

2023

# Promoting support for preterm infants and families following NICU discharge: applications for OT practice

---

<https://hdl.handle.net/2144/46609>

*"Downloaded from OpenBU. Boston University's institutional repository."*

BOSTON UNIVERSITY  
SARGENT COLLEGE OF HEALTH AND REHABILITATION SCIENCES

Doctoral Project

**PROMOTING SUPPORT FOR PRETERM INFANTS AND  
FAMILIES FOLLOWING NICU DISCHARGE:  
APPLICATIONS FOR OT PRACTICE**

by

**ERIKA STEINKE**

MSOT, Alvernia University, 2011

Submitted in partial fulfillment of the  
requirements for the degree of  
Doctor of Occupational Therapy

2023



Approved by

Academic Mentor

---

Sigal Vax, Ph.D., MScOT  
Teaching Professional of Occupational Therapy

Academic Advisor

---

Karen Jacobs, Ed.D., OT, OTR, CPE, FAOTA  
Associate Dean for Digital Learning & Innovation  
Clinical Professor of Occupational Therapy

## **DEDICATION**

I want to dedicate my work to my mother, Kathleen.

I love you.

## **ACKNOWLEDGEMENTS**

I want to thank Beth, my friend and the parent of a child born prematurely. I have had the privilege to work with her daughter for the first two years of her life. Beth has inspired me to develop this project and has allowed me to join her family on their NICU journey. I would also like to thank my fiancé, Michael for all his support and always encouraging me to follow my dreams. I would like to thank my academic mentor, Sigal Vax. She has provided me with guidance and support, allowing me to grow professionally and personally in many positive ways. I would also like to thank my peer mentor, Debbie Volpe for always keeping me grounded. And lastly, but equally important, I would like to thank the pp-OTD Boston University faculty for their support and guidance during all the many “bumps in the road” I have overcome throughout this journey.

**PROMOTING SUPPORT FOR PRETERM INFANTS AND  
FAMILIES FOLLOWING NICU DISCHARGE:  
APPLICATIONS FOR OT PRACTICE**

**ERIKA STEINKE**

Boston University, Sargent College of Health and Rehabilitation Sciences, 2023

Major Professor: Sigal Vax, Ph.D., Teaching Professional of Occupational Therapy

**ABSTRACT**

Prematurity is a worldwide healthcare problem affecting 15 million births every year. Having a child that is born prematurely brings forth numerous challenges, placing significant stress on families, impacting family dynamics and overall well-being. In addition, advancements in perinatal health care have increased the survival rates of premature infants, placing most infants at higher risk for complex medical needs and developmental impairments that extend beyond discharge from the Neonatal Intensive Care Unit. Research shows that while parental psychological support is provided while in the hospital and the infant may receive allied health services for developmental care, these services are often delayed, not accessible or discontinued following discharge. A two-part educational initiative called “The Premie Toolkit” is introduced in this doctoral project, guided by evidence and the Knowledge to Action theoretical framework. This initiative aims to fill the identified gap in care and provide accessible knowledge and support for families living in northeast Pennsylvania during this critical period. The project highlights the vital role of occupational therapists in enhancing support for preterm infants and their families. By providing a feasible avenue to provide

comprehensive care and support, families will be able to navigate the complexities of caring for their premature infants with greater confidence and well-being during the first few weeks at home until other services begin. This doctoral project includes a plan for program evaluation, funding and dissemination.

## TABLE OF CONTENTS

DEDICATION .....	iv
ACKNOWLEDGEMENTS .....	v
ABSTRACT .....	vi
TABLE OF CONTENTS .....	viii
LIST OF TABLES .....	xi
LIST OF FIGURES .....	xii
LIST OF ABBREVIATIONS .....	xiii
CHAPTER ONE: Introduction .....	1
Background .....	1
Infant and Family Functional Impact .....	3
Current approaches to Intervention .....	4
Occupational Therapy Practice .....	6
The Proposed Initiative .....	6
CHAPTER TWO: Theoretical Framework for the Solution .....	9
Family Challenges .....	12
Availability and System Challenges .....	13
Early Intervention .....	14
CHAPTER THREE: Overview of Current Approaches and Methods for the Solution ...	17
CHAPTER FOUR: Description of the Proposed Initiative .....	26
Introduction .....	26
Case Scenario .....	28
Full Logic Model .....	32
Program Participants and Resources .....	34
Interventions and Activities .....	35
Program Outputs and Outcomes .....	36
Anticipated Barriers and Challenges .....	37
Summary and Conclusions .....	37
CHAPTER FIVE: Program Evaluation Research Plan .....	39

Initiative Vision .....	39
Engagement of Stakeholders .....	39
Simplified Logic Model for Use with Stakeholders .....	41
Preliminary Exploration and Confirmatory Process .....	41
Program Evaluation Research Questions by Stakeholder Group .....	42
Research Design .....	44
Methods .....	44
Data Collection and Analysis .....	45
Anticipated Strengths and Limitations .....	46
CHAPTER SIX: Dissemination Plan.....	48
Dissemination Goals .....	48
Primary Target audiences .....	48
Secondary Target Audience .....	49
Key Messages.....	49
Sources/Messengers .....	50
Dissemination Activities .....	51
Budget .....	51
Evaluation.....	52
Conclusion.....	53
CHAPTER SEVEN: Funding Plan.....	54
Free Available Resources .....	54
Needed Resources for Cost .....	55
Estimated Expenses.....	55
Funding Sources .....	56
Conclusion.....	57
CHAPTER EIGHT: Conclusion .....	58
Importance of evaluation and dissemination.....	59
Funding for the “The Premie Toolkit” .....	59
Reflection .....	59
APPENDIX A. ....	61
OUTLINE OF THE EDUCATIONAL EXPOSURE COURSE.....	61

APPENDIX B .....	62
OUTLINE FOR THE POST NICU PARENT GUIDEBOOK .....	62
APPENDIX C .....	64
Executive Summary .....	64
Project Overview .....	66
The role of occupational therapy in NICU discharge .....	67
Anticipated parental outcomes .....	68
General Conclusions .....	69
APPENDIX D .....	70
REFERENCES .....	72
CURRICULUM VITAE.....	86

## LIST OF TABLES

Table 5.1. Stakeholder Program Evaluation Research Questions.....	43
Table 6.1 Estimated Dissemination Expenses .....	52
Table 7.1 Estimated Expenses.....	56
Table 7.2 Funding Sources.....	57

## LIST OF FIGURES

Figure 2.1 Visual Model of KTA Framework .....	11
Figure 4.1 Visual Model of Casual Pathway .....	31
Figure 4.2 Full Logic Model.....	33
Figure 5.1 Simplified Logic Model .....	41

## LIST OF ABBREVIATIONS

CME	Continuing Medical Education
EBP	Evidenced Based Practice
EI	Early Intervention
KTA	Knowledge to Action
NICU	Neonatal Intensive Care Unit
OTP	Occupational Therapy Practitioner
POTA	Pennsylvania Occupational Therapy Association
TTT	Train the Trainer

## **CHAPTER ONE: Introduction**

### **Background**

When a child is born prematurely, families will endure a journey and a change in their lives that can be challenging and overwhelming. Babies born prematurely often require more ongoing care and support, compared to healthy full-term babies, which alone places a considerable amount of stress on the families (Msall, 2019). Families can be faced with infants that may have ongoing medical concerns and long-term developmental challenges. In addition to the infant's medical status, the emotional burden of the parents can further impact family dynamics and can have long lasting effects on well-being as a family unit. The transition home from the neonatal intensive care unit (NICU) can be an exciting but also scary time as parents are faced with providing care for their infant without the continued daily guidance from the medical team. Unfortunately, many families are often left feeling overwhelmed and unsupported in daily life with their premature infant at home following discharge from the NICU. This chapter is an introduction to describe the rationale and background for the presented initiative focusing on the importance of providing comprehensive support during this transition and how occupational therapy (OT) can play a vital role in enhancing support for preterm infants and their families after a NICU hospitalization. This educational initiative aims to provide infants and families support and guidance during the first few weeks at home following discharge from the NICU.

Reported by the World Health Organization, a preterm birth is a live birth that occurs before 37 weeks gestation (Walani, 2020). The three main categories of preterm

births are based on gestational age. An extremely premature infant is born less than 28 weeks gestation, very premature infants are born between 28 weeks and 32 weeks, and moderate to late preterm infants are born between 33- and 37-weeks gestation (Walani, 2020). Prematurity is a worldwide healthcare problem that is affecting 15 million births every year and complications from prematurity is the leading cause of mortality in children under the age of five (Walani, 2020). Approximately 11% of these infants are born within the United States (Feehan et al, 2019). In Pennsylvania, there are 250 preterm babies that are born weekly (March of Dimes, n.d.). More specifically, in northeastern Pennsylvania alone, approximately 9.7% of live births result in preterm deliveries (Department of Health Informatics, n.d.).

Due to advancements in perinatal healthcare, premature infants are surviving today more than ever before. However, most of these infants are required to have prolonged NICU hospitalizations due to complex medical needs, which often continues beyond discharge home. In addition, premature infants are at high risk for significant chronic health disorders and neurodevelopmental impairments (O'Shea, 2021). When an unexpected preterm birth occurs, parents are often confronted with many stressors and uncertainties regarding the survival of their infant, medical needs and long-term complications or functional outcomes. This catastrophic event for families can lead to increased anxiety, stress, depression, and grief. It is often considered an emotional journey for these families. The NICU is a specialized hospital unit that provides lifesaving medical care to premature and sick infants, driven by family centered care involving caregivers or parents. A multidisciplinary team specializing in the care of

premature infants will guide and involve the parents throughout the hospitalization to educate them on medical needs and increase their confidence to care for their preterm infant. Typically, NICU discharge considerations include an infant being physiologically stable, the complexity of medical needs to be cared for within the home, and the readiness and ability of the parents to transition to home-care (American Academy of Pediatrics Committee on Fetus, and Newborn, 2008). Together, the medical team and the parents will prepare for discharge by creating a plan following discharge ensuring follow up care for all medical and developmental needs. Many challenges and stressors for the infant and family are present during this time of transition. The NICU provides a supportive environment that can contribute to the success of life adjustment following transition home with a medically complex premature infant. However, is not consistently and systematically offered to families in an accessible and timely manner.

### **Infant and Family Functional Impact**

While many NICU graduates are discharged home into the community, infants categorized as extremely preterm and very preterm often have more complex medical and developmental needs requiring close monitoring and follow up. As neonatal medical care continues to advance, this fragile population continues to be at a high risk for rehospitalization due to ongoing medical needs. If these infants are discharged home too early or the families are left feeling unprepared to care for them, it could potentially complicate their medical care at home (American Academy of Pediatrics Committee on Fetus and Newborn, 2008).

Many premature infants may experience ongoing health problems impairing their

daily occupations and well-being. Those impairments can also negatively impact family well-being (Grunberg et al, 2020). In reference to extremely preterm infants, “a high prevalence of intellectual disabilities, behavioral, social and emotional problems and learning difficulties continues to dominate the literature relating to childhood outcomes and recent reports have confirmed that these difficulties persist into adult life” (Johnson & Marlow, 2017, p.97). Many studies suggest that early intervention (EI) services are proved to be effective in improving neurodevelopmental outcomes, as well as family functioning. Since prematurity alone places an infant at such high risk for developmental delays, bridging the gap in continued care following discharge is essential for providing families ongoing care and support during the first few weeks at home.

### **Current approaches to Intervention**

Most premature infants will receive automatic referrals to a NICU clinic, if available, and EI services upon discharge. A NICU clinic is typically considered an additional program to regular well child checkups and is composed of specialists to provide comprehensive medical and developmental care all at one place (Ma et al., 2021). A comprehensive clinic offers medical providers including physicians, developmental specialists, allied health, care management and dietary care, the opportunity to provide support to families over a longer period post NICU discharge (O’Shea, 2021). These specialty clinics can also provide the family assistance with accessing services and resources they may benefit from, for their child and for their family as a unit. With this additional collaborative guidance, education, and support, a family would feel more prepared and supported in caring for their premature infants at home to ensure their

global needs are met, however, NICU clinics are not universally available throughout the country (Singh et al., 2019). There is no reported data on the number of current NICU clinics available due to the diversity in the structure of programs including lack of multidisciplinary approach (Kuppala et al., 2012). In northeastern Pennsylvania, the most common practice for discharge home from the local NICU for premature infants is to make a referral for EI services and to schedule follow up appointments with their pediatrician and subspecialists, as there is no local comprehensive NICU clinic available.

Early Intervention is a federal grant funded program under the Individuals with Disabilities Education Act (IDEA), Part C, that provides developmental services and support to families ages birth to three in their natural setting (Lakshmanan et al., 2022). Although most preterm infants receive an automatic referral for EI services, “there is a delay in therapy activation following NICU discharge, and some infants who warrant services do not obtain them” (Nwabara et al., 2017, p. 414). Early Intervention can take up to several weeks before a child receives services. State mandates provide a maximum of 59-day allowance for completion of the evaluation and for services to begin (U.S. Department of Education, n.d.). This lengthy time frame leaves a critical gap in services that may result in further developmental delay for this high-risk population (Pineda et al., 2020, U.S. Department of Education, n.d.). The EI model is designed to be parent driven, who are expected to carry over a plan of care provided by their therapists for advancing their child’s development as well as be their parent. Identifying and addressing the gaps in care post discharge is critical to optimize infant outcomes and provide the family with guidance and support in caring for their premature infant.

## **Occupational Therapy Practice**

The problem that this initiative aims to address falls within the domain of occupational therapy to address health, well-being and participation in life for both the patient and their caregiver. According to the Occupational Therapy Practice Framework (2020), a person's occupation refers to the everyday activities that bring purpose and meaning to their lives. These occupations are essential to a person's health, identity, sense of competence and value for individuals (AOTA, 2020). Co-occupation is a parallel occupation, requiring participation and is shared between two individuals such as with parenting. Occupational therapy in the NICU can provide a unique perspective not only on the needs of the infant in the community, but also on the family needs for co-occupation, recognizing the interactions of the parent and infant, and the reciprocal nature of all daily tasks to care for a child with complex needs (Cardin, 2020). This will achieve overall improvement in daily function for the family, while providing support to families with bonding and advancing their infants development immediately following discharge. The vital role of OT in the NICU can provide the bridge to functioning as a family during the transition home, by offering comprehensive support for families with preterm infants to further promote health, well-being and participation in all aspects of their daily lives during the hospitalization and beyond.

## **The Proposed Initiative**

This initiative seeks to improve parental support and family well-being post NICU discharge by offering a "Premie Toolkit" which includes an educational course

for occupational therapy practitioners (OTP) and a parental guidebook resource tool for families. The two parts of the toolkit collectively promote knowledge and awareness to family needs during transition home and facilitate a comprehensive discharge plan. The educational course, *Promoting support for preterm infants and families following NICU discharge: Applications for OT practice* has been developed for OTPs to provide further knowledge and awareness in order to highlight the need to assist families during the transition from the NICU to home. This educational course strives to bring awareness to the challenges and stressors families face following discharge such as delays in medical follow up including EI services, and lack of guidance, support, and resources that can improve infant and family functional outcomes, health and wellbeing. Occupational therapy practitioners will be provided with a post NICU parent guidebook to distribute to the families at discharge. This guidebook will provide community specific comprehensive resources and support for the first few weeks home with their infant until they receive EI services.

