

UNIVERSITY *of*
INDIANAPOLIS®

School of Occupational Therapy

The Development of a NICU Follow-Up Clinic

Kelsey Robertson

May, 2018



A capstone project submitted in partial fulfillment for the requirements of the Doctor of Occupational Therapy degree from the University of Indianapolis, School of Occupational Therapy.

Under the direction of the faculty capstone advisor:

Alison Nichols, OTR, OTD

A Capstone Project Entitled

The Development of a NICU Follow-Up Clinic

Submitted to the School of Occupational Therapy at University of Indianapolis in partial fulfillment for the requirements of the Doctor of Occupational Therapy degree.

By

Kelsey Robertson

Occupational Therapy Student

Approved by:

Faculty Capstone Advisor

Date

Doctoral Capstone Coordinator

Date

Accepted on this date by the Chair of the School of Occupational Therapy:

Chair, School of Occupational Therapy

Date

Abstract

Infants who are discharged from the neonatal intensive care unit (NICU) at Indiana University Health North Hospital are not typically followed by the hospital to ensure they are developing appropriately with their peers. A follow-up clinic would regularly follow these discharged infants to ensure they do not fall behind developmentally and to provide resources and support services for families. A needs analysis was conducted with hospital staff to identify the need for a follow-up clinic and the individual concerns of various disciplines. Data were collected from thirty existing follow-up clinics around the country through site visits, email contact, and individual websites. The information was analyzed and contributed to the program development plan, then presented to the hospital staff to gain support for the follow-up clinic to open. The program development plan was created to meet the needs of the infants and their families after discharge from the NICU through the provision of quality services. The components of the program development plan were realistic, specific to the facility and considered all of the factors that would facilitate success and sustainability. At the end of this project, the recommendation is to schedule the follow-up clinic as soon as the resources are received.

The Development of a NICU Follow-up Clinic

The NICU at Indiana University Health North Hospital (IU Health North) provides interdisciplinary services to infants and their families who require specialized care after birth. One long-term goal of this team was to create a follow-up clinic for infants and their families after they are discharged to make sure that no infant falls through the gaps of the healthcare system. When the infants from the NICU are discharged, they typically are not seen again or followed by the hospital to ensure they are receiving the services they need to thrive. The purpose of this Doctoral Capstone Experience (DCE) is to research and identify the need for a follow-up clinic at IU Health North and to create a program development plan to initiate the creation of a clinic.

Literature Review

Ecology of Human Performance

The theory guiding this DCE is the Ecology of Human Performance (EHP). The focus of EHP is the transaction that occurs between the person, the task, and their context to develop the performance range (Cole & Tufano, 2008). The person is unique and they have the skills that will develop their occupational performance within their environment (Cole & Tufano, 2008). The tasks are the behaviors and activities that will be completed in order to reach the person's goals and develop their occupational performance (Cole & Tufano, 2008). The context in this theory has both environmental and temporal aspects that make up the person's surroundings that can also impact performance (Cole & Tufano, 2008). When these three variables interact together and begin to affect one another interdependently, occupational performance occurs (Cole & Tufano, 2008).

The infants discharged from the NICU are a unique population who develop skills as they grow, and their experiences make them different from typical infants. They have developmental milestones and behaviors that they are completing for their occupational performance. The infants can have both a temporal and environmental context throughout their development. Examples of the temporal context could be their stage of development, their age both chronologically and gestational, and their level of disability. Their environmental context could be where they are living and performing their occupations, how they are socially engaged in their daily lives, or how their family raises them culturally.

The NICU follow-up clinic will focus on preventative care and will provide rehabilitative evaluations that will identify gaps in the occupational performance of infants strongly connecting from the focus of EHP (Cole & Tufano, 2008). The clinic will look at the infant's task performance at various stages of their life to evaluate if occupational performance is age-appropriate or if additional services are needed. The clinic can evaluate the infant's context they are being raised in to determine if that is impacting their development as well. Through the process of following up, an interdisciplinary staff can take a preventative approach to analyze the skills, environmental factors, and tasks that are delaying the developmental growth of infants who were discharged from the NICU and refer them to the services they need so they can have optimal occupational performance.

The Development of NICU Infants

Infants can be born at risk for further complications and the risks can be both biologic in nature and/or environmental (Cronin & Mandich, 2016). Biologic risks can be something genetic within the infant or contributed to by factors with the mother, such as maternal age, smoking or drug use, HIV exposure, Intrauterine Growth Restriction (IUGR), and prematurity (Cronin &

Mandich, 2016). The environmental risks that can impact the development of the infant could be their nutrition, socioeconomic level, and the level of care they receive from their caregiver (Cronin & Mandich, 2016). The NICU provides specialized care for these high-risk infants after birth (Case-Smith & O'Brien, 2015).

