event of a crash.

If using monitoring equipment during travel time, it should have portable and self-contained power available for twice the duration of the expected travel time.

Consider having someone ride in the back seat with the baby so as to respond readily to alarms from the equipment.

Every baby deserves to be protected in case of a car crash.

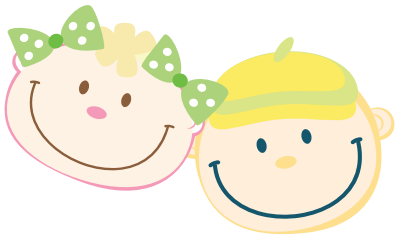
PICTURE B

Get the word out

Make sure that everyone who cares for your baby practices safe sleep.

Infants who are use to sleeping on their backs, but who are then placed to sleep on their stomachs or sides, are at an increased risk of SIDS.

Parents, grandparents, babysitters, child care providers, and everyone else in charge of putting a baby to sleep should place them on their back to sleep every time, for naps and at night.



The easiest way to remember how to create a safe sleep environment is to think of the ABC's of safe sleep:

Altru HEALTH SYSTEM

SAFE KIDS GRAND FORKS

6053-0163 MAR 14

Reduce the risk of

Sudden Infant Death Syndrome

SAFE KIDS GRAND FORKS

Practice Safe Sleep

Sudden Infant Death Syndrome (SIDS)

SIDS is the sudden unexplained death of an infant under 1 year of age.

- SIDS is the leading cause of death among infants aged one month to one year. Each year nearly 2,300 infants will die from SIDS.

Important things to know about SIDS:

- Infants who sleep on their stomach are at a greater risk of SIDS than infants who sleep on their backs.
- Sleeping on soft surfaces, such as couches & soft mattresses, is a significant risk factor for SIDS.
- Bed sharing with an infant is hazardous and is a risk factor for SIDS.
- Infants whose mothers smoke during or after pregnancy are at a greater risk of SIDS.

What can be done to reduce the risk of SIDS

BACK TO SLEEP

- Always place a baby on their back to sleep.
- Placing an infant on their back to sleep significantly lowers SIDS risk. Stomach sleeping can increase the risk of SIDS nearly 2-12 times as much from babies who sleep on their backs.

A FIRM SLEEP SURFACE

- Never place baby to sleep on pillows, quilts, sheepskins or others surfaces.
- ALWAYS place baby to sleep on a firm sleep surface, such as a safety-approved crib mattress.
- The American Academy of Pediatrics does not recommend infant car seats, strollers, swings or slings for routine sleep as they pose a risk for airway obstruction.

DO NOT SMOKE

- Do not smoke before or after the birth of the baby and do not let others smoke around the baby.

SAFE SLEEP ENVIRONMENT — NO BED SHARING

- Baby should not sleep in a bed, couch or armchair with adults or other children, but they can sleep in the same room as parents/caregivers.
- If parents bring the baby into bed to breastfeed, they need to put them back in a separate sleep area when finished.

NOTHING IN CRIB OTHER THAN BABY

- Keep soft objects, such as stuffed animals and loose bedding, out of the crib.
- Do not use blankets, pillows, quilts or crib bumpers in the baby's sleep area.
- Consider using a sleep sack for your baby. These wearable blankets replace loose blankets in the crib that can cover your baby's face and interfere with breathing.

The SwaddleMe infant wrap is available for purchase in the Altru Hospital Gift Shop.

While the family crib may not provide a safe sleeping environment for your baby, you don't have to throw it out. Be creative!
Take that crib and make it into something that can be used for another purpose in your home.

Crib Safety Checklist

- ○ Are the crib slates more than 2 3/8 inches apart?
- ○ Can you fit more than 2 fingers between the edge of the mattress and the side of the crib?
- ○ Are the corner posts higher than 1/16 of an inch?
- ○ Are there any cutouts in the head or footboard?
- ○ Can the drop latches be easily released by a child?
- ○ Are the screws and bolts that hold the crib together loose?
- ○ Are loose fitting crib sheets being used?

If you answer yes to any of these questions, your crib or playard isn't as safe as it could be.