The overall aim of this educational initiative is to improve infant functional outcomes and parental support post NICU discharge to bridge the gap in service during transition to the community. Having access to a resource within the home that is easy for families to refer to, supports the need for the proposed initiative and can also serve to complement EI once they start receiving it.

The initiative will contribute to the occupational therapy knowledge base by increasing awareness regarding family challenges during this stressful transition from hospital to home. Together, the educational course and the parental guidebook, will

provide an effective clinical practice- the “Preemie Toolkit” for comprehensive support and resources to families with premature infants in a timely manner.

The following chapters will describe in further detail the development of the initiative as well as a plan for its implementation, dissemination, and evaluation. Chapter two will discuss the theoretical framework that will guide this initiative and review the evidence to support it. Chapter three of this doctoral paper will review the current approaches and methods used to address continuing education in healthcare and evidence to support translation of knowledge into practice. Chapter four presents a further description of the proposed initiative. A detailed plan of the initiative evaluation including anticipated outcomes, methods and analysis will be discussed in chapter five. Chapter six will identify the primary audience, activities and goals in the dissemination plan for the initiative. All the details for funding will be presented in chapter seven including estimated expenses for implementation. Finally, chapter eight will present a summary of the doctoral paper and conclusions for implementation of the initiative including future considerations.

## **CHAPTER TWO: Theoretical Framework for the Solution**

Supportive community resources and therapeutic services are not being offered to families post NICU discharge in an accessible and timely manner. This gap in care causes a considerable amount of stress on the families and can impact the functional outcomes of the infant. The problem addressed by this initiative is the gap in availability of services for infants and their families post NICU discharge. This can stem from the lack of knowledge and awareness of NICU OTPs regarding these challenges. This chapter presents the theoretical framework and evidence from the literature which informed the development of “The Premie Toolkit” as a tool to enhance knowledge usage.

The Knowledge to Action (KTA) model is a theoretical framework that offers a methodology for addressing lack of awareness of novel practices and ensuring their application and sustainment in practice. This framework is frequently implemented to guide the conceptualization and delivery of evidence to healthcare professionals and other audiences. It flexibility and has received increased responsiveness within various health care practitioners (Lockwood et al., 2016).

Knowledge creation and the action cycle are the two major phases of the KTA framework. The Knowledge Creation is the first phase often referred to as a funnel, where knowledge moves through the funnel in stages. The three stages that describe this movement of knowledge include the inquiry, synthesis and creation of tools and products. (Petzold et al., 2010). As knowledge moves through these stages, it then becomes more refined from “inquiry (asking the right questions) to synthesis (pulling together research and information from other resources) and to the development of products (delivering the

right information in the right format)” (Petzold et al., 2010, p. 167). This process allows knowledge to then be tailored to specific needs of practitioners.

The next phase is the action cycle, which describes how the synthesized and packaged knowledge is applied and how it is prepared to sustain change. Within these elements, identifying the audience or the needs of various stakeholders, assessing challenges and barriers to implementation, developing goals and an action plan are essential components. This is a dynamic process where any element within the action cycle can be started at any time, elements can influence each other and can be completed sequentially or simultaneously. According to Graham et al., 2006, the seven elements in the action cycle include:

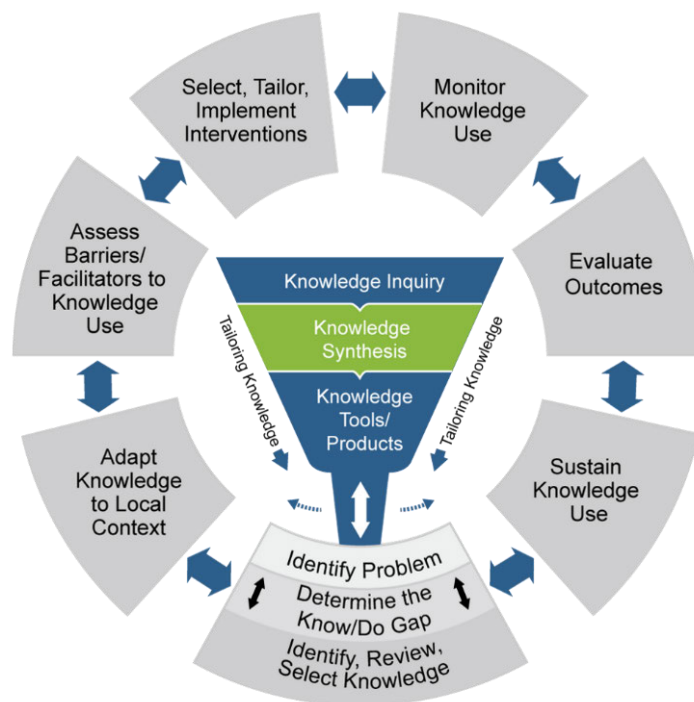
- Identifying a problem
- Adapting the knowledge
- Assessing the barriers for implementing the knowledge
- Implementing the change
- Monitoring knowledge use
- Evaluating the outcomes
- Sustaining the change of knowledge use

The basic assumption in the proposed educational course is that providing knowledge about family challenges post discharge is not sufficient to ensure translation, implementation and sustainment of supporting practices. The KTA model suggests that stakeholders should be provided with new knowledge and guidelines structured in a way that ensures effective translation and operationalization of the knowledge. The parental guidebook will provide a translational and easy-to-use tool for the OTPs to translate the knowledge for the end users in a more practical and user-friendly form than how the information is currently presented. Follow-up surveys for the OTPs will gather

information on successful implementation or barriers to translating the knowledge to this audience, as an additional way of re-evaluating the outcomes of the course and its components. The explanatory model of the theoretical foundation that is guiding the initiative is presented below in Figure 2.1.

**Figure 2.1**

*Visual Model of the KTA framework*



**Source:** Graham ID, Logan J, Harrison MB, Straus SE, Tetroe J, Caswell W, et al. Lost in knowledge translation: time for a map? *J Contin Educ Health Prof.* 2006;26(1):13-24.

A literature search was conducted to assess the evidence, based on the theoretical framework, in order to further explain the nature of the problem. The following questions were used to guide the search:

1. Is there evidence regarding the lack of availability of support and resources for families following NICU discharge?
2. Is there evidence about system and family challenges surrounding NICU discharge?

3. Is there evidence regarding the effectiveness and challenges of Early Intervention services for preterm infants?

The databases used for the search were the Cumulative Index of Nursing and Allied Health Literature (CINAHL) and PubMed to provide academic journals in the medical and allied health professions. The following keywords were used: “Preterm infant”, AND “discharge”, AND “Infants” AND “NICU discharge”; “neonatal”, AND “discharge”, OR “transition; “neonatal”, AND “transfer” AND “intensive care unit” OR “neonatal”, AND “discharge planning”; “Pediatric” OR “infant”, AND “home care facility”; “Intensive care units, neonatal[Mesh]”, AND “financial burden”, AND “family or families or relatives or parents or siblings[Mesh]”; “Barrier”, AND “NICU discharge”; “Pediatric”, AND “referrals”; “Early Intervention”, AND “pediatrician”, AND “barriers or obstacles or challenges[Mesh]”; “Referral or referral process or care pathway[Mesh]”, AND “pediatrician”, AND “barriers”; “Early intervention”, AND “medical complexity”. The literature criteria used for this search was the time frame of 2006 through 2023, linked to full text only, English language and occurred in the United States only.

### **Family Challenges**

Planning for discharge from the NICU can be a challenging time for families of infants born prematurely (Rubinos et al., 2021). Families are often overwhelmed by the amount of information that is provided at discharge, especially if the child has extensive medical needs, and feel unprepared and unsupported with the lack of community-based services once they transition home. Language barriers can be an additional challenge for effective communication between medical personnel and the families at discharge.

(Obregon et al., 2019). Parents can feel physically isolated from their traditional support systems as their family and friends may not understand or relate to their experience of having a premature infant (Hall et al., 2015). In a systematic review, (King, 2012) it was noted that the impact of financial burden on families due to out-of-pocket costs and loss of earnings while a child was hospitalized, is also a barrier that could impact care. The literature reveals that parents describe feeling a sense of withdrawal from care following discharge due to the lack of communication and information shared from their medical providers (Ballantyne et al., 2017). Many NICUs provide psychological support for the family while in the NICU, however, these services are often discontinued once the infant is discharged (Carty et al., 2018).

These challenges impact parents' capability to provide the best care to their infant and ensure family's well-being as a unit. In addition to family challenges, evidence of system barriers and lack of resource availability was also found in the literature impacting the gap in care post discharge.

### **Availability and System Challenges**

As stated in the previous chapter, the most advanced evidenced-based practice for premature infants is an automatic referral to a NICU clinic that will oversee medical and developmental care following discharge. Due to the limited availability of comprehensive clinics, many families are faced with long patient wait times to see a specialist and may need to travel far distances to reach them (Ma et al., 2021). Preterm infants require ongoing medical care following discharge, placing them at risk for readmissions to the hospital. The literature shows that many pediatricians have difficulty

accessing subspecialties or may lack confidence in recommending supports within the healthcare system, particularly patients with public insurance. This results in limited referrals for the compromised preterm infant to appropriate services (Okumura et al., 2018; Jetelina et al., 2020) so that discharge resources and additional medical care are not being offered to families in an accessible and timely manner. A lack of home health care nursing is the most frequent system barrier resulting in longer hospitalizations and delayed discharges home (Maynard et al., 2019). Specifically, if a child is technology dependent upon discharge, longer hours of home nursing is needed for a safe discharge home. Home health care can also assist the family with prevention of burnout and reducing the risk of readmission to the hospital (Maynard et al., 2019).

### **Early Intervention**

Preterm infants often require early therapy intervention following discharge due to their high risk of developmental delays. Based on the literature, Early Intervention services can have a significant positive effect on an infant's functional outcomes. Many studies report improvements in functional motor skills, support accuracy with early diagnosis and improve school age functional skills for children who have been discharged from a NICU, compared to children with delayed enrollment in EI (Tanner et al., 2020; Litt et al., 2018). Parents are critical to their infant's developmental outcomes and early intervention services can provide a foundation for future development (Ballantyne et al., 2017)

There are also many family challenges noted in the literature regarding EI services for preterm infants. Families are experiencing poor access to services based on

low socioeconomic status, high psychosocial risk, having private insurance requiring co-pays and/or living in disadvantaged neighborhoods (Heiny et al., 2020). Other system related barriers to enrollment of early therapy services include poor communication from providers to the families regarding coordination of care, understanding the referral process and services which, in turn, results in decreased acceptance of services due to family stress, denial, or limited understanding. (Heiny et al., 2020). According to Washington & Coker-Bolt (2022), 50% of families believe they did not receive services in a timely manner and the parents' needs were not being addressed. Services may be delayed, despite state mandates, which can impact parental support and developmental progression of the infant. The route of referral is varied, and pediatricians may be more hesitant to refer for services unless a child has an identified diagnosis (Decker et al., 2020). Like nursing care within the home, lack of staffing in EI services and location continue to be barriers for effective outcomes. Overall, in several studies that have been reviewed, families report that due to the lack of an organized system for referral, varying from state to state, the referral process can be confusing and complex (Decker et al., 2020; Atkins et al., 2019).

This chapter introduces the KTA framework and describes how the process of knowledge is structured in a way that ensures its effective translation and operationalization. The evidence reveals the limited availability of support as well as system and family challenges that can occur post NICU discharge. The next chapter will further review evidence on how to apply this knowledge in order to first increase

awareness to the need and continue through the dynamic process of the KTA action phase in preparation to sustain change in healthcare practice.

### **CHAPTER THREE: Overview of Current Approaches and Methods for the Solution**

The problem identified through this initiative is the gap in care and lack of support for families of premature infants following NICU discharge in northeastern Pennsylvania. A proposed solution to the problem is to address the lack of knowledge and awareness of OTPs regarding the common family and system challenges that can occur post NICU discharge for premature infants and for their families. Continuing medical education (CME) courses have been found to be the most effective way to build knowledge and improve clinicians' skills to ultimately improve patient outcomes (Cowie et al., 2020). However, providing knowledge is not sufficient to ensure a clinical behavior change, and implementation of the knowledge at the end-client level. Therefore, a literature search was conducted to identify barriers and effective methods to knowledge implementation, as well as effective methods for sustainment of a practice change in healthcare settings. The following questions were used to guide the literature search:

1. What are the barriers to implementing knowledge about new healthcare practices?
2. What are effective methods to implement knowledge about new healthcare practices?
3. What are effective ways of sustaining knowledge of new healthcare practices?

The databases used for the search were the Cumulative Index of Nursing and Allied Health Literature (CINAHL), PubMed, ProQuest, Education Full Text, and Cochrane Library to provide academic journals in the medical and allied health professions. The following keywords were used: "Teaching methods" AND healthcare

AND “continuing education”, “Healthcare” AND “teaching strategies”; “knowledge translation” AND “healthcare” AND “barriers” OR “obstacles” OR “challenges” AND “continuing education” OR “CME” OR “continuing professional development”; “knowledge sustainment” AND “healthcare” AND “education”; “sustaining knowledge” AND “sustainment” AND “healthcare”; “sustaining knowledge” AND “implementation” AND “healthcare” AND “education” OR “teaching”; “sustainment” AND “professional education” AND “implementation science”. The literature criteria used for this search was the time frame 2006 through 2022, linked to full text and English language only.

Continuing medical education aims to improve medical professionals’ knowledge, skills, and performance to ensure high quality healthcare services through evidence-based practice (EBP). Many medical professions are mandated by professional or regulatory bodies to assure and maintain competence (Forsetlund et al, 2021), followed by receiving incentives, such as educational units added to their salary or certifications. However, many barriers to implementing knowledge have been identified in the literature. On an individual or personal level, the lack of secured time to complete CME is the most frequently found barrier to not only gain knowledge but also transfer the new knowledge into practice. The lack of time can negatively impact the motivation of the medical professional to seek out educational opportunities (Reis et al., 2022). It was also found that many practitioners are challenged with implementing EBP due to the lack of time to research full text articles, and lack of skills in finding the articles and understanding the studies (Mota de Silva et al., 2014). According to Wang et al., (2019), practitioners that have a more formal education on EBP, have an increased likelihood of implementation

from independent research. It was also found that practitioners become frustrated when studies have conflicting results or do not represent information that can be clinically applied to their setting, ultimately resulting in lack of interest (Mota de Silva et al., 2014). Similarly, practitioners may also be uncomfortable with changing their behaviors or practice, hindering the implementation of knowledge of new healthcare practice (Price et al., 2010).

An alternative way to address the practitioners lack of time to complete CME's, the option of online learning or use of a digital platform can be appealing, as they are able to complete education at their own pace and at a lower cost than traditional methods of learning. However, there are several factors that can be a barrier to implementation, when knowledge is presented through a digital platform (Reis et al., 2022). Medical education has limited learning opportunities such as laboratory experiences, assisting and observing medical procedures, and clinical rotations (Gismalla et al., 2021). Liaw et al., (2022), reported the use of virtual platforms in interprofessional education and found that participants that struggle with the familiarity of a virtual platform or environment, will in turn, display varying levels of participation or interest that impacts the ability to implement the knowledge presented. In regard to interprofessional education, in person education is also found to be a barrier due to the variability in schedules when mixing professions (Rak et al., 2021).