Many studies have looked into the developmental and behavioral patterns that occur in common diagnoses seen in the NICU. Infants who are considered preterm or very low birth weight (<1000 g) are at a higher risk for motor, cognitive and behavioral problems (American Academy of Pediatrics, 2004). Preterm infants are born prior to 37 weeks gestational age, and they are at a greater risk for immediate and distant delays and complications with their development (Cronin & Mandich, 2016). Many of these complications are due to their physiologic immaturity and can impact many of the infants' body systems. Examples of complications could include respiratory distress syndrome, bronchopulmonary dysplasia, gastroesophageal reflux, change in muscle tone and reflexes, encephalopathy, periventricular leukomalacia, retinopathy and intraventricular hemorrhage (Cronin & Mandich, 2016). As the infant's gestational age decreases, their risk for developmental delay increases (American Academy of Pediatrics, 2004). Risk factors for neurodevelopmental deficits were identified as severe preterm delivery, lung disease, those with severe growth restrictions, meningitis, sepsis, hydrocephalus, multiple births, males, complications and abnormalities, and the environmental stress from the NICU stay itself (American Academy of Pediatrics, 2004). Infants who had a stay in the NICU may have difficulty with feedings and require alternative feeding strategies that are challenging to manage at home. They may require early intervention services to follow them to improve their skills (Cronin & Mandich, 2016). Infants born in both extremely (<1000 g) and

very low (<1500) birth weight categories later demonstrated deficits with executive function, visual motor integration and fine motor delays (American Academy of Pediatrics, 2004).

Preterm infants are commonly treated in the NICU where the lighting, noise, and somatosensory conditions are unlike what they would be in the womb, causing an abnormal sensory experience (Cronin & Mandich, 2016). In the womb, their environment would be dark and they would be flexed in their aquatic surroundings (Cronin & Mandich, 2016). The NICU typically will have high lighting, increased noise, and physical contact is often a negative medical procedure or experience for the infant. These conditions can have negative effects on their physiology and behavior (Cronin & Mandich, 2016). When looking at children aged four years and six months who were born very preterm (<32 weeks gestational age), Crozier et al. (2016) found that almost half of the 160 children in the sample were atypical for sensory processing. They also found significantly lower birth weight, lower APGAR (appearance, pulse, grimace, activity, and respiration) scores, more days of ventilation, and a longer stay in the NICU correlated with atypical sensory processing in the very preterm population (Crozier et al., 2016). The authors determined that over 40% of those children that were atypical had sensory seeking behavior and over one-third demonstrated sensory sensitivity. As these children begin to enter school, they may have increased difficulties with social adaptive behaviors and academic participation due to their sensory processing differences (Crozier et al., 2016). This high prevalence of atypical sensory processing and the impact it had on these children at a later age may indicate a need for early referral to be evaluated for therapy (Crozier et al., 2016). In addition to sensory processing difficulties, a different study determined that of the 85 infants who were preterm, 31% had mild delays in the area of expressive language and 47% in their gross motor skills in their first year of life (Greene, Patra, Nelson, & Silvestri, 2012).

Another population commonly seen in the NICU are those with Neonatal Abstinence Syndrome (NAS); these infants commonly demonstrated poor sleeping, feeding, increased tone and tremors and a high-pitched cry (Logan, Brown, & Hayes, 2013). These symptoms began to appear around 24 to 72 hours after birth and sometimes required pharmacological intervention to wean the infant in order to be fully withdrawn from the addictive substance (Logan et al., 2013). Infants who were exposed to methadone had motor deficits, poor social participation and attention span; these difficulties continued into toddler years (Logan et al., 2013). Illicit drugs and licit drugs affected motor and cognitive performance long-term in infants (Logan et al., 2013). Those exposed to alcohol had poor coordination, delayed gross and fine motor skills and poor cognition (Logan et al., 2013).

Early Intervention

As some children begin to miss their developmental milestones and families notice their lack of age-appropriate behaviors, developmental screens may occur to identify areas of delay (Cronin & Mandich, 2016). If the developmental screen identifies an area of delay, the children are referred to specialists to assist the child in catching up to their peers. Those specialists involved in early intervention could include occupational therapy, physical therapy, speech therapy, neurology, developmental pediatrics, and geneticists (Cronin & Mandich, 2016). Because children have great neuroplasticity in their brain, the earlier they can receive interventions, the better the outcomes (Cronin & Mandich, 2016). When the infant has positive early experiences, their brain is strengthened and they have better development of their physical, cognitive and social health (Case-Smith & O'Brien, 2015). Neuroplasticity is greatest in the first three years of life and supports the need for early intervention to improve the child's development and health early (Case-Smith & O'Brien, 2015).

Nwabara, Rogers, Inder, and Pineda (2016) studied early therapy services in preterm infants and the accessibility of those services. Thirteen out of the 57 participants did not receive therapy after they were discharged from the NICU despite that 85% of these infants had received a referral at discharge (Nwabara et al., 2016). Over half of those that did not receive therapy demonstrated developmental delay at two years when assessed (Nwabara et al., 2016). The infants that participated in therapy services within the first two years of life were more likely to have been ventilated longer, had a single mother, or had abnormal behavior when leaving the NICU (Nwabara et al., 2016). There was found to be a delay in time between discharge and early intervention beginning. Physical therapy was started at a mean age of 4.3 months with occupational therapy following at 5.1 months of age (Nwabara et al., 2016). Speech therapy was typically initiated much later at the mean age of 14.0 months. This was believed to occur due to the more apparent nature of gross motor delays seen by parents (Nwabara et al., 2016). A major concern identified with provision of early intervention to this population was the gap that occurs after discharge during an important period of development (Nwabara et al., 2016).