Playard Safety Checklist

- ○ Is the mesh weave greater than 1/4 of an inch?
- ○ Are there tears, holes or loose threads on the mesh?
- ○ Is the mesh loose that secures the top rail and floor plates?
- ○ Are there any tears or holes on the top rail cover?
- ○ Is a soft pillow, comforter or soft bedding provided?

6053-0343 OCT 15

Crib Repurposing

How to use a family crib that doesn't meet safety standards.

SAFE KIDS GRAND FORKS

What You Need To Know
5 Federal Requirements about Cribs

- Traditional drop-side cribs can no longer be made or sold; immobilizers and repair kits are not allowed.
- Wood slats must be made of stronger material to prevent breakage.
- Crib hardware must have anti-loosening devices to keep it from coming loose or falling off.
- Mattress supports must be more durable.
- Safety testing must be more rigorous.

As of June 28, 2011, all cribs sold in the United States must meet updated requirements for overall crib safety.

Making sure your little ones are safe and sound.

- To address these deadly hazards, all homes, child care facilities, family child care settings, and places of public accommodation must replace their current cribs with the updated regulations for safe cribs.
- Noncompliant cribs should not be resold, donated or given away. Consider repurposing!

See back page for crib and playard checklist.

Why the need for this change in standards?

- Rules and regulations are in place to improve the quality of cribs and make them safer for babies.
- Cribs on the market today prohibit drop-side rail cribs, have stronger slats and mattress supports, better quality hardware, and undergo more safety testing.
- Babies are small, so it is important that your crib slats are no more than 2 3/8 inches apart.
- The mattress and the side of the crib should have a tight fit. No more than two fingers should fit between them.
- Avoid any holes, tears, and shape cutouts.
- Avoid any bed accessories such as pillows, thick blankets, loosely fitted sheets and stuffed animals.
- Once the crib is assembled, give it a firm shake to ensure all bolts and screws are tightly secured.
- To help ensure a safe place for your baby, follow the crib safety checklist.

References

References

American Academy of Pediatrics (2015). *A guideline to the milestones in a child's development.* Retrieved from HealthyChildren.org.html

American Academy of Pediatrics (2011). *Pulse oximetry: A viable, readily available screening tool for infants with suspected critical congenital heart disease.* Retrieved from https://www.aap.org/en-us/about-the-aap/aap-press-room/Pages/Pulse-Oximetry-a-Viable,-Readily-Available-Screening-Tool-for-Infants-with-Suspected--Critical-Congenital-Heart-Disease.aspx

American Academy of Pediatrics (2012). *Safety for your child: Birth to 6 months.* Retrieved from https://www.healthychildren.org/English/ages-stages/baby/Pages/Safety-for-Your-Child-Birth-to-6-Months.aspx

American Academy of Pediatrics (2015). *When baby needs oxygen at home.* Retrieved from https://www.healthychildren.org/English/ages-stages/baby/preemie/Pages/When-Baby-Needs-Oxygen-At-Home.aspx

Arnett (1989). *Caregiver Interaction Scale.* Retrieved from http://fpg.unc.edu/sites/fpg.unc.edu/files/resources/assessments-and-instruments/SmartStart_Tool6_CIS.pdf

Baron, K., Kielhofner, G., Iyenger, A., Goldhammer, V., & Wolenski, J. (2006). *Occupational self assessment version 2.2.* Retrieved from http://www.cade.uic.edu/moho/productDetails.aspx?aid=2

Beck, A., Steer, R., & Brown, G. (1996). Beck depression questionnaire. Retrieved from http://www.pearsonclinical.com/psychology/products/100000159/beck-depression-inventoryii-bdi-ii.html

Benasich, A. A., & Brooks-Gunn, J. (1996). Maternal attitudes and knowledge of child rearing: Associations with family and child outcomes. *Child Development, 67,* 1186-1205.

Best Practice (2010). *Positioning of preterm infants for optimal physiological development.* Retrieved from http://connect.jbiconnectplus.org/viewsourcefile.aspx?0=5391

Boon, A. (2015). NICU to home: a perspective on feeding difficulties. Retrieved from http://handtohold.org/resources/helpful-articles/nicu-to-home-a perspective-on-feeding-difficulties/

Bourne, E. (2010). *The anxiety and phobia workbook* (4th ed.*)*. New Harbinger Publications: Oakland, CA.