Traditionally, CME is delivered in person at a single point in time through a lecture-based format and the certificate of completion is usually provided based on hours attended, rather than if the knowledge, competence, or performance have improved

(Schreiber et al, 2015). From an organizational level, lack of administrative support to provide adequate training, available resources, and incentives such as monetary support for travel or time, can also lead to additional barriers to implementation (O'brien Pott et al., 2021). Some professionals may be challenged by organizational structure such as system policies, workload, staffing, priorities, and available supplies or equipment. In a systematic review conducted by Hailemariam et al., (2019), it was stated that although some organizations will offer incentives to healthcare professionals for funding of CME, it is often limited per year and there is typically no additional funding to support the continuation of implementation into practice.

Whether barriers are from individual or organizational level, or whether the CME is presented online, in person, or a combination of both, each of these methods may present an individual with barriers regarding their preferred learning methods or accessibility. By identifying these barriers, educators and medical professionals can seek out effective methods to facilitate learning and promote ways to then implement the new knowledge into healthcare practices. There are effective ways that have been identified in the literature including learning strategies and how education is presented. First, delivering knowledge through educational meetings or sessions, such as conferences, workshops, symposia and educational courses, are preferred as they are more locally available, therefore, making it a more affordable method of learning. (Forsetlund et al, 2021). The results of a systematic review by Forsetlund et al., (2021), suggested that while planning an educational meeting, utilizing opinion leaders as teachers, creating and identifying strategies to increase attendance are keys to maximize the effectiveness of the

meeting. Further findings suggest that the importance of the content, number of participants, and length and frequency of educational meetings may further facilitate learning and impact improvements in practice. Shortened lectures or brief interactive education sessions or meetings have been found in the literature as an effective way to promote a change in knowledge for medical professionals. Brief interactive education, particularly with online learning, allows the professional the convenience of participating from home on a day off from work (Waltz et al., 2022). Online delivery of CME's has become popular due to its convenience and flexibility for medical professionals and can play a substantial role in implementing new knowledge into practice. More specifically, the use of social media platforms has been found to be an effective tool used by physicians for knowledge translation and education (Chan et al., 2019). Social media platforms can promote shared knowledge and collaboration within the medical field. Online delivery of education is also known to bring together individuals from different professions for interprofessional education. Interprofessional education has been found to positively impact organizational structure and provide a supportive environment for changing practice (Vasli et al., 2018).

In addition to how the education is provided, there are a few learning strategies that have the potential to support implementation. Some of these strategies may be providing feedback to learners, including additional take-home materials, and goal setting. These were found to be beneficial behavior changing techniques that will lead to improved compliance (Giguere et al., 2020). According to Forsetlund et al., (2021), it is recommended to build an educational meeting based on an explicit theory or framework

to identify the many factors or strategies that may influence behavior change. As stated above, additional educational materials or handouts have been found to be beneficial with improving the practice of healthcare professionals, with no probable difference in distribution technique, whether it be computerized or printed (Giguere et al., 2020). According to Bucklin et al., (2021), when active learning strategies are incorporated in medical education, it can further foster “learner engagement, critical thinking and problem-solving abilities” (p.9). Overall, whether continuing education is delivered in person, virtually, or a combination of both, the use of self-evaluation is an effective tool that can also be utilized to assist the participant with further understanding of the content and provide opportunity for reflection on utilizing new knowledge or skill in practice (Weiss et al., 2021).

Once knowledge has been implemented into practice, it is important to identify effective ways to sustain the new knowledge in the healthcare setting. According to a systematic review by Cowie et al., (2020), how knowledge is delivered is essential in sustaining effective interventions by building practitioners’ confidence in implementing their new knowledge. This can be presented either within a CME or within an organization. It is suggested that CMEs “are more likely to lead to clinical behavior change if activities explicitly aimed at supporting knowledge translation are included” (Schreiber et al., 2015, p.42). Sustainability is a continuous and dynamic process that requires resources to support them (Cowie et al., 2020).

The most frequently reported facilitator that can influence the sustainability of healthcare interventions is the initiative design and delivery, meaning the ability to

monitor long term progress and provide adequate training (Cowie et al., 2020). Other facilitators may include establishing the credibility of the intervention, the priority or relevance of the problem that the intervention proposes to address, supportive leadership and appropriate infrastructure to support the change. Healthcare leadership will not only facilitate the use of EBP but can create and support a structured environment and framework for sustainability (Bianchi et al., 2018). It was found that the use of a standardized framework or protocol not only assists with team collaboration in regard to continuing education but coordinates a plan for sustainability for the use of EBP (Contrada et al., 2018). For example, some studies have shown that medical education courses that are specifically aimed towards knowledge translation and have implemented the KTA framework principles in education, are more likely to lead to clinical change (Schreiber et al., 2015). Essentially, the goal of the KTA model is to reduce the gap between research and practice through synthesis, dissemination, exchange, and application of knowledge to improve health services (Graham et al., 2006). In a study conducted by Slaughter et al., (2018), knowledge translation interventions, guided by the KTA model, were implemented to promote the sustainability of a new healthcare daily practice of medical professionals in a long-term care facility. The most effective strategies for sustainment in this study were found to be written reminders and follow up discussion groups for clarification and to support teamwork. Similarly, Gabrielian et al., (2022), developed an implementation playbook, which is an online resource for staff that serves as a “how to” guide including processes, quick tip sheets with small, targeted,

informational bytes, as well as, copies of leadership briefings and frequently asked questions, to promote implementation and sustainment in a community-based program.

In addition to supporting training and continued use of new interventions, the use of the Train-the-Trainer (TTT) technique has also been beneficial to support sustainability in the healthcare system (Hailemariam et al., 2019). The purpose of TTT is to have champions within sites train and educate their colleagues on a specific topic or intervention. The trainers do not only learn and apply the information but develop the ability to train, supervise and mentor others to reinforce learning (Woda et al., 2022). Support from supervisors or champions will assist organizations with the ability to adapt and improve the effectiveness of new interventions to achieve sustainment. The use of this model in healthcare education has been found to be cost effective, more efficient in reaching multiple individuals in a setting, and allow for multiple learning opportunities to master a skill or new healthcare practice (Woda et al., 2022). Overall, the use of the TTT model was found to be an effective way to create behavior change (Vivanti et al., 2015).

In conclusion, in alignment with the KTA model that guided this initiative, several barriers have been identified to gaining and implementing knowledge about new healthcare practices. Once these barriers have been identified, effective methods to overcome these barriers can be utilized to further develop and expand the medical professional's knowledge, skills, and performance to optimize quality healthcare services. The sustainability of new implemented knowledge is crucial to ensure the effectiveness of changing healthcare practices and ultimately optimizing healthcare delivery (Cowie et al., 2020).

The evidence gathered from the literature search in this chapter will be incorporated in the design and development of the “Premie Toolkit” described in chapter four. The chapter will thoroughly describe all aspects of the “Premie Toolkit” including a causal pathway and logic model further discussing the expected outcomes, as well as potential barriers or challenges.

## CHAPTER FOUR: Description of the Proposed Initiative

### Introduction

Evidence presented in the previous chapters revealed that parents feel unsupported, due to the delay in services and limited availability of comprehensive clinics for NICU follow up care post discharge. This can create significant challenges for families seeking medical care and support. In this chapter, the proposed initiative will be described in further detail, specifically addressing one community in northeast Pennsylvania challenged with this gap in care.

The Lehigh Valley area is in northeastern Pennsylvania and includes Lehigh and Northampton counties. There are two local hospital organizations in this area that have NICUs. Based on the most recent public data from 2021, the two organizations had a combined total of 1,010 admissions to the NICU following birth in that year (Department of Health, n.d.). Currently, in northeast Pennsylvania, approximately 9.7% of live births result in preterm deliveries (Department of Health Informatics, n.d.). For infants born prematurely, specifically in this area of Pennsylvania, there is a lack of comprehensive follow up care, therefore, limiting resources and additional medical care that could be offered to families in an accessible and timely manner.

This initiative has two parts, collectively referred to as “The Premie Toolkit”. The first part is an educational course, *Promoting support for preterm infants and families following NICU discharge: Applications for OT practice*, designed for occupational therapy practitioners (OTPs) working in a NICU setting and involved with discharge planning. This one hour in-person course will be offered at the two identified

hospital organizations that have NICU units in the Lehigh Valley. The course is not intended to provide in depth learning but rather an exposure to families' needs following discharge. The course will focus on the knowledge base of occupation and co-occupation to support parents' daily lives post NICU hospitalization. This course will identify system challenges and availability, family challenges, and the impacts on family well-being and infant developmental progression. In addition to this course, OTPs will be provided with a post NICU parent guidebook to distribute to the families at discharge. The guidebook will provide comprehensive resources and support to the families following the first few weeks home from the NICU. The guidebook is an easy-to-use resource for parents to ease their transition home and provide support as they begin their journey of caring for their premature infant at home.

The long-term vision for this initiative is to improve functional outcomes of premature infants and improve the wellbeing of the families in the Lehigh Valley despite the gap in care during this transition. The author anticipates that this will result in a positive impact on the community and improved quality of life for families and infants. The evaluation findings will contribute to evidence-based practice in neonatal healthcare and may be adopted by other hospital organizations to potentially create a similar tool to support their patients in their transition to the community.

Below is a case scenario that further explains the challenges and emotional journey families of a premature infant can encounter bringing their child home from the hospital, let alone a premature infant with medical needs. This is an example of how parents can use the guidebook to utilize resources within their community, as supporting

parental functioning and well-being is crucial during this transition.

### **Case Scenario**

**Beth and her husband, Joe, have always dreamed of being parents. Shortly after they got married, they had their first child, Joseph, “Junior”. He was a healthy full-term baby. After being married for three years, they found out she was pregnant again. She was healthy throughout her pregnancy and they were beginning to get the nursery in their home ready for their new arrival. Unfortunately, Beth had gone into labor early as her pregnancy was complicated by Preeclampsia. Her daughter, Eliana, was born at 26 weeks with respiratory distress and weighed one and a half pounds. She was immediately taken to the NICU. Eliana was in the NICU for 96 days. Beth and her husband drove to the NICU every day to spend time with their newborn, taking turns staying home with their toddler. They were exhausted, scared and overwhelmed. They have received extensive medical education on how to care for their premature infant as Eliana would require oxygen when she went home. Eliana received occupational therapy services while in the NICU one time a week and Beth was educated on developmental milestones, as Eliana is a risk for developmental delays due to prematurity.**

**Once the day of discharge finally arrived, Beth and Joe were provided with an extensive and overwhelming amount of information including upcoming medical appointments, medications and oxygen management, to name a few. The occupational therapist that has been seeing Eliana, provided a post NICU guidebook and explained that this is a tool that can provide them with support and resources for the next upcoming weeks.**

**When Beth and Joe arrived home with Eliana, they were over the moon. Joe had returned to work and Beth had to resign from her position as a teacher to care for her two children. Beth began to struggle with managing the daily needs of her children and was feeling unsupported in the first week home. She became familiar with having Eliana in the NICU and having the nurses support her when she had questions but felt like she had no one to reach out to for support at home. She was challenged with:**

- Lack of sleep- Beth slept on the couch in fear that the oxygen would come off Eliana’s face during the night. Eliana was not sleeping well since the house was loud during the day and she was often overstimulated. During the night, Beth felt the house was too quiet as Eliana became familiar with white noise and the sounds of the machines in the NICU. Beth did see an improvement in Eliana’s sleep at night when she used a sound machine.**
- The disorganization of “living space” as she needed to frequently manage carrying Eliana’s oxygen from room to room to provide her daily care.**

- **Managing a toddler and a newborn with medical needs- knowing how to help keep Eliana safe from the toddler “exploring” her oxygen tubing**
- **Feeling overwhelmed that she was not sure she was providing Eliana with her developmental needs.**
- **Managing a daily schedule between multiple medical appointments, feedings and sleep**
- **Feeling financial and marital stress**
- **Feeling that she did not have any support from friends or family as they do not have experience with caring for a preemie and a toddler and do not understand the amount of stress she is feeling.**

**Beth remembered that she received a post NICU guidebook from the occupational therapist at discharge. As she began to review the guidebook, she was pleased to see a helpful list of resources within her community. Although some of the information was provided to her at discharge, she was so overwhelmed at that time that she realized she did not remember everything. She was able to utilize all the information and suggestions to assist her with getting organized, suggestions for sibling interaction, was able to review the information on EI services and when to expect services to begin, provide basic developmental activities as well as provide some suggestions for her self-care. She decided to reach out to one of the suggested local online support groups for mothers with premature babies and they were able to provide her with support and comfort knowing that her fear and stress are validated.**

**Beth and Joe both agree that they felt overwhelmed and stressed when they brought Eliana home from the hospital. Since there was no comprehensive NICU follow up clinic in their area, they felt like the NICU did not prepare them enough for challenges of managing the infant at home and the delay in activation of therapy services, Beth felt unsupported. The post NICU guidebook provided resources to assist them during the first few weeks at home until she was able to get to her first pediatrician appointment and for when EI services began.**

The visual model in Figure 4.1 presents the causal pathway that will lead to improved infant and family outcomes post NICU in the Lehigh Valley. Occupational therapy practitioners have the important and unique role of addressing not only the occupation of the infant but also co-occupation to promote the development of the family unit and support parents beyond the medical setting (Cardin, 2020). Increasing OTPs knowledge and awareness of the challenges that can occur post discharge will result in resources provided to families in an accessible and timely manner. The family is

considered the primary audience, as they are considered the main beneficiary of the intervention.