The NICU follow-up clinic at Rush University Medical Center completed a retrospective study to better understand the early intervention referral and use with infants that were preterm (Greene & Patra, 2016). The amount of preterm infants that were enrolled in early intervention services increased from 56% at four months corrected age to 66% at twenty months (Greene & Patra, 2016). The need for early intervention referral was twice as likely for babies who were less than 1000 grams at birth than those above 1000 grams (Greene & Patra, 2016). Preterm infants were more likely to receive early intervention by the age of two if they had abnormal head ultrasounds, were older at NICU discharge or had a language index score on the Bayley Scales of

Infant and Toddler Development-III (Bayley-III) that was identified as delayed at one year of life (Greene & Patra, 2016).

Current Follow-up Programs

NICU follow-up programs can provide infants with specialized and coordinated care that can identify delays in development, growth, and behavior (Bockli, Andrews, Pellerite, & Meadow, 2014). Services that have been identified as beneficial are nutrition services, occupational therapy, physical therapy, speech therapy, feeding assessment, social worker assistance, education on managing medical devices and behavioral assessments (Kuppala, Tabangin, Haberman, Steichen, & Yolton, 2012). Of 143 NICU programs that responded to a survey, 93% of the NICUs stated that they had a follow-up clinic and 37% completed research in addition to their clinical care (Kuppala et al., 2012). A neonatologist was most likely to be the primary care provider of the clinics, and other common staff included a developmental pediatrician, physical and occupational therapists, and a developmental psychologist (Bockli et al., 2014). Roles of the follow-up clinic staff were addressed by Lipner & Huron (2018), which included physical therapists, occupational therapists, developmental pediatricians, audiologists, speech therapists, and a social worker. Physical and occupational therapy services were recommended to assess the infant between one and two months of age for surveillance of motor skills, visual-motor skills, and functional performance (Lipner & Huron, 2018). The developmental pediatrician identified referrals that were necessary based on comorbidities seen, developmental performance, and their social behavior (Lipner & Huron, 2018). The speech therapist provided education and services to the infants who had swallowing or oral feeding issues (Lipner & Huron, 2018). Financial and informative resources were provided through consultation with the social worker to improve the support provided (Lipner & Huron, 2018).

The majority of the funding that supported the clinics were from the NICU department itself and the hospital with some assistance from the state (Bockli et al., 2014). Kuppala et al. (2012) found the majority of the respondents identified multiple funding sources for the programs that included department, hospital, state, and research funds, but the most common sources was patient insurance. Funding was identified as a primary struggle faced by follow-up clinics (Bockli et al., 2014). In a survey of high-risk infant follow-up programs, lack of qualified personnel and financial resources were identified as additional barriers to follow-up clinics (Kuppala et al., 2012). Another common struggle identified was the high no-show rate and the need to improve the coordination of care after discharge (Bockli et al., 2014). Harmon, Conaway, Sinkin, and Blackman (2013) sought to determine what factors could cause poor follow-up compliance, as they found 42 of their 133 participants (31.6%) were noncompliant. Appointment noncompliance was more likely caused by the cost of travel and the distance from the hospital for the families; however, individual factors that were common included maternal drug use and multiple gestation pregnancies (Harmon et al., 2013). Similar information was found in follow-up programs in Canada where they identified younger mothers, single parents, greater distance to the clinic, and concern about alcohol and drug use as having poor attendance (Ballantyne, Stevens, Guttman, Willan, & Rosenbaum, 2012). Of the 42 families that were noncompliant, 43.4% identified that “appointments during times when parents were busy/working” was a minor reason for noncompliance (Harmon et al., 2013, p.392). To improve compliance, researchers suggest that providing an appointment for follow-up is provided at the time of discharge in addition to physician education and that they have set standards for who receives the referral (Harmon et al., 2013). Another suggestion for improved compliance

included strong relationships with pediatricians who can encourage follow-up rather than waiting for parents to notice missed developmental milestones (Lipner & Huron, 2018).

Criteria used for determining who attends follow-up clinics included the infant's birth weight, gestational age, diagnosis when in the NICU, and a referral from a provider (Kuppala et al., 2012). The majority of the participating clinics had clinic appointments 2-5 times a month and the first clinic visit occurred between 3-4 months of age up to approximately 36 months of age (Kuppala et al., 2012). The American Academy of Pediatrics (2004) identified that follow-up clinics should have the minimum referral qualifications of extremely low birth weight, less than 28 weeks' gestation, and those born with hypoxic ischemic encephalopathy or hyperbilirubinemia that requires a transfusion. They generally stated that any child that had a stay in the NICU should participate in a follow-up clinic for the preventative assessment that is performed (American Academy of Pediatrics, 2004). It was found that most follow-up occurs under the age of two but can go up to the age of five with referrals made at the time of discharge (American Academy of Pediatrics, 2004). Additional guidelines for those who can attend clinic are typically set by their gestational age and birth weight, and it is suggested that those who are high-risk could be those who were premature, had single mothers, were admitted to NICU, and/or had a birth defect (Bockli, Andrews, Pellerite, & Meadow, 2014). A study completed by Lipner & Huron (2018) identified that preterm infants who were born under 34 weeks or had a genetic or pre-existing medical condition when they were discharged should be referred to follow-up clinic.