Boykova, M., & Kenner, C. (2012). Transition from hospital to home for parents of preterm infants. *Journal of Perinatal Neonatal Nursing, 26*(1), 81-87. doi: 10.1097/JPN.0b013e318243e948

Developmental Services (2013). *NICU positioning protocol*. Retrieved from http://www.archildrens.org/documents/Services/IPC/NICU_positioning_guidelines_revised2013.pdf

Feeding Tube Awareness Foundation (2015). *Raising awareness and sharing knowledge.* Retrieved from http://www.feedingtubeawareness.com/index.html

Hamilton, M. (1959). The assessment of anxiety states by rating. *British Journal of*

Medical Psychology, 32, 50-55.
Heras, C.G., Geist, R., Kielhofner, G., & Li, Y. (2007). *The volitional questionnaire version 4.1.* Retrieved from http://www.cade.uic.edu/moho/productDetails.aspx?aid=8
Hess, C. R., Teti, D. M., & Hussey-Gardnerc, B. (2004). Self-efficacy and parenting of high-risk infants: The moderating role of parent knowledge of infant development. *Journal of Applied Developmental Psychology, 25*(4), 423–437. doi: 10.1016/j.appdev.2004.06.002
Kielhofner, G. (2009). The model of human occupation. In G. Kielhofner's (Ed.), *Conceptual Foundations of Occupational Therapy Practice (4th ed.)*, 147-173. Philadelphia, PA: F.A. Davis Company.
Leonard, L. (1998). Depression and anxiety disorders during multiple pregnancy and parenthood. *Journal of Obstetric, Gynecologic & Neonatal Nursing,* 27(3), 329-337.
March of Dimes (2015). *What's normal development for your premature infant?*. Retrieved from http://www.babycenter.com/0_whats-normal-development-for-your-premature-baby_10300025.bc
National Association of Neonatal Nurses (2014). *Baby steps to home.* Retrieved from http://babystepstohome.com
Parkinson, S., Forsyth, K., & Kielhofner, G. (2006). *The model of human occupation screening tool version 2.0.* Retrieved from http://www.cade.uic.edu/moho/productDetails.aspx?aid=4
Plomgaard, A., Hansen, B., & Greisen, G. (2006). Measuring developmental deficit in children born at gestational age less than 26 weeks using a parent-completed developmental questionnaire. *Acta Padiatrica, 95*(11), 1488-1494. doi: 10.1080/08035250600684438
Richards, E., & Digger, K. (2011). Compliance, motivation, and health behaviors of the learner. In S.B. Bastable, P. Gramet, K. Jacobs, & D.L. Sopczyk (Eds.), *Health Professional as Educator (pp. 199-225).* Sudbury, MA: Jones and Bartlett Learning.
Spicer, A., Pinelli, J., Saigal, S., Wu YW, Cunningham, C., DiCenso, A. (2008). Health status and health service utilization of infants and mothers during the first year after neonatal intensive care. *Advanced Neonatal Care, 8*(1), 33-41.
Spielman, V., & Taubman-Ben-Ari, O. (2009). Parental self-efficacy and stress-related growth in the transition to parenthood: a comparison between parents of pre- and full-term babies. *Health & Social Work, 34*(3), 201–212.
University of Iowa Children's Hospital. (2015). UI children's hospital's specialized neonatal transport team. Retrieved from: www.uichildrens.org
Zanardo, V., Freato, F., & Zachello, F. (2003). Maternal anxiety upon NICU discharge of high-risk infants. *Journal of Reproductive & Infant Psychology, 21*(1), 69-75.
Zung, W.K. (1971). A rating instrument for anxiety disorders. *Psychosomatics, 12*(6), 371-379.

CHAPTER V

SUMMARY

The product developed for this scholarly project was designed to be utilized as a user-friendly resource manual for occupational therapists to use with parents as they transition home from the NICU with their infant. In this product, there are numerous handouts and worksheets that the occupational therapist can utilize with parents in order to improve aspects of volition, habituation, performance capacity, and the environment. This resource manual is not meant to stand alone but is meant to guide and supplement the therapy process.

This product is limited by the minimal research addressing this specific population of individuals. This resource guide is also limited because it does not include an evaluation of effectiveness for the therapist to measure the efficacy of the resources. This product will require frequent updates to assure current and accurate information is being provided to parents.