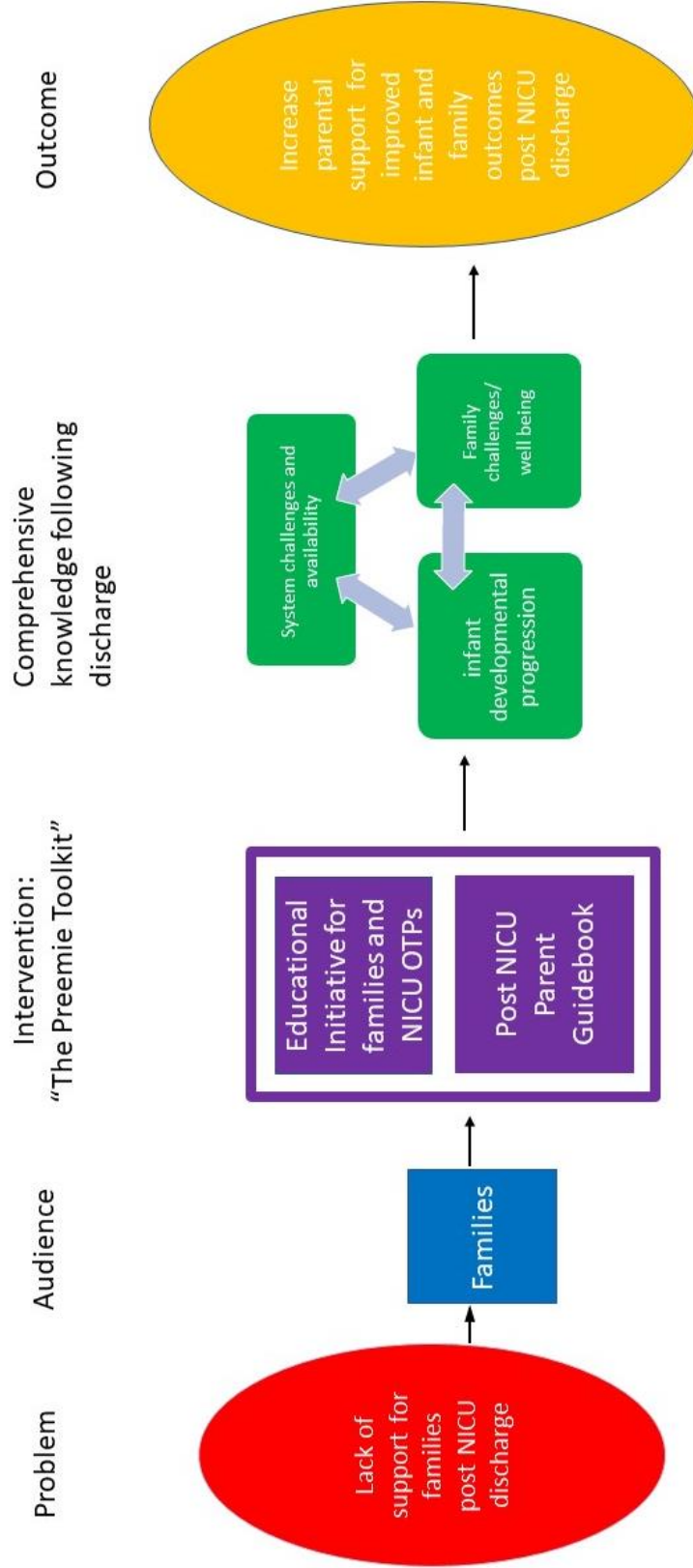
There are three aspects that families with limited to no support are faced with post discharge that have been identified: System challenges, family challenges, and infant medical needs. As noted in Figure 4.1, each barrier can cycle into another, which is the reason a comprehensive approach was created.

The intervention provides education and resources to address the three areas found to be the barriers or gaps in comprehensive care post discharge. The educational exposure for OTPs will provide awareness of these barriers within the community and the parent guidebook will inform parents of resources and helpful hints that address these challenges based on the findings in the literature.

Three levels of relevant stakeholders to support the initiative were identified, at a Micro, Mezzo, and Macro level: At the micro or individual level, the premature infant and their caregivers will benefit from the initiative by receiving additional support following discharge to promote health and wellness. At the Mezzo level, the OTPs who will be receiving this education will be provided with knowledge regarding system, individual and family challenges affecting the health and wellbeing of families with premature infants within their organization and community. Through this education, OTPs will develop awareness of these challenges within the community to promote more intentional guidance with discharge planning. Other stakeholders at the community level may include advocacy groups for family support, hospital administration for additional support and funding. At a Macro level, policymakers including public health agencies can

**Figure 4.1**

*Visual Model of Causal Pathway*



benefit from increased awareness regarding the gap in services for families within their community to consider additional support and reassure high quality healthcare.

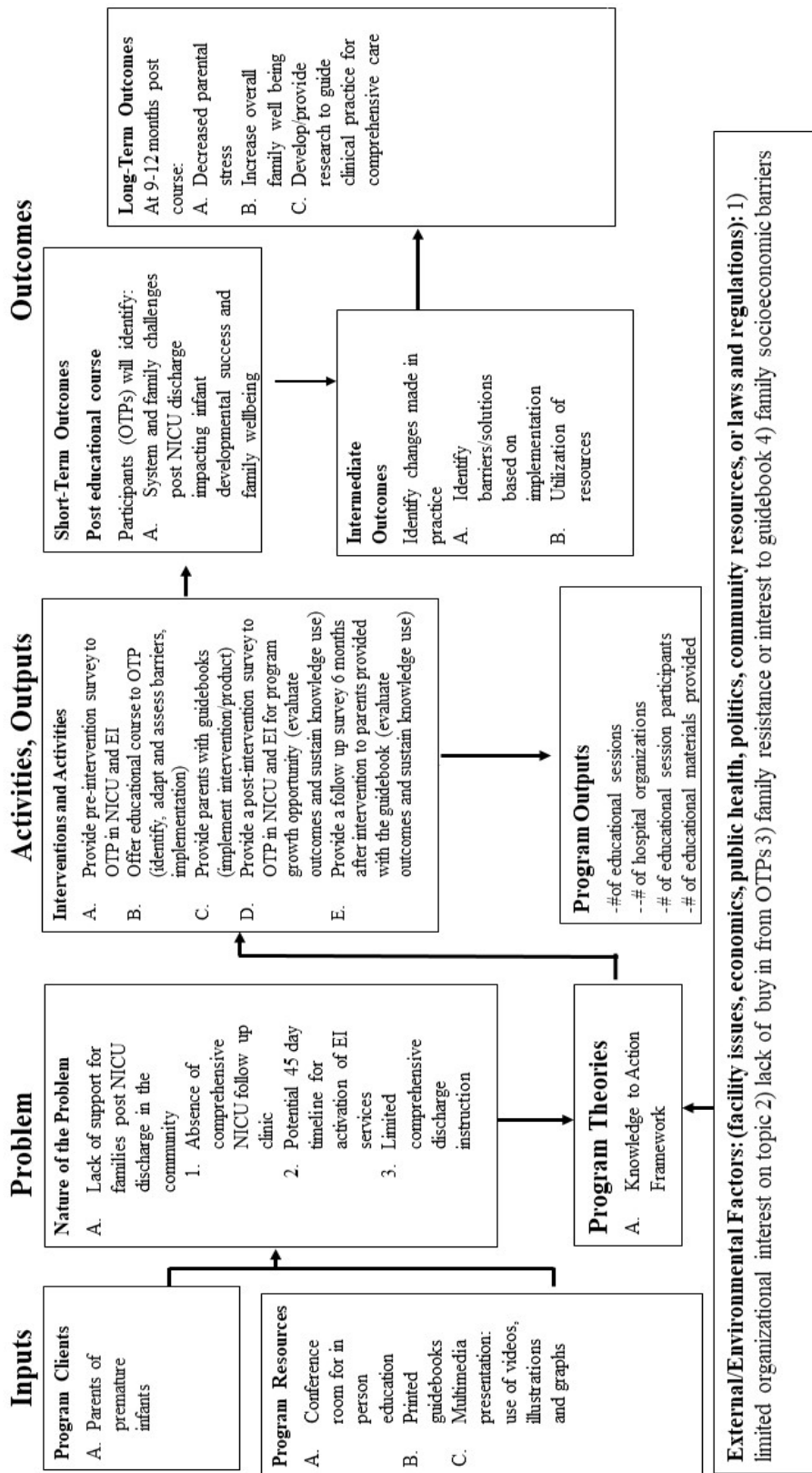
Policymakers may be interested in the potential of saving healthcare costs, for example, reducing risk for rehospitalization due to the infants' ongoing medical needs or the mental health impact on the families as they may not be able to return to work

This initiative will be implemented by providing OTPs, who are currently working in the NICU of two hospital organizations, the "Premie Toolkit" to support parents during their NICU journey with their transition home.

### **Full Logic Model**

A full Logic Model has been designed for the initiative to further understand the purpose, progress and its intended outcomes. This logic model will be utilized as a dynamic guide throughout the implementation process and the evaluation efforts to monitor the program's impact. The comprehensive design of the full logic model represents the development of the initiative as a clear and structured roadmap. It serves as a tool to provide stakeholders with a view of all the components to enhance understanding of the initiative. The model is presented below in Figure 4.2.

**Figure 4.2**  
*Full Logic Model*  
**Program title: Promoting support for preterm infants and families following NICU discharge: Applications for OT practice**



### **Program Participants and Resources**

The participants of the educational course are considered the key stakeholders; these will be the OTPs that are currently working in the NICU and are involved in discharge planning. These participants will be selected by their management within two hospital organizations in northeastern Pennsylvania that currently have NICU units.

The design of “The Premie Toolkit” has considered all the insights of the KTA framework, which guides the conceptualization and delivery of the evidence gathered, for successful implementation and sustainment of this initiative into healthcare practice. This initiative will take place at the community level, specifically in the Lehigh Valley area of Pennsylvania. First, the author will be contacting and coordinating with the management team from each organization to express the need within this community and gain support to coordinate the educational course at their organization. The author will also be gathering information about each organization's structure, procedures, and culture of their NICU to further identify current policies and practices regarding patient discharge. Then, an email for the educational opportunity will be sent to each participant as well as their management team. The duration of the course will be one hour and presented by this author and a parent speaker over a designated educational time allotted during the professional’s day by their management. This time will need to be coordinated with the parent speaker. The course materials including post NICU parental guidebook, and the monetary amount provided for the parent speaker will be funded through various grants and local foundation donations. The responsibilities of this author as the leader will include connecting with both hospital organizations’ management teams to gain buy-in

and support and complete requests with grants and donations for funding. The creation and leading of all aspects of the educational course including scheduling the courses, organizing the conference rooms for learning, the development of the guidebook, distribution of guidebooks to hospital units and distributing pre/post surveys via email will also be solely completed by this author.

To provide opportunity for this educational initiative to be implemented, there are a few resource materials that will need to be supplied. The leader of the initiative will provide the interactive presentation, however, will need access to a conference or educational space within each organization that has the technology available to present the presentation. If there is a cost to use this educational space, funding from the grants and foundations will be utilized. The educational course for the initiative will require one-hour donated time by this author at each hospital organization and an estimated additional hour to distribute surveys prior and after implementation via email.

### **Interventions and Activities**

The first part of “The Premie Toolkit” is the educational course provided by this author and takes place in a conference room at two different local NICUs in Northeast Pennsylvania. The course will require one hour of the participant’s time. The “Premie Toolkit” is guided by the KTA framework to reduce the gap between research and deliver sustainable interventions for healthcare professionals. This interactive course will include illustrations and graphs on current data, review of the system and family challenges following discharge, the impact on the infant’s developmental progression and family wellbeing. It will also include a parent speaker to discuss her personal experience with

discharge into the community. The course will be concluded with introduction of the post NICU parent guidebook to provide comprehensive resources for families and the OTPs role in distribution and contribution. The essential resources for implementation include the author or leader, the parent speaker, and the post NICU guidebook.

### **Program Outputs and Outcomes**

The program outputs that are considered are the number of hospital organizations that will be participating, the number of educational sessions that will take place, the number of participants in each session, and the number of educational materials that will be provided. There will be two hospital organizations that will be offered this educational course and there are an estimated ten participants total. Each organization will be provided with 50 parent guidebooks, 25 in English and 25 in Spanish to begin implementation. Consideration for printed books in other languages will be based on organizational need. A laptop, which will be provided by this author, will be utilized to gather data from surveys for further research and to provide follow up contact with the participants. The outputs will provide the author valuable insight into program modifications to ensure its effectiveness and sustainability.

For the first part of this initiative, short term and intermediate outcomes have been identified. The short-term outcomes anticipated immediately following the educational course include:

- Participants (OTPs) will identify system and family challenges post NICU discharge impacting infant developmental success and family wellbeing.

The intermediate outcomes anticipated 6 months following the educational course are:

- Participants will identify changes made in practice through barriers/solutions to implementation.
- Participants will identify changes made in practice through utilization of resources.

### **Anticipated Barriers and Challenges**

Environmental or external barriers shall be considered when implementing and sustaining an initiative. Identifying organizational resistance of interest in this initiative for OTPs to provide this resource at discharge or lack of management support, may be a barrier prior to and during implementation. Another barrier may be the lack of buy-in from the practitioners themselves to make a change in their daily practice of discharge preparation. Additional educational support may be required for OTPs and other staff members. A review of the literature reveals that the providers themselves may be uncomfortable with changing their behaviors or practice, hindering the implementation of knowledge of new healthcare practice (Price et al., 2010). Family resistance or interest in the guidebook, or additional barriers such as socioeconomic challenges may hinder families from utilizing the resources. Unanticipated copies of the guidebook may need to be printed or digitizing it may be required for sustainability.

### **Summary and Conclusions**

This chapter described the initiative in further detail including the identification of stakeholders, the development of the intervention, the expected outcomes, as well as potential barriers or challenges. The main key element of the initiative is to provide OTPs a resource tool to promote a comprehensive discharge plan for families and their premature infants. The program is guided by the KTA framework to reduce the gap in

care and provide a sustainable intervention for OTPs. The families of premature infants born in the Lehigh Valley will greatly benefit from this initiative by receiving additional guidance, support and resources following the transition home from the hospital to ultimately improve infant and family health outcomes and wellbeing. This chapter presented with a description of the “Premie Toolkit” as an intervention to address the identified gap in care following NICU discharge. Chapter five will describe the importance and plan for conducting program evaluation research.

## **CHAPTER FIVE: Program Evaluation Research Plan**

### **Initiative Vision**

The vision for this initiative is to provide a comprehensive support guide that will provide the necessary resources, specific to their community, to ensure a smooth transition for preterm infants and their families home from the NICU, ultimately enhancing infant's functional outcomes and family well-being.

The research findings will promote evidence-based practice in neonatal healthcare by providing an effective clinical practice tool for comprehensive support and resources to families with premature infants in a timely manner. It will also increase the knowledge and awareness of occupational therapists regarding the needs of families and infants upon transitioning from the NICU to the community. Once the data is collected and analyzed, the findings will also support change for future development and expansion.

This chapter intends to provide a comprehensive examination of the program's evaluation including identification of primary stakeholders, formulated research questions, appropriate methods, and data collection. The chapter will also address the potential limitations providing potential challenges that may influence the findings.

### **Engagement of Stakeholders**

A primary stakeholder for the evaluation will be the management team including the occupational therapy department manager and the medical director of the NICU from both hospitals. Collaboration and buy-in from these members of leadership is crucial to ensure long-term engagement of participating staff for successful research completion. Each invested organization will be able to utilize the findings to present improvement in

clinical practice and collaborative care, as well as supporting families with premature infants in transition to the community.

Other key stakeholders involved in the evaluation will be the author, identified as the leading researcher, the parent speaker, the participating OTPs and the families. For the program to be implemented, the researcher will ensure the education is relevant, monitored, and sustainable. This author is seeking interest in the results of the evaluation to achieve the long-term goal of increasing support for families with premature infants within the community, despite the mentioned challenges.