Benefits of a follow-up clinic include a reduction of re-admission rates after discharge through preventative care and solving medical issues (Bockli et al., 2014). Through the reduction of inpatient visits, some of the financial cost that occurs within the hospital could be decreased

(Bockli et al., 2014). The hospital may not profit from these clinics, but infants that are high risk often have a high cost related to their healthcare that may be lowered with the preventative services provided (Kuppala et al., 2012).

Summary

The current processes at IU Health North in the NICU involve a discharge where the infants are rarely followed by an interdisciplinary team unless they are directly referred to early intervention. The literature has identified common diagnoses and conditions that are seen in the NICU and the developmental delays that may follow their stay within their first few years of life (American Academy of Pediatrics, 2004; Cronin & Mandich, 2016; Crozier et al., 2016; Logan et al., 2013). Early intervention services can be provided to children in their first few years of life to decrease the gap in these developmental delays and grow age appropriate behaviors. For many of the infants seen at IU Health North, they do not always qualify for early intervention services. This leads to poor occupational performance and an environment that does not enhance their skill development in order to perform their daily tasks appropriately. Using a developmental follow-up clinic, the infants and their families can be followed in the first few years of life by a team of specialists who can identify any services they may need before they reach school-age. NICU follow-up clinics that are currently documented can provide a framework and evidence-based support for the development of a clinic at IU Health North.

Screening and Evaluation

The screening and evaluation process that was performed to develop the plan for this project involved the input of those who work with the NICU population and the evidence that supports the development of a NICU follow-up clinic. The evaluation process included a needs assessment through an interview with varying staff members of the NICU and a review of the

literature to develop a questionnaire for other follow-up clinics. This questionnaire was created to collect data on the currently existing NICUs, both in the state of Indiana as well as out-of-state. Using the outline of a business plan developed by Jacobs & McCormack (2011), all of the factors were identified that would need to be addressed in the implementation phase when creating the proposal for the clinic. The literature identified the Bayley-III as a developmental evaluation tool for use in the NICU follow-up clinic, which will be further discussed in this section (Kuppala et al., 2012).

Needs Assessment

A needs assessment was completed to identify the factors that needed to be addressed in this program proposal. Scaffa & Reitz (2014) noted that the purpose of the needs assessment was to recognize the priorities of the program and services that would benefit the people being served. These authors stated the needs assessment can locate the factors that are a part of the overarching issue and use the priorities identified to make the interventions address the population's needs (Scaffa & Reitz, 2014). The population addressed in this project included infants in the NICU who may not have age-appropriate occupational performance. This project used two forms of the data collection that are typically used in a needs assessment: the written questionnaire and a face-to-face interview (Scaffa & Reitz, 2014). Multiple disciplines were interviewed to determine the information that would need to be obtained in order to develop a follow-up clinic at IU Health North. The program developer met with members of the NICU interdisciplinary team to determine the questions that would need to be answered in order for this clinic to be started. Interviewed individuals included the occupational therapist, physical therapist, neonatologist, social worker, two nurse practitioners and the NICU manager. The

evidence found in the literature was also requested by staff members to provide support for the development of the follow-up clinic.

There was significant overlap in the discussions that occurred during the meetings with staff members. This brought about areas of concern that would play a significant role in the adoption of a follow-up program, along with less significant areas of concern that would increase the quality of the program development plan. Important areas of concern included the location of the clinic, funding and reimbursement, staffing, consumers, and services that would be provided. These concerns were used to help develop the questionnaire given to facilities with pre-existing clinics. The questions that were included in the questionnaire were transferred to Microsoft Excel so the data could be collected and organized. The list of questions can be found in Appendix A.

After obtaining the data from various clinics using the questionnaire, they were combined with the information from interviews to develop the program proposal. Ten areas that need to be addressed in the program were identified, which correlated with the areas identified in the initial needs assessment. These areas include the background and trends of the service sector, services, market analysis, marketing, management and ownership, staffing, finances, facilities, program evaluation and risks (Jacobs & McCormack, 2011). These are all factors that needed to be researched and identified in the implementation phase in order to create the proposal. This outline for a business plan guided the proposal and ensured that all necessary information was provided in order to decide whether or not to move forward with this program (Jacobs & McCormack, 2011).

Comparison with Other Areas of Practice in Occupational Therapy

The needs assessment process used in this project was consistent with developing a program in the field of occupational therapy. However, the purpose is different than the typical

existing areas of occupational therapy. The majority of the existing areas of practice will use the needs assessment to find diagnostic information about the individual who is being treated, whereas this needs assessment looked at how the services provided by the new plan would affect a group of people (Scaffa & Reitz, 2014). The written questionnaire was used within a community to collect data (Scaffa & Reitz, 2014). This strategy was used in this project in order to obtain information from clinics both in-state and out-of-state. This would not be typical of an occupational therapist who is working with an individual. If an occupational therapist is looking specifically at the occupational performance of an individual, they may choose to perform a more standardized assessment tool in order to measure outcomes. The needs assessment is still collecting valuable and measureable information; however, its goal is to improve the occupational performance of the population of NICU infants. This evaluation process is most consistent with that of a community or program development setting in the field of occupational therapy (Scaffa & Reitz, 2014).