The successful implementation of this product into clinical practice would require a supplemental program plan to promote the use of this product throughout the transition to the home environment. Packaging and pricing for the product would also need to be determined in order to make it accessible to occupational therapists. Furthermore, additional photographs would be beneficial to further illustrate concepts and facilitate understanding.

The authors would recommend that a pilot study be conducted in order to determine the efficacy of this product. In this pilot study, a satisfaction survey would be provided to parents of infants who spent time in the NICU following the transition to the home environment. Recommendations for a survey would include questions pertaining to usefulness, ease of understanding, and the value of the resources in assisting them throughout this vital transitional period. These surveys would also provide parents with the opportunity to provide feedback that the occupational therapist can use to make appropriate adjustments to the resource manual. These recommendations will also serve as a way to promote research regarding additions to the manual.

REFERENCES

American Academy of Pediatrics (2015). *A guideline to the milestones in a child's development.* Retrieved from HealthyChildren.org.html

American Academy of Pediatrics (2011). *Pulse oximetry: A viable, readily available screening tool for infants with suspected critical congenital heart disease.* Retrieved from https://www.aap.org/en-us/about-the-aap/aap-press-room/Pages/Pulse-Oximetry-a-Viable,-Readily-Available-Screening-Tool-for-Infants-with-Suspected--Critical-Congenital-Heart-Disease.aspx

American Academy of Pediatrics (2012). *Safety for your child: Birth to 6 months.* Retrieved from https://www.healthychildren.org/English/ages-stages/baby/Pages/Safety-for-Your-Child-Birth-to-6-Months.aspx

American Academy of Pediatrics (2015). *When baby needs oxygen at home.* Retrieved from https://www.healthychildren.org/English/ages-stages/baby/preemie/Pages/When-Baby-Needs-Oxygen-At-Home.aspx

Arnett (1989). *Caregiver Interaction Scale.* Retrieved from http://fpg.unc.edu/sites/fpg.unc.edu/files/resources/assessments-and-instruments/SmartStart_Tool6_CIS.pdf

Baron, K., Kielhofner, G., Iyenger, A., Goldhammer, V., & Wolenski, J. (2006). *Occupational self assessment version 2.2.* Retrieved from http://www.cade.uic.edu/moho/productDetails.aspx?aid=2

Beck, A., Steer, R., & Brown, G. (1996). Beck depression questionnaire. Retrieved

from http://www.pearsonclinical.com/psychology/products/100000159/beck-depression-inventoryii-bdi-ii.html

Benasich, A. A., & Brooks-Dunn, J. (1996). Maternal attitudes and knowledge of child rearing: Associations with family and child outcomes. *Child Development, 67,* 1186-1205.

Best Practice (2010). *Positioning of preterm infants for optimal physiological development.* Retrieved from http://connect.jbiconnectplus.org/viewsourcefile.aspx?0=5391

Boon, A. (2015). NICU to home: a perspective on feeding difficulties. Retrieved from http://handtohold.org/resources/helpful-articles/nicu-to-home-a perspective-on-feeding-difficulties/

Bourne, E. (2010). *The anxiety and phobia workbook* (4th ed.*)*. New Harbinger Publications: Oakland, CA.

Boykova, M., & Kenner, C. (2012). Transition from hospital to home for parents of preterm infants. *Journal of Perinatal Neonatal Nursing, 26*(1), 81-87. doi: 10.1097/JPN.0b013e318243e948

Brazy, J., Anderson, B., Becker, P., & Becker, M. (2001). How parents of premature infants gather and obtain support. *Neonatal Network, 20*(2), 41-48.

Broedsgaard, A., & Wagner L. (2005). How to facilitate parents and their premature infant for the transition home. *International Nursing Review, 52*(3), 196–203.

Callery, P. (2002). Mothers of infants in neonatal nurseries had challenges in establishing feelings of being a good mother. *Evidence-Based Nursing, 5*(1), 91–92.