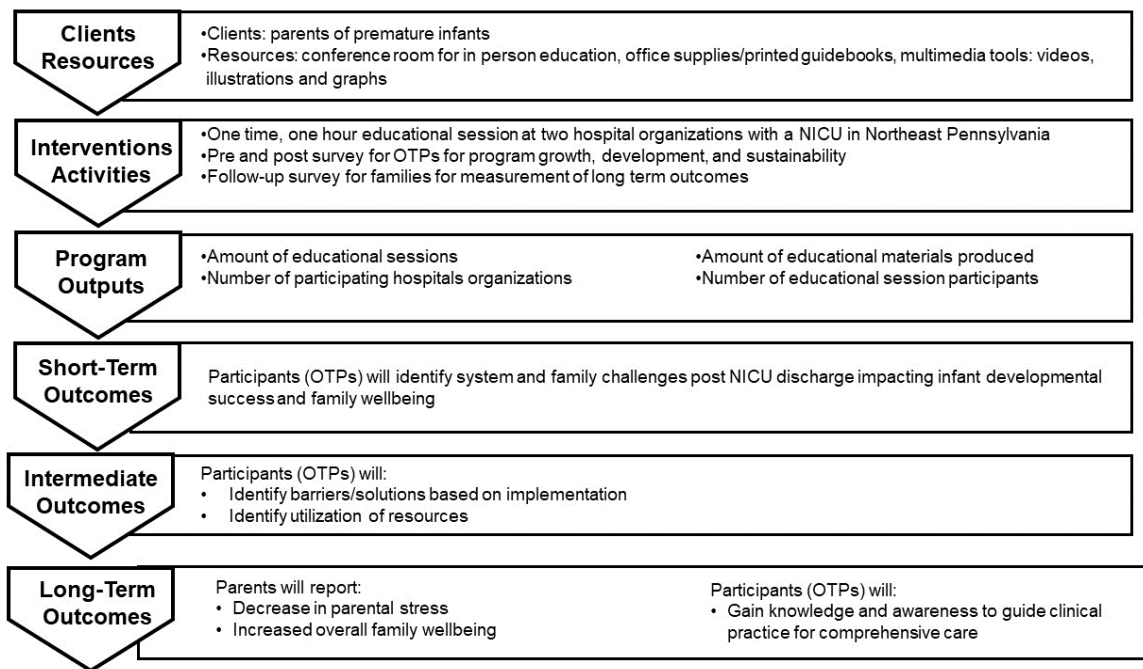
There are approximately 10 OTPs currently working in the NICUs who will be participating in the educational course. The occupational therapy department manager will ensure all the participants will attend the course. Approximately 40 families total will receive the guidebook, 20 from each hospital. The families receiving the guidebook have infants hospitalized in either one of the identified NICUs, are receiving occupational therapy services and are preparing for discharge. The treating occupational therapist will introduce the families to the guidebook and engage them in the initiative. Feedback from all stakeholders regarding their experiences of implementation and if and how the guidebook was utilized will contribute to the evaluation of the program and the findings. Occupational therapy practitioners will benefit from the outcome of the evaluation to optimize their evidence-based clinical practice skills of supporting families' engagement and well-being beyond NICU discharge within their community.

### Simplified Logic Model for Use with Stakeholders

During the educational course, the stakeholders will be presented with a simplified logic model to further understand the programs’ purpose, progress and its intended outcomes. This logic model will be utilized as a guide throughout the process of the evaluation and will monitor the program’s impact and implementation. The simplified logic model is listed in Figure 5.1 below.

**Figure 5.1**

*Simplified Logic Model*



### Preliminary Exploration and Confirmatory Process

The author will coordinate a meeting with the management team of each hospital organization, to provide information about the initiative, current literature and research, expected outcomes, methodology and the logic model. The author will seek support to

coordinate the educational course at their organization. The parent speaker will also be present to provide personal experience and discuss involvement with the initiative. This meeting will take place in person with the goal of achieving and maintaining buy-in from the stakeholders. Prior to the meeting, the author will gather information about each organization's structure, procedures and culture of their NICU to further identify current policies and practices regarding patient discharge as well as send all information regarding the initiative to each management team for review. During the meeting, the stakeholders will be invited to provide feedback on the research questions and design, and to provide insights on how the research findings will be utilized. If more time is needed, an additional meeting can be arranged at the stakeholder's request.

### **Program Evaluation Research Questions by Stakeholder Group**

Table 5.1 presents a list of formative and summative research questions that could be answered through the research findings. Each question is directly related to the key stakeholder's engagement and interest.

**Table 5.1 Stakeholder Program Evaluation Research Questions**

Stakeholder	Types of Program Evaluation Research Questions
Author/ Researcher and parent speaker	<p><b>Formative:</b></p> <ul style="list-style-type: none"> <li>• Was the content and delivery of the educational course sufficient for the participants to begin implementation?</li> </ul> <p><b>Summative:</b></p> <ul style="list-style-type: none"> <li>• Did participants in the educational course change their clinical practice and improve collaborative care when preparing families for discharge?</li> <li>• Did the participants find the guidebook as an effective tool to provide resources for families at discharge?</li> </ul>
Management of Occupational Therapy department	<p><b>Formative:</b></p> <ul style="list-style-type: none"> <li>• Is the content and delivery of the educational course sufficient for the participants to begin implementation?</li> </ul> <p><b>Summative:</b></p> <ul style="list-style-type: none"> <li>• Did participation in this initiative lead to improved effectiveness of care and patient experiences following NICU discharge?</li> <li>• Did participation lead to reduced hospital readmissions for the NICU population?</li> </ul>
OTPs working in the NICU	<p><b>Formative:</b></p> <ul style="list-style-type: none"> <li>• Was the educational course information provided relevant and applicable?</li> <li>• Is there anything that should be changed to improve the course content or delivery?</li> </ul> <p><b>Summative:</b></p> <ul style="list-style-type: none"> <li>• Did participation improve awareness about the system and family challenges that occur following discharge?</li> <li>• Did participation lead to changes in practice regarding the discharge process for NICU patients and their families?</li> <li>• Did you find that the post NICU guidebook that was provided for families established a comprehensive transition from hospital to home for the families?</li> </ul>
Parents of preterm infants	<p><b>Summative:</b></p> <ul style="list-style-type: none"> <li>• Was the post NICU guidebook utilized following discharge?</li> <li>• Did you and your family find the post NICU guidebook provided you with resources to support you following discharge?</li> <li>• Did you feel that the post NICU guidebook improved your family wellbeing and decreased stress following the transition home from the NICU?</li> </ul>

## **Research Design**

A feasibility study will be conducted to determine the viability of the initiative. A mixed methods research design will gather formative and summative evaluation surveys regarding the educational course using online questionnaires. The questionnaires will be administered to the participants immediately following the completion of the course via SurveyMonkey. The same surveys will be distributed again to the same participants after six months following the completion of the course.

In conjunction with the six-month surveys, a summative evaluation will also be sent out to 20 randomly selected families that have received the guidebook at discharge regarding the use and effectiveness of the guidebook.

## **Methods**

Inclusion criteria for the participants receiving the educational course will be: a current licensed occupational therapist in the state of Pennsylvania, currently working in a NICU located in the Lehigh Valley, active full or part time employment, and involved with discharge planning. The inclusion criteria for the randomly selected families will be: live in the Lehigh Valley, have a preterm infant that has been hospitalized in a NICU located in the Lehigh Valley, has received the post NICU guidebook upon discharge, and are at least one month post discharge. The guidebook and evaluation will be introduced to the families by the treating OTP. Following agreement to participate, when the guidebook is presented to the families, the OTP and the parent will both sign a consent form created by the author and will be secured in a locked cabinet by the author following completion. To ensure confidentiality, each participant and families name will be coded using

assigned numbers and all information collected will be secured on the encrypted laptop of the researcher. The Institutional Review Board's ethical research protocol will be followed once the researcher has completed each organization's required training, prior to implementation of the course.

After participants sign up for the course, contact information will be gathered for the surveys to be sent electronically immediately following the course and six months after via SurveyMonkey, as stated above. It will include questions regarding their perception of the initiative, their opinions and feedback for areas of improvement, and what change they can make to their daily practice following this course.

In conjunction with the six-month surveys the participants will receive, a different evaluation will also be sent out to 20 families, chosen randomly by number at discharge from each organization, for a total of 40 families. These survey questions will be designed using a visual analog scale with ratings from one to ten. A rating of one will indicate low or never and ten will indicate high or always. They will include questions such as the awareness of challenges that occur following discharge, impacts of change in practice and use of the guidebook for improved family wellbeing.

### **Data Collection and Analysis**

The formative data will be collected by the researcher within two weeks following the completion of the education course. Data will be collected and secured on the encrypted laptop of the researcher. Responses from the open-ended questions on the survey will be coded using the computer application, NVivo. This computer application will help identify recurring themes and similar connections between the participants'

responses. The formative data will provide qualitative feedback on the current process of the initiative and suggestions for improvement.

The summative data will be collected and transferred into a Microsoft Excel spreadsheet to organize responses from each participant and family member and then grouped by each organization. A mixed methods design will be used to analyze the data.

Dissemination of the findings will be completed by nine months following the launch of the initiative and will be communicated to the participants. Through formative evaluation, the results will provide data on the impact of the educational course, whereas the summative data will measure the impact on the families in the community. A one-page combination of a quick report and infographics will be utilized and sent to each participant's email. It will include a brief paragraph, like the one written above, to describe the underlying reason for the course and will include both text and graphics to display the results of the data, the related costs of the initiative and potential reduction of re-hospitalizations. This will provide the participants with a quick, unique way of presenting the results and can be easily shared with future stakeholders.

### **Anticipated Strengths and Limitations**

This overall evaluation relies heavily on the active participation and feedback of participants and families. Therefore, limitations of outcomes may be influenced based on the number of responses from participants and families that are willing to complete the surveys.

The main limitation of this proposed study regarding the feasibility and viability of the initiative is the potential for lack of buy-in from management at each organization.

Management may not allocate time for the OTP to attend the educational course, allow time to work with the families upon discharge or respond to the surveys which are all crucial needs for successful implementation and program evaluation. If the management team does not reinforce the “toolkit” within their units, the OTP may not apply the learning or provide guidebooks, leading to a reduction in the number of potential families for the study. Another limitation may be the transferability of the findings to another geographical location across Pennsylvania as the community needs may differ.

The main strengths of this evaluation are the limited timeframe required to complete the initiative for quick results and the ease of online delivery of the surveys. This allows feasibility in gathering data and opportunity to make changes for successful implementation. The delivery of online surveys allows the participants and parents easy access to participate in the evaluation and eliminates the need for additional in person meetings to gather data. The research findings from the evaluation plan described in this chapter will contribute to the knowledge base and awareness gap regarding the transition into the community post discharge. The following chapter will address the dissemination plan for the “The Premie Toolkit”.

## **CHAPTER SIX: Dissemination Plan**

This chapter presents a dissemination plan to increase the impact of “The Premie Toolkit” on families of premature infants living in the Lehigh Valley post NICU discharge. The “Premie Toolkit” is meant to be disseminated in other geographic locations and to other allied health professionals working in a NICU to ultimately support all families that have infants in the NICU across Pennsylvania. The dissemination plan includes short term and long-term goals.

### **Dissemination Goals**

Dissemination is expected to begin once the research results have been gathered following implementation, estimated to be after 9 months. The first short-term goal is to disseminate the program locally in the Lehigh Valley and ensure its sustainability. Once the initiative is found to be successful and sustainable, then the next goal will be to expand the initiative beyond occupational therapy to other allied health professionals in the region, allowing more availability to families within this community. Once the short-term goals have been achieved successfully, the long term goal is to then expand the use of “The Premie Toolkit” to other geographic areas within Pennsylvania.

### **Primary Target audiences**

The main beneficiaries and the primary audience for the initiative are the families of premature infants. The toolkit was created as a comprehensive, educational and accessible tool to support families in caring for their infant at home for the first few weeks following NICU discharge. The dissemination phase seeks to be able to provide

support to all families of the 250 preterm infants born prematurely in Pennsylvania each week. (March of Dimes, n.d.).

### **Secondary Target Audience**

In line with the short-term dissemination goals, expansion to other healthcare professionals locally, including the allied health management teams, is critical for dissemination. These professionals working in a NICU can be provided with “The Premie Toolkit” to implement within their organization. This will increase overall staff awareness of family needs, access to the guidebook and its utilization post discharge. The management team can disseminate the initiative within their unit as they seek to reassure high quality healthcare and positive discharge outcomes.

### **Key Messages**

The key messages to other healthcare professionals regarding the result of this initiative are:

1. OTPs have improved confidence in providing comprehensive, transferable and sustainable discharge plans.
2. The parental guidebook is an easy-to-use comprehensive discharge tool for supporting families with preterm infants within the community. The results of the program evaluation present evidence that the toolkit transfers knowledge and resources to the families to improve overall transition experience, as well as infant and family functional outcomes.

3. OTPs have identified positive changes in practice through the utilization of resources within their community.

The key messages for the management or leadership team of other allied health professions:

1. The educational course is brief and concise. It can be offered over a one hour scheduled meeting time.
2. Utilization of the guidebook improves effectiveness in care for discharge planning, increases patient experience satisfaction and outcomes and reduces hospital readmissions.
3. Increased awareness of the initiative has improved clinical practice guidelines and provides marketing opportunities for a unique and innovative practice.

### **Sources/Messengers**

The OT manager within each organization is considered a key spokesperson to support and assist with expanding the use of the initiative to other allied health professionals. Consistency for providing this education for all current and new staff OTPs will be crucial for sustainment of the initiative. The parent speaker is another key spokesperson for the families by sharing personal experience. Drawing from the KTA model, personal experience illuminates the perspective on challenges, anxiety and fears that families encounter during their NICU journey (Graham et al., 2006). By transforming knowledge into action, shared experiences can foster a more supportive environment for other families in similar situations.

**Dissemination Activities**

Once sustainment has been achieved and all data has been collected, results are shared with participants and members of leadership to ensure sustainability and expand initiative to other professionals within the organization. Further discussion on other means of utilization for the guidebook may be considered at that time, such as digitizing it for a mobile application or a website, or having the guidebook printed in multiple languages beyond English and Spanish.

In accordance with the established long-term goal, the positive results of the initiative will be disseminated by the author at the Pennsylvania Occupational Therapy Association (POTA) annual conference. This will provide other OTPs from various institutions across Pennsylvania the opportunity to learn about the initiative and review the results. Consideration of a webinar on the POTA website would also be helpful in reaching a greater number of professionals within the state.

**Budget**

This section will describe the total budget required for the dissemination. A designer will be hired following completion of the research data, to create an infographic handout to professionally present the results of the initiative. The author will donate personal time to coordinate and conduct a meeting to present the infographic with the leadership teams. The parent speaker, who will be presenting personal experience during the educational courses, will also be present at this meeting and will be compensated \$25.00 through author's personal funding. The cost of attendance and presentation at the Pennsylvania Occupational Therapy Association annual conference is \$350.00, in

addition to having a large poster printed for \$50.00 (POTA, n.d.; Office Depot, n.d.). All costs for dissemination will be covered by the author's personal funding.

These expenses are presented in Table 6.1 below.