In a typical setting of occupational therapy, there would most likely be a face-to-face interview with the individual to identify his or her needs. This project also incorporated a face-to-face interview in the needs assessment with various individuals who work with the population that is of interest and to voice their discipline's needs in this program. Similar to traditional occupational therapy practice of working with an individual, by performing the needs assessment in this project, the population will receive client-centered and interdisciplinary care through the development of this program. The Bayley-III is the assessment tool that was recommended for use in the follow-up clinic, and it is more comparable to a traditional evaluation in a pediatric setting.

Bayley Scales of Infant and Toddler Development III (Bayley-III)

Developmental assessments can identify an infant's abilities and needs across all areas of development in order to recommend the appropriate services and interventions that the child needs (Cronin & Mandich, 2016). The NICU follow-up clinic at IU Health North needed a developmental assessment tool to identify any developmental concerns and the need for further services. The Bayley Scales have been used consistently to refer children to early intervention services and to identify improvement and performance for infants who are labeled high-risk; however, there is limited research on the third version (Greene et al., 2012). The Bayley-III is a developmental assessment tool that assesses the function of children between the ages of one and 42 months (Bayley, 2006). If the children are identified to have developmental delay using the assessment tool, it can provide assistance with intervention planning to improve function for the children (Bayley, 2006). The five subscales that are assessed include: cognitive, language, motor, social-emotional and adaptive (Bayley, 2006). The language scale can be divided into receptive and expressive subtests while the motor scale can be divided into fine and gross motor subtests (Bayley, 2006). The caregiver of the child completes a questionnaire for the social-emotional and adaptive scales whereas the other sections are completed on the record form by the individual administering the assessment (Bayley, 2006).

Test scores of the Bayley-III are norm-referenced and they include scaled scores, composite scores, percentile ranks, and growth scores. Additionally, they can provide confidence intervals and developmental age equivalents for the various subtests (Bayley, 2006). All of the scores that are collected can be used to compare the child at their adjusted age with their peers and can be performed as a diagnostic test by an interdisciplinary team (Bayley, 2006). It is recommended that the members of the interdisciplinary team that administer the test be

experienced and trained or have completed some formal graduate or professional training (Bayley, 2006). The Bayley-III Administration Manual provides the instructions to score and administer the assessment tool and the standard procedures of the test to ensure standardization (Bayley, 2006). The test can be administered in approximately 50 minutes for infants under the age of 12 months and approximately 90 minutes if they are older (Bayley, 2006). The Technical Manual of the Bayley-III includes information on the history, revisions of the scales, research procedures, evidence of reliability and validity, and interpretive considerations that can be used to support the use of this developmental assessment tools with various populations of children (Bayley, 2006).

The previous version of the Bayley only divided the scores into psychomotor and mental sections, compared to the five subscales that are in the new version (Greene et al., 2012). The use of the specific subscales was suggested to be more effective to refer to various disciplines for services (Green et al., 2012). Bos (2013) provided commentary on the comparison of the second and third versions and suggested that the second version may underestimate development and the third version may overestimate development. These differences could impact the severity of disability found and the referrals that could follow (Bos, 2013). Pearson Education, Inc. (2008) attributed the differences of the scores to the normative representative populations at the time the assessments were created. Parent education levels, ethnic and racial backgrounds, cultural, and socioeconomic characteristics changed from 1988 to 2000 and could have changed the normative scores from one test to another (Pearson Education, Inc., 2008). Another change was that 9.8% of the normative sample in the third version were clinical cases, which would have provided the population a full range of abilities whereas the second version had no clinical cases and the norms were higher (Pearson Education, Inc., 2008). The Bayley-III demonstrated good

sensitivity, specificity and discrimination to recognize the clinical cases, and the scores correlate with the expected performance of a certain diagnosis (Pearson Education, Inc., 2008).

The Bayley-III was a common assessment tool used in follow-up clinics and ninety-nine percent of the follow-up clinics make early intervention referrals if they determine a need in their visit (Kuppala et al., 2012). The Bayley-III was used at Rush University Medical Center NICU Follow-Up Clinic as their primary neurodevelopmental testing to determine qualification for early intervention services (Greene & Patra, 2016). If the child had above a thirty-percent delay in any of the index scores, he or she qualified for services in Illinois (Greene & Patra, 2016).

Identifying the Program Needs

The evaluation process conducted for this project is comparable to that of the emerging practice areas of program development or community practice. The needs assessment of IU Health North was completed with the interdisciplinary team members that best know the NICU population. Following the face-to-face interviews conducted on-site and in addition to the literature review, the questionnaire for existing follow-up clinics was developed in preparation for the implementation phase of this project. The steps involved in a business plan were also included in the questionnaire to ensure that all information was provided to the decision makers and to provide a format for the proposal itself.