Developmental Services (2013). *NICU positioning protocol*. Retrieved from http://www.archildrens.org/documents/Services/IPC/NICU_positioning_guidelines_revised2013.pdf

Feeding Tube Awareness Foundation (2015). *Raising awareness and sharing knowledge.* Retrieved from http://www.feedingtubeawareness.com/index.html

Fenwick, J. M., Barclay, L., & Schmied, V. (2001). Chatting: An important clinical tool in facilitating mothering in neonatal nurseries. *Journal of Advanced Nursing, 33*(5), 583–593.

Hamilton, M. (1959). The assessment of anxiety states by rating. *British Journal of Medical Psychology, 32,* 50-55.

Heras, C.G., Geist, R., Kielhofner, G., & Li, Y. (2007). *The volitional questionnaire version 4.1.* Retrieved from http://www.cade.uic.edu/moho/productDetails.aspx?aid=8

Hess, C. R., Teti, D. M., & Hussey-Gardnerc, B. (2004). Self-efficacy and parenting of high-risk infants: The moderating role of parent knowledge of infant development. *Journal of Applied Developmental Psychology, 25*(4), 423–437. doi: 10.1016/j.appdev.2004.06.002

Hutchinson, S. W., Spillett, M. A., & Cronin, M. (2012). Parents' experiences during their infant's transition from neonatal intensive care unit to home: A qualitative study. *The Qualitative Report, 17*(23), 1–20.

Katz, K. S. (1993). Project headed home: Intervention in the pediatric intensive care unit for infants and their families. *Infants and Young Children, 5*(3), 67-75.

Kielhofner, G. (2009). The model of human occupation. In G. Kielhofner's (Ed.),

Conceptual Foundations of Occupational Therapy Practice (4th ed.), 147-173. Philadelphia, PA: F.A. Davis Company.

Leonard, L. (1998). Depression and anxiety disorders during multiple pregnancy and parenthood. *Journal of Obstetric, Gynecologic & Neonatal Nursing,* 27(3), 329-337.

March of Dimes (2015). *What's normal development for your premature infant?*. Retrieved from http://www.babycenter.com/0_whats-normal-development-for-your-premature-baby_10300025.bc

National Association of Neonatal Nurses (2014). *Baby steps to home.* Retrieved from http://babystepstohome.com

Parkinson, S., Forsyth, K., & Kielhofner, G. (2006). *The model of human occupation screening tool version 2.0.* Retrieved from http://www.cade.uic.edu/moho/productDetails.aspx?aid=4

Plomgaard, A., Hansen, B., & Greisen, G. (2006). Measuring developmental deficit in children born at gestational age less than 26 weeks using a parent-completed developmental questionnaire. *Acta Padiatrica, 95*(11), 1488-1494. doi: 10.1080/08035250600684438

Potijk, M, Kerstjens, J., Bos, A., Reijneveld, S., & Winter, A. (2013). Developmental delay in moderately preterm-born children with low socioeconomic status: Risks multiply. *The Journal of Pediatrics, 163*(5), 1289-1295. doi: 10.1016/j.jpeds.2013.07.001

Richards, E., & Digger, K. (2011). Compliance, motivation, and health behaviors of

the learner. In S.B. Bastable, P. Gramet, K. Jacobs, & D.L. Sopczyk (Eds.), *Health Professional as Educator (pp. 199-225).* Sudbury, MA: Jones and Bartlett Learning.

Singer, L., Fulton, S., Kirchner, H., Eisengart, S., Lewis, B., Short, E., & ... Baley, J. (2010). Longitudinal predictors of maternal stress and coping after very low-birth-weight birth. *Archives of Pediatrics & Adolescent Medicine*, *164*(6), 518-524. doi:10.1001/archpediatrics.2010.81

Spicer, A., Pinelli, J., Saigal, S., Wu YW, Cunningham, C., DiCenso, A. (2008). Health status and health service utilization of infants and mothers during the first year after neonatal intensive care. *Advanced Neonatal Care, 8*(1), 33-41.

Spielman, V., & Taubman-Ben-Ari, O. (2009). Parental self-efficacy and stress-related growth in the transition to parenthood: a comparison between parents of pre- and full-term babies. *Health & Social Work, 34*(3), 201–212.

Underwood, M.A., Danielsen, B., & Gilbert, W.M. (2007). Cost, causes and rates of rehospitalization of preterm infants. *Journal of Perinatology, 27*, 614-619.