**Table 6.1**

*Estimated Dissemination Expenses*

<b>Resource</b>	
Infographic designer	\$25.00
Parent speaker compensation	\$25.00
Poster	\$50.00
Conference Presentation	\$350.00
<b>Dissemination Total</b>	<b>\$450.00</b>

**Evaluation**

Evaluation of the dissemination activities is essential to determine the effectiveness of the plan and to make modifications as needed. The primary measurement for the dissemination will be the same method as the program evaluation for participants and the families regarding the effectiveness of the course and the utilization and effectiveness of the guidebook. Additional data will be collected, as the program expands, including the number of organizations that have adopted the initiative across Pennsylvania, number of professionals who participated in the course, and number of families that were reached through the initiative. Once the initiative is implemented, the results of the distributed surveys will determine the feasibility of the Toolkit and if changes need to be made to increase usability for the specific community within Pennsylvania.

**Conclusion**

The main goals for the dissemination of this initiative are to ensure its sustainability locally, expand the initiative beyond occupational therapy to other allied health professionals locally, and extend its reach by expanding its use to other geographic locations within Pennsylvania.

Increasing awareness of the gap in services, the lack of support following NICU discharge, in addition to the positive outcomes of this initiative will further support the need to promote a more comprehensive discharge plan and increase access to medical and community services in the future. The initiative's feasibility and effectiveness can be duplicated and shared throughout other regions of Pennsylvania or nationally with specific community adaptations.

The funding plan presented in the next chapter will provide an overview of the estimated expenses for implementation and sustainment for the proposed initiative.

## **CHAPTER SEVEN: Funding Plan**

The “Preemie Toolkit” is an evidence-based and theoretically driven initiative that aims to fill the identified gap in care and provide accessible knowledge and support for families living in northeast Pennsylvania during the transitional period between hospital and home. Funding needs are identified to provide educational exposure and a resource within the home that is easy for families to refer to, ultimately increasing family well-being and improving outcomes for infants and families.

### **Free Available Resources**

The creator and author of this educational initiative will begin by holding a meeting with management of the hospitals to gain interest and buy in of the initiative. Marketing materials such as flyers for the course will be created by the author through a free online design platform and will be distributed digitally to the NICU OTPs and members of leadership. Once buy-in from management has been established, then the free interactive in-person educational presentation to OTPs will be presented by this author at no cost. The estimated time required to complete the presentations at each organization is approximately one hour. The guidebooks will be distributed by the author to each hospital at the time of the course. As described in chapter 5, this author intends to develop and carry out research on the impact of the educational course and the use of the guidebooks in supporting families following discharge from a NICU in the Lehigh Valley. Surveys for evaluation will be sent to families and OTPs digitally by the researcher via the free online platform SurveyMonkey, to eliminate any postage costs.

**Needed Resources for Cost**

Utilization of a conference or educational space within each organization will be provided by the organization. The parent speaker will be compensated for presenting personal experience during the educational portion of the initiative and initial meeting with hospital leadership. A medical translator will be utilized to transcribe the guidebook in Spanish before production of the guidebooks begin.

**Estimated Expenses**

Rental of a conference room at both organizations is estimated at \$200.00. A free design platform will be utilized to create the parent guidebooks. Each organization will be provided with 100 parent guidebooks for distribution, equally in English and Spanish. The cost of hiring a medical translator to transcribe the guidebook in Spanish is estimated at \$100.00. Each guidebook will be printed and spiral bound through Lulu.com with an estimated cost of \$1539.64 for 200 books with approximately 40 pages in each book, including shipping (Lulu, n.d.). Compensation for the parent speaker will be estimated at \$200.00 for presenting personal experience during the educational course portion of this initiative, in addition to the \$25.00 received to attend the initial meeting with leadership. This expense will be funded by grants received from identified foundations. These expenses are presented in Table 7.1 below.

**Table 7.1***Estimated Expenses*

<b>Resource</b>	<b>Implementation</b>
Printing, binding, and shipping of guidebook	\$1539.64
Parent speaker compensation	\$225.00
Medical Translator	\$25.00
Conference Room rental	\$200.00
<b>Total</b>	<b>\$1989.64</b>

**Funding Sources**

Potential funding sources are listed below in Table 7.2. Lily's Hope Foundation has agreed to provide initial funding to have all 200 parent guidebooks printed to support the implementation of the initiative. The guidebook aligns with their mission to support and provide care packages for families during the transition home from the NICU.

Personal funds for time and travel will be utilized for the implementation of the educational course from this author. A grant proposal will be written to two national foundations, March of Dimes and Little Giraffe, to provide funding and support for this initiative. Since the Lily's Hope Foundation will be covering the cost of the guidebooks, the remaining need for funding is \$550.00. The March of Dimes Foundation has raised 6.4 million dollars to support funding for innovative ideas to address maternal and infant health challenges (March of Dimes Innovation Fund, n.d.). The Little Giraffe Foundation provides medical professionals and organizations \$15,000 through fifteen different NICU support grants to promote greater quality of life for infants and their families (Little Giraffe Foundation, n.d.).

**Table 7.2***Funding Sources*

<b>Funding Type</b>	<b>Funding Source</b>	<b>Description</b>
Foundation Donation	Lily's Hope Foundation	A local nonprofit organization provides funding to support families during their transition home through Transition Home and Sibling care packages. (Lily's Hope Foundation, n.d.).
Grant	March of Dimes Foundation	Provides funding through a local chapter of national foundation to support healthcare professionals to promote change within the community by providing support to preterm infants and their families before, during, and after a NICU hospitalization (March of Dimes, n.d.)
Grant	Little Giraffe Foundation	Provides funding to hospitals and healthcare professionals to ease the NICU experience for families and ensure greater quality of life (Little Giraffe Foundation, n.d.)
Personal Funds	Author/Creator	Personal funds will be utilized related to time and travel to create and distribute educational resources to local NICUs.

**Conclusion**

The funding plan discussed in this chapter describes the expenses and budget required to create, implement and evaluate the initiative, as the dissemination focuses on sustainment. Overall, “The Premie Toolkit” is a low-cost intervention to support families with premature infant’s post NICU discharge. The support of local and national foundations makes it feasible to implement and sustain the initiative within this community and further promotes expansion to support more families in need.

## **CHAPTER EIGHT: Conclusion**

This doctoral project presented a two-part educational initiative, called: “The Premie Toolkit”, aimed to address the gap in care and lack of support provided to families of preterm infants living in northeast Pennsylvania, following a NICU discharge. The current challenges within the system leave parents feeling overwhelmed and unsupported post discharge, with delays in accessing essential services and a lack of guidance and resources which can have a negative impact on the infant’s developmental progression and family wellbeing. The project includes an in-depth understanding of the challenges that are leading to the problem, such as lack of knowledge and awareness among families and NICU healthcare providers, the absence of comprehensive NICU follow up clinics, and resources that are not being offered in a timely manner in the community, such as EI. An extensive search within the literature provided evidence to identify the problem, support the need for intervention and gather evidence based effective methods to address the problem.

The development of the educational initiative was guided by the KTA model which provided a methodology for addressing the gap in knowledge and awareness both for OTPs and the families. “The Premie Toolkit” includes an educational course for OTPs, to raise awareness of the system and family challenges post discharge, as well as provide a resource tool to promote a comprehensive discharge plan for families with preterm infants. The initiative offers a comprehensive and timely approach to support families, by providing clinical practice resources in the community during the period before they receive EI services or medical follow-up.

**Importance of evaluation and dissemination**

The vision for the initiative is to bridge the gap in care for preterm infants and their families during the critical transition home from the NICU, while focusing on improving infant and family functional outcomes through the promotion of knowledge and awareness among NICU OTPs. The evaluation will determine the feasibility of the program and identified changes that may need to be made to increase the usability of the toolkit. The findings will support the dissemination and will be presented at professional conferences to inform other health care professionals, and other geographic locations, about the benefits of providing comprehensive resources during this critical transition period to improve the overall well-being of families and promote better developmental outcomes for premature infants.

**Funding for the “The Premie Toolkit”**

The low-cost funding plan aligns with the KTA model by promoting efficient knowledge translation, sustainability and maximizing the integration of evidence into new practices. Several local and national foundations play a vital role in promoting new practices by supporting healthcare professionals to implement change within the community to ease the NICU transition home for families. Commitment from some of them was already achieved, making it feasible to implement and sustain the initiative and further promote expansion to support more families in need.

**Reflection**

Overall, the initiative aims to improve infant functional outcomes and parental

support post NICU discharge by bridging the service gap during the transition into the community. The initiative contributes to the occupational therapy knowledge base to address health, well-being and participation in life for both the infant and their caregiver. My hope for the initiative is not only to have a positive impact and improve the quality of life for the infants and families in the Lehigh Valley, but to also have it adopted by other healthcare organizations to ultimately contribute to the advancement of healthcare practices and the enhancement of family centered care.

During the process of developing this initiative, I have gained increased awareness on the critical impact that delays in care can have on an infant during this vital time of growth and development, as well as, how important the focus of co-occupation is for the infant and the parent throughout their daily lives. The KTA framework has guided me to learn the importance of collaboration between researchers, practitioners, and stakeholders. Overall, it has led me to use the skills and knowledge I have as an OT to improve outcomes for infants and their families by utilizing research findings to ensure effective translation of knowledge into action.

**APPENDIX A.****The Premie Toolkit****OUTLINE OF THE EDUCATIONAL EXPOSURE COURSE  
FOR OCCUPATIONAL THERAPY PRACTITIONERS****Introduction of the Problem:**

- Statistics
- Mission and Vision
- Challenges leading to the identified problem:
  - System challenges and availability
    - Absence of NICU follow up clinics
    - Delayed EI
    - Lack of knowledge and awareness
  - Family challenges and effects on family well-being while adjusting to life outside of NICU:
    - Person:
      - lack of emotional support/stress
      - overwhelmed by amount of information provided at discharge
    - Occupation:
      - Parenting/ spouse roles
      - managing equipment, schedules
    - Environment:
      - Caring for other children
      - home set up/ challenges
      - community/network

**Impacts on infant developmental progression****Introduction of Parent Speaker to share personal experience post NICU story****Introduction: The Post NICU parent guidebook**

- Purpose
  - encourage meaningful occupations in home environment and parental support/guidance for first few weeks at home
  - OTP distribution and how to introduce at discharge, making adaptations to personalize
- Research and follow up

**APPENDIX B.****The Premie Toolkit****OUTLINE FOR THE POST NICU PARENT GUIDEBOOK:  
SURVIVING THE FIRST FEW WEEKS AT HOME**

- Areas of Development
  - How to calculate for prematurity for developmental age
  - General Milestones
  - Developmental home activities suggestions and adaptations
    - Positioning
    - Head shape
    - Engaging in play
    - Ways of bonding
  - Examples of overstimulation
    - reading baby cues and strategies for self-regulation
  - Sleep considerations/strategies- safe sleep
- Remember to Ask...
- Establishing Routines
  - Sleep/feeding/medications
    - Provide blank schedules template
- Sibling Interaction activities and ideas
- Home safety and set up considerations- pet care, managing equipment
- Self-care for parents
  - Activity ideas- networking, spouse, friends/family
  - Opportunity for journaling
  - Sibling Interaction activities and ideas
  - Personal reflections (at end or throughout the book)- quotes/short stories, sentences
- What is Early Intervention?
  - What to expect
  - Role of therapy
- Contact List – care team/personal emergency contacts

- National Foundations- March of Dimes, Graham's Foundation, Lily's Hope Foundation websites
- Community support
  - **In-Person** Local support groups
    - International MOM club- Bethlehem and Easton chapters
    - St Luke's Baby and Me Support Center
  - **Online** Local support groups
    - Lehigh Valley Moms Support Group Facebook Group
    - Lehigh Valley Moms Connect Online
    - Moms supporting Moms of the Lehigh Valley Facebook Group
    - Lehigh Valley Postpartum Support Facebook Group

## APPENDIX C.

### Executive Summary

The overall aim of this initiative is to improve parental support and family well-being post NICU discharge by providing a “toolkit” which includes an educational course for OTPs and a parental guidebook resource tool for families, collectively promoting a comprehensive discharge plan. The educational course, *Promoting support for preterm infants and families following NICU discharge: Applications for OT practice* has been developed for OTPs to equip them with knowledge and awareness to assist families during the transition from the NICU to home. This educational course strives to bring awareness to the challenges and stressors families face following discharge such as delays in medical follow up including EI services, and lack of guidance, support, and resources that can improve infant and family functional outcomes, health and wellbeing. Occupational therapy practitioners will be provided with a post NICU parent guidebook to distribute to the families at discharge to provide comprehensive resources and support to the families following the first few weeks home from the NICU.

Defined by the World Health Organization, a preterm birth is a live birth that occurs before thirty-seven weeks gestation (Walani, 2020). Prematurity is a worldwide healthcare problem that is affecting 15 million births every year and complications from prematurity are the leading cause of mortality in children under the age of five (Walani, 2020). Approximately 11% of these infants are born within the United States (Feehan et al, 2019). More specifically, across Pennsylvania, there are 250 preterm babies that are born weekly (March of Dimes, n.d.).

Due to advancements in perinatal healthcare, premature infants are surviving today more than ever before. However, most of these infants are required to have a prolonged neonatal intensive care unit (NICU) hospitalization due to their complex medical needs, which often continues beyond discharge home. Premature infants are at high risk for significant chronic health disorders and neurodevelopmental impairments (O’Shea, 2021). Babies born prematurely often require more ongoing care and support, compared to healthy full-term babies, which alone places a considerable amount of stress on the families (Msall, M.E., 2019). When an unexpected preterm birth occurs, parents are often confronted with many stressors and uncertainties regarding the survival of their infant, medical needs and long-term complications or outcomes of the infant. This catastrophic event for families can lead to increased anxiety, stress, depression and grief in response to learning how to care for their infant in an unexpected environment with unknown outcomes and is often considered an emotional journey for these families.

Upon discharge, the medical team and the parents will prepare for discharge by creating a plan to ensure follow up care for all medical and developmental needs. Unfortunately, is a lack of knowledge and awareness regarding the system and family challenges post NICU discharge, resulting in discharge resources that are not being offered to families in an accessible and timely manner. Early Intervention can take up to several weeks before a child receives services, despite state mandates, which can result in further developmental delay for this high-risk population (Pineda et al., 2020). Families are often overwhelmed and stressed by the amount of information that is provided at discharge, especially if the child has extensive medical needs, and feel unprepared and

unsupported with the lack of community-based services once they transition home.

Most premature infants will receive an automatic referral to a NICU clinic for comprehensive medical and developmental care, however, NICU clinics are not universally available throughout the country (Singh et al., 2019). Among many other areas within the United States, the Lehigh Valley, including Lehigh and Northampton counties, in northeast Pennsylvania, currently has an absence of a NICU clinic. This educational initiative aims to provide further support and guidance for families living in the Lehigh Valley following discharge from two local NICUs.

### **Project Overview**

The educational initiative aims to improve premature infants' functional outcomes by ensuring a more comprehensive and accessible parental support for the overall wellbeing of families following discharge home from a neonatal intensive care unit (NICU). The educational course, *Promoting support for preterm infants and families following NICU discharge: Applications for OT practice*, is designed for the primary audience of occupational therapy practitioners (OTPs) working in a NICU setting, although families of premature infants are the main beneficiaries of this initiative.