Implementation Phase

The implementation phase of this project was completed at IU Health North and three off-site visits were conducted to collect data. During the first portion of the implementation phase, data were collected from various follow-up clinics nationally and locally through the use of a questionnaire, one-on-one interviews, onsite visits, and information from hospital websites. The data collected were combined and analyzed to provide a summary of the important factors

involved in the follow-up clinics that were researched. This comprehensive analysis was used to develop the recommendations and program development plan for the creation of a follow-up clinic at IU Health North.

Data Collection and Organization

The implementation phase of this project consisted of two parts. The first part included the data collection and organization of information on follow-up clinics. Thirty follow-up clinics that existed were found through an internet search. The clinics found were located throughout the country and had a website that provided varying amounts of basic information on their follow-up clinic. Contacts were found either on websites or through peers that had relationships with individuals who were involved with follow-up clinics at their site. A draft email was developed to send to the varying follow-up clinics to obtain support, information, or an opportunity to observe for this project. This email was sent to individuals from the various follow-up clinics as their contact information became available. For seven of the clinics, phone calls were made to locate individuals who may be able to provide information. Of those seven clinics, one clinic responded and provided an email contact. Four of the individuals contacted were not involved in their follow-up clinics and provided contacts who were. All of the follow-up clinics were contacted a minimum of two times to collect information. For those that did not respond, the information on their websites was used for data collection.

Following the initial email contact of the follow-up clinics, three site visits were scheduled in the city of Indianapolis. The follow-up clinics visited were Community Hospital North, Franciscan Health and Eskenazi Health. During each of the visits, I observed a typical day of follow-up clinic at that location and shadowed each of the disciplines involved to better understand their role in the process. Notes were completed based on the observation and the

questionnaire was completed through one-on-one interviews with the individuals at the follow-up clinic. Once the available data was collected from all sites, the information was organized into an Excel spreadsheet to identify the similarities and differences of the follow-up clinics. All of the data collected provided valuable information for the program development plan and was used in the recommendations for the creation of a follow-up clinic at IU Health North.

Program Development Plan

The program development plan for the NICU follow-up clinic at IU Health North was created based on existing literature, data collection, and the input and resources of the hospital. The program development plan can be found in Appendix B. This part of the implementation phase used the ten areas of program development identified by Jacobs and McCormack (2011) to outline the format of the program development plan and presentation to the hospital. This outline ensured that the program development plan was comprehensive and contained the quality information that was required to make the decision for the creation of the follow-up clinic. The program development plan addressed all ten areas, as well as answered staff questions, which were identified at the beginning of the project. These areas include the background and trends of the service sector, services, market analysis, marketing, management and ownership, staffing, finances, facilities, program evaluation and risks (Jacobs & McCormack, 2011). All sections of the proposal outline were completed based on current follow-up clinics and the literature in conjunction with the resources and needs assessment of IU Health North to create a plan that was realistic and specific to the hospital.

Leadership and Staff Development

Through the completion of a survey from Rath (2007), I received my top five themes of leadership strengths and in order they were: Woo, Empathy, Positivity, Futuristic, and Belief. An

individual who is talented in the Woo theme is described as someone who finds satisfaction in making connections with others and meeting new people, often used to develop networks of people around them (Rath, 2007). This strength was used throughout this project to make connections with members of the team to ensure their best interests and concerns were met by the services provided. It was also used when reaching out to the various follow-up clinics to obtain information and the opportunity to visit to collect data. The second strength that was identified was Empathy. The description of this strength included imagining yourself in others' situations and understanding feelings of other individuals (Rath, 2007). This includes engaging others in conversation about their feelings or key ideas (Rath, 2007). I utilized this strength in the beginning of this project when meeting with the individuals who played a role in the development of the follow-up clinic and obtaining the key ideas they had. I also used it when relating it to the populations who would benefit from this new program and developing the plan to best fit their needs and concerns.

Positivity was an additional strength that was identified, which is the ability to spark enthusiasm in others about what they are going to do and are optimistic about your results regardless of the value others put on them (Rath, 2007). This was an effort I made throughout the entire process of my project with all of the individuals that I interacted with. When I first met with the individuals at IU Health North, their expectations were not that a clinic would be developed, but that they would obtain as much information on what it would take to develop a follow-up clinic. I put a lot of effort in to build excitement for this program development plan with members of all disciplines to gain their support and also to educate them on the ability for this dream to become a reality. The strength that was the most predominant in this project was the futuristic theme. Individuals with this strength have the ability to be inspired and inspire

others with a vision for the future (Rath, 2007). These individuals put tireless efforts towards goals and have the ability to envision the future based on big dreams of themselves and others (Rath, 2007). From the start of this process, I was motivated to make the dreams of the staff at IU Health North a reality and to meet the needs of the NICU population through the development of a follow-up clinic. I developed the program plan with the vision that the follow-up clinic would be a reality, and all of my best efforts were given with the hope that a good quality program would be started. The final strength that was identified was Belief. This theme is described as motivation to make the world a better place than you found it and using talents to benefit individuals (Rath, 2007). A follow-up clinic could make a big impact in the lives of infants and their families that discharge from the NICU. My motivation throughout this whole project has been the quality of life that can be improved for these individuals and the quality of services that can be provided at IU Health North through follow-up services.