University of Iowa Children's Hospital. (2015). UI children's hospital's specialized neonatal transport team. Retrieved from: www.uichildrens.org

Willis, V. (2008). Parenting preemies: A unique program for family support and education after NICU discharge. *Advances in Neonatal Care*, *8*(4), 221-230.

Zanardo, V., Freato, F., & Zachello, F. (2003). Maternal anxiety upon NICU discharge of high-risk infants. *Journal of Reproductive & Infant Psychology, 21*(1), 69-75.

Zung, W.K. (1971). A rating instrument for anxiety disorders. *Psychosomatics, 12*(6), 371-379.

Appendix

Photo Release Form

I grant permission for Alyssa Briggs and Nicholle Clouse to use and publish photographs of me for their scholarly project entitled *A Resource Manual for Occupational Therapists to use with Parents of Infants Transitioning Home from the NICU.*

Signature_____

Printed Name Jenny Clouse

Date 11/29/15

☒ I give permission to use photo(s) of my child/children who are under 18 years of age.

Savannah Clouse

Photo Release Form

I grant permission for Alyssa Briggs and Nicholle Clouse to use and publish photographs of me for their scholarly project entitled *A Resource Manual for Occupational Therapists to use with Parents of Infants Transitioning Home from the NICU.*

Signature _____

Printed Name Andy Graves

Date 12/2/15

☑ I give permission to use photo(s) of my child/children who are under 18 years of age.

Photo Release Form

I grant permission for Alyssa Briggs and Nicholle Clouse to use and publish photographs of me for their scholarly project entitled *A Resource Manual for Occupational Therapists to use with Parents of Infants Transitioning Home from the NICU.*

Signature Cherie Graves

Printed Name Cherie Graves

Date 12-1-15

☑ I give permission to use photo(s) of my child/children who are under 18 years of age.

Photo Release Form

I grant permission for Alyssa Briggs and Nicholle Clouse to use and publish photographs of me for their scholarly project entitled *A Resource Manual for Occupational Therapists to use with Parents of Infants Transitioning Home from the NICU.*

Signature Beth Mairs

Printed Name Beth Mairs

Date 11/29/15

☐ I give permission to use photo(s) of my child/children who are under 18 years of age.

Photo Release Form

I grant permission for Alyssa Briggs and Nicholle Clouse to use and publish photographs of me for their scholarly project entitled *A Resource Manual for Occupational Therapists to use with Parents of Infants Transitioning Home from the NICU.*

Signature Krista Simengaard

Printed Name Krista Simengaard

Date 11-28-15

☒ I give permission to use photo(s) of my child/children who are under 18 years of age. Brady + Lauren

Photo Release Form

I grant permission for Alyssa Briggs and Nicholle Clouse to use and publish photographs of me for their scholarly project entitled *A Resource Manual for Occupational Therapists to use with Parents of Infants Transitioning Home from the NICU.*

Signature Paul Simengaard

Printed Name Paul Simengaard

Date 11-28-15

☑ I give permission to use photo(s) of my child/children who are under 18 years of age.

Photo Release Form

I grant permission for Alyssa Briggs and Nicholle Clouse to use and publish photographs of me for their scholarly project entitled *A Resource Manual for Occupational Therapists to use with Parents of Infants Transitioning Home from the NICU.*

Signature Jessica Triller

Printed Name Jessica Triller

Date 11/30/15

☐ I give permission to use photo(s) of my child/children who are under 18 years of age.

Safe Kids Resources

CH

CARMA HANSON <safekids@altru.org>

To: Clouse, Nicholle; Cc: Briggs, Alyssa;

Reply all

Thu 11/19/2015 9:00 PM

Flag for follow up. Start by Sunday, November 22, 2015. Due by Sunday, November 22, 2015.

Absolutely. Use them as you wish!! Glad they helped!!

Carma

Sent from my iPhone

CN

Clouse, Nicholle

To: CARMA HANSON <safekids@altru.org>; Cc: Briggs, Alyssa;

Thu 11/19/2015 5:58 PM

Carma,
Thank you so much for those resources! They are great! We will let you know if we end up needing hard copies but the electronic ones should be good for now. Is it okay that this email serves as consent from you for us to use these resources in our scholarly project?

Thanks Again,
Nicholle Clouse, MOTS and Alyssa Briggs, MOTS