The initiative will be completed in two parts. First, the educational course *Promoting support for preterm infants and families following NICU discharge: Applications for OT practice*, will be offered at two different hospital organizations located in Northeastern Pennsylvania. The course is guided by the Knowledge to Action (KTA) framework to reduce the gap between research and delivery of sustainable interventions for health care professionals. This interactive course will include

illustrations and graphs on current data, review of the system and family challenges following discharge, the impact on the infant's developmental progression and family wellbeing. It will also include a parent speaker to discuss personal experiences with the discharge transition into the community. For the second part of the initiative, OTPs will distribute a guidebook to the families to utilize during the first few weeks at home following discharge. The guidebook will include activities to promote the infant's development, recognize their infant's needs or stressors, promote engaging and nurturing relationships, parental self-care activities, and contact information for local support. Collaboratively, the two parts of this initiative will raise awareness for identified parental needs within the community and provide a preventative and supportive tool, the guidebook, as a resource to overcome these challenges.

The secondary audience, but as with equal importance, is the management or leadership team to support, implement and disseminate the initiative within their organizations as they seek to reassure high quality healthcare and positive discharge outcomes. The initiative can support these policymakers in developing clinical practice guidelines for the organization to optimize patient care. Utilization of this "toolkit" includes free education for OTPs and a parental guidebook designed to improve effectiveness in care for discharge planning, increase patient experience outcomes, and reduce hospital readmissions.

### **The role of occupational therapy in NICU discharge**

Occupational therapy is an essential profession to assist with filling this gap as the focus is directly linked to the people, their environment, community and their

occupations. According to the Occupational Therapy Practice Framework (2020), a person's occupation refers to the everyday activities that bring purpose and meaning to their lives. These occupations are essential to a person's health, identity, sense of competence and value for everyone (AOTA, 2020). Co-occupation is a parallel occupation, requiring shared participation within two individuals such as with parenting. Occupational therapy practitioners have the important and unique role of providing opportunity to expand their focus to not only the occupation of the infant but co-occupation to promote the development of the family unit and support parents beyond the medical setting (Cardin, 2020). There is a gap in the literature regarding the role of occupational therapy as part of the NICU team facilitating the transition from hospital to home. It is anticipated that OTPs will utilize their previous knowledge, in addition to the information and tools within the initiative, to guide change in their discharge practices and increase the parental support that is provided during this transition home within this community. This initiative will highlight the important and unique role that the occupational therapy profession provides to the medical field and to local communities.

### **Anticipated parental outcomes**

Lack of communication from medical professionals to families regarding information that is provided at discharge remains problematic (Peacock, 2014). Many studies have reported that parental mental health, difficulties with navigating system and community support, addressing family adjustment needs including maintaining ongoing responsibilities and general guidance with parenting a premature infant are the most common challenges families are facing post NICU discharge (Grunburg et al., 2020; Ma

et al., 2021; O'Shea, 2021). According to Ma et al. (2021), education for medical professionals on transitions in care is essential for both the caregiver and the infant to maximize emotional support and minimize stress during this time.

Based on the evidence in the literature, the anticipated outcome of this educational initiative will have a positive impact for this population in the Lehigh Valley. Ultimately, it will lead to decreased family stress, improvement in infant's functional outcomes and increased awareness of family needs during their NICU journey following discharge.

### **General Conclusions**

Despite the education and training parents receive on caring for a premature infant upon discharge from the NICU, there are many families that are often left feeling overwhelmed and unsupported in daily life with their premature infant at home. Premature infants are considered at risk for developmental delays and need to be medically monitored for appropriate growth, therefore, referrals to follow up appointments are typically made to address these concerns at discharge. However, these resources are not being offered to families in an accessible and timely manner. This gap in care causes a considerable amount of stress on the families and can impact the functional outcomes of the infant. Promoting a resource within the home that is easy for families to refer to, supports the need for the proposed initiative and will ultimately increase family well-being and engagement, is essential for the effectiveness of care and outcomes for infants and families.

**APPENDIX D.**

Promoting support for preterm infants and families following NICU discharge: Applications for OT practice

Erika Steinke MS, OTR/L  
OTD Candidate

Prematurity is a worldwide healthcare problem affecting 15 million births every year. (Walani, 2020).

Complications from prematurity is the leading cause of mortality in children under the age of five (Walani, 2020).

Across Pennsylvania, there are 250 preterm babies born weekly (March of Dimes, n.d.). More specifically in northeast Pennsylvania, approximately 9.7% of live births result in preterm deliveries (Department of Health Informatics, n.d.).



<http://www.vox.com/science-and-health/22949159/nicu-babies-pain-treatments-podcast-unexplainable>

### Introduction to the Problem

#### Identified Problem:

There is a gap in care and lack of support for families of premature infants following a Neonatal Intensive Care Unit (NICU) discharge in northeastern Pennsylvania.

Underlying challenges that are leading to the problem are:

- lack of knowledge and awareness regarding the system and family challenges post NICU discharge. Discharge resources that are not being offered to families in an accessible and timely manner.
- Although premature infants receive an automatic referral for Early Intervention services, “there is a delay in therapy activation following NICU discharge, and some infants who warrant services do not obtain them” (Nwabara et al., 2017, p.414), impacting functional outcomes.
- Many premature infants will be referred to a NICU clinic for comprehensive medical and developmental care, however, NICU clinics are not universally available throughout the country (Singh et al., 2019). The Lehigh Valley area in northeast Pennsylvania, among other areas within the United States, currently lacks an available NICU clinic.

---

## The Proposed Solution

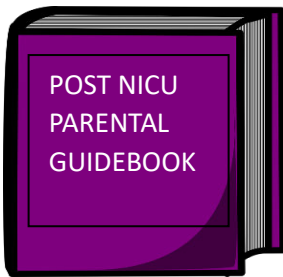
An educational toolkit is offered to provide a comprehensive and accessible parental support following the first few weeks after discharge. This will initially be offered at two local NICUs in northeast Pennsylvania.

- Each hospital will receive the “Premie toolkit” which includes:
  - A one hour in person professional educational course for NICU occupational therapy practitioners. This course includes:



- Current data and evidence-based literature
- System and family challenges following discharge
- Premies’ developmental progression and family wellbeing
- A parent speaker sharing the NICU discharge experience and the transition into the community

- A parental guidebook - a community specific resource tool for families. Includes information on:



- Early intervention services and therapy roles
- General milestones development
- Establishing routines
- Activities for parent self-care and sibling interactions
- Home modifications and safety
- Care Team contact list
- In person and online community support groups

---

## Projected Outcomes

Bridge the gap in care during the transition from hospital to community by:

- improving infant and family functional outcomes
- promoting knowledge and awareness of system and family challenges to NICU OTPs

---

## Occupational Therapy Role

Occupational therapy practitioners have the important and unique role of:

- Supporting the dynamic interaction of the family unit to improve functioning and well-being.
- Promoting the infant’s health by supporting parents beyond the medical setting (Cardin, 2020)

---

## References



## References

- American Academy of Pediatrics Committee on Fetus, and Newborn, (2008). Hospital Discharge of the High-Risk Neonate. *Pediatrics*, *122*(5), 1119–1126.  
10.1542/peds.2008-2174
- American Occupational Therapy Association. (2020). Occupational therapy practice framework: Domain and process (4th ed.). *American Journal of Occupational Therapy*, *74*(Suppl. 2), Article 7412410010.  
<https://doi.org/10.5014/ajot.2020.74S2001>
- Atkins, K. L., Dolata, J. K., Blasco, P. M., Saxton, S. N., & Duvall, S. W. (2019). Early Intervention Referral Outcomes for Children at Increased Risk of Experiencing Developmental Delays. *Maternal and Child Health Journal*, *24*(2), 204-212.  
10.1007/s10995-019-02830-4
- Ballantyne, M., Orava, T., Bernardo, S., McPherson, A. C., Church, P., & Fehlings, D. (2017). Parents' early healthcare transition experiences with preterm and acutely ill infants: a scoping review. *Child: Care, Health and Development*, *43*(6), 783-796. <https://doi.org/10.1111/cch.12458>
- Bucklin, B. A., Asdigian, N. L., Hawkins, J. L., & Klein, U. (2021). Making it stick: use of active learning strategies in continuing medical education. *BMC Medical Education*, *21*(1), 44. <https://doi.org/10.1186/s12909-020-02447-0>
- Cardin, A. D. (2020). Parents' Perspectives: An Expanded View of Occupational and Co-Occupational Performance in the Neonatal Intensive Care Unit. *American*

*Journal of Occupational Therapy*, 74(2), 7402205030p1–7402205030p12,

<https://doi.org/10.5014/ajot.2020.034827>

- Carty, C. L., Soghier, L. M., Kritikos, K. I., Tuchman, L. K., Jiggetts, M., Glass, P., Streisand, R., & Fratantoni, K. R. (2018). The Giving Parents Support Study: A randomized clinical trial of a parent navigator intervention to improve outcomes after neonatal intensive care unit discharge. *Contemporary Clinical Trials*, 70, 117–134. 10.1016/j.cct.2018.05.004
- Chan, T. M., Dzara, K., Dimeo, S. P., Bhalerao, A., & Maggio, L. A. (2019). Social media in knowledge translation and education for physicians and trainees: a scoping review. *Perspectives on Medical Education*, 9(1), 20–30.  
<https://doi.org/10.1007/s40037-019-00542-7>
- Chapman, E., Haby, M. M., Toma, T. S., De Bortoli, M. C., Illanes, E., Oliveros, M. J., & Barreto, J. O. M. (2020). Knowledge translation strategies for dissemination with a focus on healthcare recipients: an overview of systematic reviews. *Implementation Science: IS*, 15(1), 14. <https://doi.org/10.1186/s13012-020-0974-3>
- Contrada, E. (2018). 1.5 CE Test Hours: Original Research: Exploring Clinicians' Perceptions About Sustaining an Evidence-Based Fall Prevention Program. *The American Journal of Nursing*, 118(5), 34–46.  
10.1097/01.NAJ.0000532807.43595.37
- Cowie, J., Nicoll, A., Dimova, E. D., Campbell, P., & Duncan, E. A. (2020). The barriers and facilitators influencing the sustainability of hospital-based interventions: a

systematic review. *BMC Health Services Research*, 20(1), 588. 10.1186/s12913-020-05434-9

Decker, K. B., Williams, E. R., Cook, G. A., & Fry, M. M. (2020). The Early Intervention Referral Process for Rural Infants and Toddlers with Delays or Disabilities: A Family Perspective. *Maternal and Child Health Journal*, 25(5), 715-723. 10.1007/s10995-020-03067-2

Department of Health. (n.d.). *Hospital reports*. Retrieved from <https://www.health.pa.gov/topics/HealthStatistics/HealthFacilities/Hospitals/Reports/Pages/hospital-reports.aspx>

Department of Health Informatics (n.d.). *Pennsylvania County Health Profiles. Maps: Births*. Retrieved from <https://www.health.pa.gov/topics/HealthStatistics/VitalStatistics/CountyHealthProfiles/Documents/current/maps-births.aspx>

Feehan, K., Kehinde, F., Sachs, K., Mossabeb, R., Berhane, Z., Pachter, L. M., Brody, S., & Turchi, R. M. (2019). Development of a Multidisciplinary Medical Home Program for NICU Graduates. *Maternal and Child Health Journal*, 24(1), 11-21. 10.1007/s10995-019-02818-0

Fiverr. (n.d.). *Infographic Design*. Retrieved from <https://www.fiverr.com/categories/graphics-design/infographics-design>

Forsetlund, L., Forsetlund, L., O'Brien, M. A., Forsén, L., Mwai, L., Reinar, L. M., Okwen, M. P., Horsley, T., & Rose, C. J. (2021). Continuing education meetings and workshops: effects on professional practice and healthcare

outcomes. *Cochrane Database of Systematic Reviews*, 2021(9), CD003030.

10.1002/14651858.CD003030.pub3

Gabrielian, S., Finley, E. P., Ganz, D. A., Barnard, J. M., Jackson, N. J., Montgomery, A.

E., Nelson, R. E., & Cordasco, K. M. (2022). Comparing two implementation strategies for implementing and sustaining a case management practice serving homeless-experienced veterans: a protocol for a type 3 hybrid cluster-randomized trial. *Implementation Science: IS*, 17, 67.

<https://doi.org/10.1186/s13012-022-01236-1>

Giguère, A., Giguère, A., Zomahoun, H. T. V., Carmichael, P., Uwizeye, C. B., Légaré,

F., Grimshaw, J. M., Gagnon, M., Auguste, D. U., & Massougbdji, J. (2020). Printed educational materials: effects on professional practice and healthcare outcomes. *Cochrane Database of Systematic Reviews*, 2020(8), CD004398.

10.1002/14651858.CD004398.pub4

Gismalla, M. D.-A., Mohamed, M. S., Ibrahim, O. S. O., Elhassan, M. M. A., &

Mohamed, M. N. (2021). Medical students' perception towards E-learning during COVID 19 pandemic in a high burden developing country. *BMC Medical Education*, 21(1), 377. <https://doi.org/10.1186/s12909-021-02811-8>

Graham, I. D., Logan, J., Harrison, M. B., Straus, S. E., Tetroe, J., Caswell, W., &

Robinson, N. (2006). Lost in knowledge translation: Time for a map? *Journal of Continuing Education in the Health Professions*, 26(1), 13–24.

<https://doi.org/10.1002/chp.47>

- Griffith, T., Singh, A., Naber, M., Hummel, P., Bartholomew, C., Amin, S., White-Traut, R., & Garfield, L. (2022). Scoping review of interventions to support families with preterm infants post-NICU discharge. *Journal of Pediatric Nursing, 67*, e135–e149. 10.1016/j.pedn.2022.08.014
- Grunberg, V. A., Geller, P. A., & Patterson, C. A. (2020). Infant illness severity and family adjustment in the aftermath of NICU hospitalization. *Infant Mental Health Journal, 41*(3), 340-355. 10.1002/imhj.21848
- Hall, S. L., Ryan, D. J., Beatty, J., & Grubbs, L. (2015). Recommendations for peer-to-peer support for NICU parents. *Journal of Perinatology, 35* (Suppl 1), S9-S13. 10.1038/jp.2015.143
- Hailemariam, M., Bustos, T., Montgomery, B., Barajas, R., Evans, L. B., & Drahota, A. (2019). Evidence-based intervention sustainability strategies: a systematic review. *Implementation Science: IS, 14*(1), 57. <https://doi.org/10.1186/s13012-019-0910-6>
- Harmon, S. L., Conaway, M., Sinkin, R. A., & Blackman, J. A. (2013). Factors Associated With Neonatal Intensive Care Follow-up Appointment Compliance. *Clinical Pediatrics, 52*(5), 389–396. 10.1177/0009922813477237
- Havens, L., McCarty, J. (2013). Bottom Line: Who Pays the Bill for Early Intervention Services? *The ASHA Leader, 18*(2), 26–27. <http://pubs.asha.org/doi/10.1044/leader.BML.18022013.26>
- Heiny, E., Wolf, S., Collins, M., Durant Kellner, P., & Pineda, R. (2020). Factors related to enrolment in early therapy services following neonatal intensive care unit

discharge. *Acta Paediatrica*, 110(5), 1468–1474.