In addition to leadership, staff development was promoted during the implementation phase to strengthen the development and support of the program proposal. I met with various disciplines that have a role on the NICU treatment team to understand the needs of the program from their perspective. This allowed for me to better understand their current participation in the NICU along with the discharge process and how they could be involved in a follow-up clinic. Additionally, the first meetings with these individuals included education from the literature review and the goals of the project that were created. As the project evolved, I met with individuals and the team as a whole to provide updates on the data collection from other clinics and the various factors that were addressed in the program development plan outline. This provided the team with the opportunity to raise questions and anticipate challenges they may face to strengthen the quality of the program proposal.

Outcome Phase

The implementation phase of the project resulted in the completion of a program development plan that was proposed to IU Health North. This plan included the individuals who will staff the follow-up clinic and their role as a member of the interdisciplinary team. Following the data collection and literature review, I was able to advocate for positions of the various disciplines and the services they would provide in the development plan. The staff was educated on the follow-up clinic and the purpose of the individuals who will be staffing the clinic during the proposal presentation. The outcomes that will be addressed for this project include the data from existing follow-up clinics, the additional documents created based on feedback from staff to strengthen the program plan and the program evaluation recommendations for the future if the follow-up clinic is started.

Data Collection Results

Data was collected from thirty existing follow-up clinics around the country. The majority of the information was collected from the facilities websites. A list of those sites can be found in Appendix C. Additionally, three site visits were conducted locally to collect information and observe the follow-up clinics while they were occurring to better understand the process. Individual interviews were conducted with the individuals who were followed at these sites. Lurie Children's Hospital sent their handbook for the follow-up clinic for review to collect data.

All of the collected data was documented and organized into an Excel spreadsheet. The data was then distributed into six separate spreadsheets of categories that would provide quality information to guide the program development plan. The first category was the staffing of the follow-up clinics. The identified disciplines ranked from most commonly used in a follow-up clinic to least commonly used were physical therapy, occupational therapy, social work, dietitian,

speech therapy, neonatologist, developmental pediatrician, nurse practitioner, psychologist, nursing, therapies, physiatrist, and neurology. In the category that identified the ages the infants were seen in clinic, the responses were more sporadic in nature. Two age sets were more commonly seen that included either a start date at six months and follow-up every six months or start at two months and follow-up every six months. The next category that was measured reviewed the qualifications for referral to the follow-up clinic. From the most common to least common responses it included: NICU graduate, detailed specifications for that facility, received therapy in the NICU, or were labeled “high risk.”

Out of the 30 clinics that were reviewed, 22 indicated that they provided services for the parents of the infants. Twenty-three of the follow-up clinics discussed the assessment tools they administered. The most commonly used assessment tool was the Bayley-III, a developmental assessment tool, psychology evaluation, feeding evaluation and neurological exam. The scheduling process of follow-up clinics for this population revealed that 90% of the infants were discharged from the NICU with an appointment and referral made. All of the data that was collected for this project assisted in the development of a realistic program development plan for IU Health North. Areas that were addressed in the program development plan were focused on the needs of the infant and family population identified in the literature review. The data collected in this project supported the services and standards developed for the follow-up clinic.

Continuous Quality Improvement

Continuous Quality Improvement (CQI) was the management process used to evaluate the current procedures at IU Health North and what needs to be addressed to enhance the quality of the follow-up clinic (Jacobs & McCormack, 2011). There is a nine-step process that has been shown to produce higher quality performance in a program. The first step is finding what needs

to be improved in the process (Jacobs & McCormack, 2011). For IU Health North, the process of follow-up after discharge for the infants and families needed to be improved to prevent the infants from falling behind developmentally. This was identified by both staff and the literature in the beginning stages of this project.

The next three steps are creating a group that recognizes the issues, clarifying the problems with the current performance and understanding why, and how they can be improved (Jacobs & McCormack, 2011). This was completed in the evaluation and implementation process with the various members of the staff that are employed in both the NICU and rehabilitation. The needs assessment identified the group of individuals who understand and are impacted by the current discharge process. Throughout the implementation process and as the program recommendations were presented to various members of the team at IU Health North, feedback was received to strengthen the development plan. The following resources were developed to meet the needs of the staff and population being served to enhance the services provided. The first request was that a schedule example would be provided based on the recommendations and services to better understand how to conduct the appointment. The example created can be seen in Appendix D. In addition to the appointment example, a sample of a note template was requested in order to guide the development of a formal template for documentation in the follow-up clinic. The template can be found in Appendix E. Both of these requests were added to the program development presentation to strengthen the quality and to increase the support for the follow-up clinic to occur.

The next component is identifying what will improve the performance (Jacobs & McCormack, 2011). In this project, this step was seen with the recommendation to start a follow-up clinic for NICU graduates. The final step that occurred in this project was the development of

a plan for change (Jacobs & McCormack, 2011). The program development plan created for the follow-up clinic provides details for the whole process for it to be successful. The implementation, evaluation, and maintenance stages are not seen during this process but the plans and recommendations for these portions can be found in the program development plan.