<https://doi.org/10.1111/apa.15700>

- Hintz, Susan R., Gould, Jeffrey B., Bennett, M. V., Gray, E. E., Kagawa, K. J., Schulman, J., Murphy, B., Villarín-Duenas, G., & Lee, Henry C. (2015). Referral of Very Low Birth Weight Infants to High-Risk Follow-Up at Neonatal Intensive Care Unit Discharge Varies Widely across California. *The Journal of Pediatrics*, 166(2), 289–295. 10.1016/j.jpeds.2014.10.038
- Jetelina, Katelyn K.; Rodriguez, Patricia; Oke, Oluwaseun K.; Mathew, M. Sunil; Schoppa, Susan; Booker-Nubie, Quiera; and Messiah, Sarah E. (2020). Factors Influencing the Implementation of Social Determinants of Health Screening and Referral Processes in Pediatric Settings Serving Medically Complex Patients. *The Journal of Applied Research on Children*, 11(1)  
<https://search.proquest.com/docview/2535379169>
- Johnson, S., & Marlow, N. (2017). Early and long-term outcome of infants born extremely preterm. *Archives of Disease in Childhood*, 102(1), 97.  
<http://dx.doi.org/10.1136/archdischild-2015-309581>
- Kilbride, H. W., M.D., Aylward, Glen P., Ph.D., A.B.P.P., & Carter, B., M.D. (2018). What Are We Measuring as Outcome? Looking Beyond Neurodevelopmental Impairment. *Clinics in Perinatology*, 45(3), 467–484. 10.1016/j.clp.2018.05.008
- King, A. C. (2012). Long-term home mechanical ventilation in the United States. *Respiratory Care*, 57(6), 921–930. <https://doi.org/10.4187/respcare.01741>

- Kuppala, V. S., Tabangin, M., Haberman, B., Steichen, J., & Yolton, K. (2012). Current state of high-risk infant follow-up care in the United States: results of a national survey of academic follow-up programs. *Journal of Perinatology*, *32*(4), 293–298. 10.1038/jp.2011.97
- Lagatta, J., Malnory, M., Fischer, E., Davis, M., Radke-Connell, P., Weber, C., & Cohen, S. (2022). Implementation of a pilot electronic parent support tool in and after neonatal intensive care unit discharge. *Journal of Perinatology*, *42*(8), 1110–1117. 10.1038/s41372-021-01303-3
- Lakshmanan, A., Sunshine, I., Escobar, C. M., Kipke, M., Vanderbilt, D., Friedlich, P. S., & Mirzaian, C. B. (2022). Connecting to Early Intervention Services After Neonatal Intensive Care Unit Discharge in a Medicaid Sample. *Academic Pediatrics*, *22*(2), 253–262. 10.1016/j.acap.2021.10.006
- Lakshmanan, A., Sunshine, I., Calvetti, S., Espinoza, J., Santoro, S., Butala, S., House, M., & Kipke, M. (2022). Designing a Mobile Health Solution to Facilitate the Transition from NICU to Home: A Qualitative Study. *Children (Basel)*, *9*(2), 260. <https://doi.org/10.3390/children9020260>
- Liaw, S. Y., Ooi, S. L., Mildon, R., Ang, E. N. K., Lau, T. C., & Chua, W. L. (2022). Translation of an evidence-based virtual reality simulation-based interprofessional education into health education curriculums: An implementation science method. *Nurse Education Today*, *110*, 105262. 10.1016/j.nedt.2021.105262

- Litt, J. S., Glymour, M. M., Hauser-Cram, P., Hehir, T., & McCormick, M. C. (2018). Early Intervention Services Improve School-age Functional Outcome Among Neonatal Intensive Care Unit Graduates. *Academic Pediatrics, 18*(4), 468–474. 10.1016/j.acap.2017.07.011
- Little Giraffe Foundation, (n.d.). *Grant Application*. Retrieved 5/27/2023 from <https://www.littlegiraffefoundation.org/grant-application>
- Lockwood, C., Stephenson, M., Lizarondo, L., van Den Hoek, J., & Harrison, M. (2016). Evidence implementation: Development of an online methodology from the knowledge-to-action model of knowledge translation. *International Journal of Nursing Practice, 22*(4), 322–329. <https://doi.org/10.1111/ijn.12469>
- Lulu (n.d.). *Pricing Calculator*. Retrieved 5/26/2023 from <https://www.lulu.com/pricing>
- Ma, R. H., Zhang, Q., Ni, Z. H., & Lv, H. T. (2021). Transitional care experiences of caregivers of preterm infants hospitalized in a neonatal intensive care unit: A qualitative descriptive study. *Nursing Open, 8*(6), 3484–3494. <https://doi.org/10.1002/nop2.899>
- Macdonald, C. J., Archibald, D., Stodel, E., Chambers, L. W., & Hall, P. (2008). Knowledge Translation of Interprofessional Collaborative Patient-Centered Practice: The Working Together Project Experience. *McGill Journal of Education/Revue des sciences de l'éducation de McGill, 43*(3), 283–307 <https://doi.org/10.7202/029700ar>
- March of Dimes. (n.d.). *State Summary for Pennsylvania*. Retrieved from <https://www.marchofdimes.org/peristats/state->

summaries/pennsylvania?lev=1&obj=3&reg=99&slev=4&sreg=42&stop=55&top=3

March of Dimes. (n.d.). *Grants and Awards*. Retrieved from

<https://www.marchofdimes.org/our-work/research/grants-awards>

March of Dimes Innovation Fund (n.d.). *Innovation Fund News*. Retrieved from

<https://marchofdimes.org/ways-to-give/innovation-fund-news>

Maynard, R., Christensen, E., Cady, R., Jacob, A., Ouellette, Y., Podgorski, H., Schiltz,

B., Schwantes, S., & Wheeler, W. (2019). Home Health Care Availability and

Discharge Delays in Children With Medical Complexity. *Pediatrics*, *143*(1),

e20181951. <https://doi.org/10.1542/peds.2018-1951>

Mota da Silva, T., da Cunha Menezes Costa, L., Garcia, A. N., & Costa, L. O. P. (2014).

What do physical therapists think about evidence-based practice? A systematic

review. *Manual Therapy*, *20*(3), 388–401. 10.1016/j.math.2014.10.009

Msall, M. E. (2019). Promoting Parenting Supports and Engagement for Infants Born

Preterm. *The Journal of Pediatrics*, *210*, 10–12. 10.1016/j.jpeds.2019.03.036

Nwabara O, Rogers C, Inder T, Pineda R. (2017). Early therapy services following

neonatal intensive care unit discharge. *Physical & Occupational Therapy in*

*Pediatrics*, *37*(4):414–424. doi: 10.1080/01942638.2016.1247937.

O'Brien Pott, M., Blanshan, A. S., Huneke, K. M., Baasch Thomas, B. L., & Cook, D. A.

(2021). Barriers to identifying and obtaining CME: a national survey of

physicians, nurse practitioners and physician assistants. *BMC Medical*

*Education*, *21*(1), 168. <https://doi.org/10.1186/s12909-021-02595-x>

- O'Shea, T. M. (2021). Families' perspectives on monitoring infants' health and development after discharge from NICUs. *Pediatric Research*, 89(4), 722–724.  
10.1038/s41390-020-01243-2
- Obregon, E., Martin, C. R., Frantz III, I., D., Patel, P., & Smith, V. C. (2019). Neonatal Intensive Care Unit discharge preparedness among families with limited English proficiency. *Journal of Perinatology*, 39(1), 135–142.  
<https://doi.org/10.1038/s41372-018-0255-z>
- Office Depot. (n.d.). *Posters*. Retrieved by  
<https://www.officedepot.com/vendor/vendorRouter.do?id=818654&configurableItemType=CPD#size>
- Okumura, M. J., Knauer, H. A., Calvin, K. E., & Takayama, J. I. (2018). Caring for Children with Special Health Care Needs: Profiling Pediatricians and Their Health Care Resources. *Maternal and Child Health Journal*, 22(7), 1042–1050.  
10.1007/s10995-018-2484-3
- Pennsylvania Department of Health (n.d.) *Hospital Reports*. Retrieved from  
<https://www.health.pa.gov/topics/HealthStatistics/HealthFacilities/HospitalReports/Pages/hospital-reports.aspx>
- Pennsylvania Occupational Therapy Association. (n.d.). *POTA 2023 Annual Conference: Pittsburgh PA*. Retrieved by <https://pota.site-ym.com/events/EventDetails.aspx?id=1708556>

- Petzold, A., Korner-Bitensky, N., & Menon, A. (2010). Using the knowledge to action process model to incite clinical change. *The Journal of Continuing Education in the Health Professions*, 30(3), 167–171. 10.1002/chp.20077
- Pineda, R., Heiny, E., Nellis, P., Smith, J., McGrath, J. M., Collins, M., & Barker, A. (2020). The Baby Bridge program: A sustainable program that can improve therapy service delivery for preterm infants following NICU discharge. *PLoS ONE*, 15(5), 1–12. 10.1371/journal.pone.0233411
- Price, D. W., Miller, E. K., Rahm, A. K., Brace, N. E., & Larson, R. S. (2010). Assessment of barriers to changing practice as CME outcomes. *The Journal of Continuing Education in the Health Professions*, 30(4), 237–245. 10.1002/chp.20088
- Rak, K. J., Kahn, J. M., Linstrum, K., Caplan, E. A., Argote, L., Barnes, B., Chang, C. H., George, E. L., Hess, D. R., Russell, J. L., Seaman, J. B., Angus, D. C., & Girard, T. D. (2021). Enhancing Implementation of Complex Critical Care Interventions through Interprofessional Education. *ATS Scholar*, 2(3), 370–385. 10.34197/ats-scholar.2020-0169OC
- Reis, T., Faria, I., Serra, H., & Xavier, M. (2022). Barriers and facilitators to implementing a continuing medical education intervention in a primary health care setting. *BMC Health Services Research*, 22(1), 638. <https://doi.org/10.1186/s12913-022-08019-w>
- Rubinos, L. H., Foster, C. C., Machut, K. Z., Snyder, A., Simpser, E., Hall, M., Casto, E., & Berry, J. G. (2021). Risk factors for hospital readmission among infants with

prolonged neonatal intensive care stays. *Journal of Perinatology*, 42(5), 624–630. <https://doi.org/10.1038/s41372-021-01276-3>

Schreiber, J., Perry, S., Downey, P., & Williamson, A. (2015). Knowledge Translation Outcomes Following Innovative Continuing Education. *Journal of Physical Therapy Education*, 29(4), 42–51. 10.1097/00001416-201529040-00007

Singh M, Parvez B, Banquet A, Kase JS. (2019). Habilitation of very preterm infants at a post-acute care inpatient rehabilitation (PACIR) center after neonatal intensive care unit (NICU) discharge. *Developmental Neurorehabilitation*, 22(1), 53–60. doi: 10.1080/17518423.2018.1437841.

Slaughter, S. E., Bampton, E., Erin, D. F., Ickert, C., Wagg, A. S., Allyson Jones, C., Schalm, C., & Estabrooks, C. A. (2018). Knowledge translation interventions to sustain direct care provider behaviour change in long-term care: A process evaluation. *Journal of Evaluation in Clinical Practice*, 24(1), 159-165. 10.1111/jep.12784

Tanner, K., Schmidt, E., Martin, K., & Bassi, M. (2020). Interventions Within the Scope of Occupational Therapy Practice to Improve Motor Performance for Children Ages 0–5 Years: A Systematic Review. *American Journal of Occupational Therapy*, 74(2), 7402180060p1–7402180060p40. <https://doi.org/10.5014/ajot.2020.039644>

U.S. Department of Education. (n.d.). *Post-referral timeline*. Retrieved from <https://sites.ed.gov/idea/regs/c/d/303.310>

- Upwork. (n.d.). *How much does it cost to build a mobile app?* Retrieved on 5/27/2023 from <https://www.upwork.com/resources/cost-build-mobile-app>
- Upwork. (n.d.). *Hire the best medical translator.* Retrieved from [https://www.upwork.com/hire/medical-translators/?utm\\_campaign=SEM\\_GGL\\_US\\_NonBrand\\_Marketplace\\_DSA&utm\\_medium=cpc&utm\\_content=1260041254028240&utm\\_term=%2Fhire%2F&campaignid=291242713&matchtype=b&device=c&partnerId&utm\\_source=bing&msclkid=97b8bc7c4e661b9d04f2d8eb2011c117](https://www.upwork.com/hire/medical-translators/?utm_campaign=SEM_GGL_US_NonBrand_Marketplace_DSA&utm_medium=cpc&utm_content=1260041254028240&utm_term=%2Fhire%2F&campaignid=291242713&matchtype=b&device=c&partnerId&utm_source=bing&msclkid=97b8bc7c4e661b9d04f2d8eb2011c117)
- Vasli, P., Dehghan-Nayeri, N., & Khosravi, L. (2018). Factors affecting knowledge transfer from continuing professional education to clinical practice: Development and psychometric properties of a new instrument. *Nurse Education in Practice*, 28, 189–195. 10.1016/j.nepr.2017.10.032
- Vivanti, A., Ferguson, M., Porter, J., O’Sullivan, T., & Hulcombe, J. (2015). Increased familiarity, knowledge and confidence with Nutrition Care Process Terminology following implementation across a statewide health-care system. *Nutrition & Dietetics*, 72(3), 222–231. 10.1111/1747-0080.12199
- Walani, S. R. (2020). Global burden of preterm birth. *International Journal of Gynecology and Obstetrics*, 150(1), 31–33. 10.1002/ijgo.13195
- Waltz, L. A., Munoz, L., Miller, R. A., & Weber Johnson, H. (2022). Measuring the Impact of an Educational Intervention on Evidence-Based Practice. *The Journal of Continuing Education in Nursing*, 53(3), 109–114. 10.3928/00220124-20220210-05

- Wang, Yali,OTD, OTR, King, Kaitlann,OTD, OTR, Moran, Brady,OTD, OTR, Talian, Elizabeth,OTD, OTR, Lampe, Angela,OTD, OTR/L, Mu, Keli,PhD, OTR/L, & Qi, Y., MS. (2019). Occupational and Physical Therapists' Perception of Evidence-Based Practice. *Journal of Allied Health, 48*(2), 119–126C.
- Washington, D., & Coker-Bolt, P. (2022). How to Address Challenges With Early Intervention for Infants of Underrepresented Families: Helping the Babies at the Medical University of South Carolina's High-Risk Clinic. *American Journal of Occupational Therapy, 77*(Suppl. 1), 7710393050.  
<https://doi.org/10.5014/ajot.2023.77s10005>
- Weiss, M. E., Piacentine, L. B., Candela, L., & Bobay, K. L. (2021). Effectiveness of using a simulation combined with online learning approach to develop discharge teaching skills. *Nurse Education in Practice, 52*, 103024.  
10.1016/j.nepr.2021.103024
- Woda, A., Hansen, J., Thomas Dreifuerst, K., Johnson, B. K., Loomis, A., Nolan, C., & Bradley, C. S. (2022). Debriefing for Meaningful Learning: Implementing a Train-the-Trainer Program for Debriefers. *The Journal of Continuing Education in Nursing, 53*(7), 321–327. <https://doi.org/10.3928/00220124-20220603-08>

**CURRICULUM VITAE**