Program Evaluation

The follow-up clinic at IU Health North was not adopted during the time of this project and could not formally be evaluated. I have identified future recommendations for a program evaluation for once this program has been functioning for a year. The first component would be data collection that could evaluate appointment compliance, results of the Bayley-III and referrals, diagnosis from NICU, documentation, and other continuous quality improvement items. The second component could be related to reviewing billing and reimbursement to examine the financial aspects of the follow-up clinic. This portion would look at the cost of the program for the first year and compare it to the reimbursement received for therapy services in the follow-up clinic. Both of these program evaluations could improve the quality of the program, increase longevity, and can validate the need for a follow-up clinic at IU Health North. The program development plan that was created during this project was intended to meet the needs of the infants and families who leave the NICU. The future program evaluations will continue to ensure quality services and that those needs continue to be met as the program grows. This will allow for any changes that occur within this infant population to be addressed regularly through program evaluation standards set in the future.

Meeting the Needs of Society

Existing evidence states that infants who are very low birth weight or preterm are at greater risk for developmental delays and complications (American Academy of Pediatrics,

2004). Over half of the infants that received referrals for early intervention after discharging from the NICU did not receive services and demonstrated developmental delay (Nwabara et al., 2016). The infants that did receive services for the various disciplines waited for months at a time to be seen (Nwabara et al., 2016). The NICU at IU Health North typically does not follow-up with infants who are discharged after a length of stay. Three of the infants in one month who were seen and were referred to early intervention never received a phone call for evaluation. The number of infants who are discharged are increasing as outcomes are improving with technology and care, and they will need to be followed during their early development. The NICU follow-up clinic would follow the infants who discharge from IU Health North to ensure that they are not missed by early intervention or do not fall behind if they are not seen immediately by early intervention services. The follow-up clinic would provide developmental evaluations to identify the common delays that occur with this population, provide the resources, and make referrals to various services that will improve quality of life and function for these infants. This would promote preventative care for this population and meet their need to fill the developmental gap that is often seen.

Overall Learning

Throughout the DCE at IU Health North, learning and growth occurred daily. This occurred through observational experiences, the completion of the project, development of the paper, and communications with individuals of varying disciplines. I observed the NICU from admission to discharge through the lens of multiple disciplines to better understand the experience of the infants and their families. I documented the discharge process to understand all of the aspects that occur currently and how it would be affected if a follow-up clinic was opened. Additionally, I observed the evaluations and treatments of infants who were discharged from the

NICU but were not seen for therapies or followed after discharge in an outpatient setting. These observations allowed me to look at the current process and determine if it was meeting the needs of the population being served at IU Health North. Interviews and meetings occurred frequently throughout this project to communicate with the various members of the team at IU Health North to meet the needs of the various disciplines and ensure the program proposal addressed those needs. The project was completed in written format with multiple resources attached to provide a comprehensive report that was presented to the staff at IU Health North.

I was able to learn and grow from this experience both as a practitioner and a professional. I learned about a specialty area that we typically do not go into a lot of depth about in the classroom and the roles of various healthcare professions, not just the occupational therapist. I was able to conduct a formal needs assessment and collected data to develop a program development plan that would benefit many families that are served at IU Health North. I learned how to write a paper independently that was evidence-based and created something that would be valuable. I learned how to write a comprehensive program development plan that was required for a follow-up clinic to start. I learned more about the billing and reimbursement process and the information required for a new program to begin at a hospital. For my future practice, this experience has given me the tools and experience to develop a sustainable and realistic program that promotes occupational therapy interventions. This experience has also allowed me to understand non-traditional areas of practice and the specialty skills involved with providing services. I now have a greater understanding of the roles of other disciplines through experiences working with them and advocating for their services.

The interdisciplinary members of IU Health North taught me a lot about teamwork and leadership. I was able to participate in rounds where members of the team discussed patient care

and programming weekly. I interviewed various individuals throughout this process to make sure that the program development plan advocated for the needs of all of the disciplines involved with this population. I had the opportunity to observe the other disciplines practice with the infant population that was targeted to obtain a holistic picture of the development. I learned a lot about leadership as I was offered opportunities with other team members to participate in projects and advocacy for the NICU. My interactions with the team members developed initiative, interpersonal communication and self-drive throughout the entire process.

I demonstrated the five leadership qualities described in the implementation phase of this project for the entire duration that I was at IU Health North. Additionally, I demonstrated leadership as the individual who researched and developed the follow-up program to create the comprehensive plan that was proposed to IU Health North. I completed this project with passion and energy to better serve and improve the quality of life in the families that leave the NICU. Advocacy was required throughout the project. To gain the support for the development of a follow-up clinic, I found evidence and data that supported the plan. I proposed this plan to various members of the team to advocate for the needs of the infants and their families who discharge from the NICU. Additionally, I advocated for all of the disciplines that would participate in the follow-up clinic. As an occupational therapy student, it was clear the role that occupational therapy could play, therefore making advocacy an easy component to implement. I was able to research, observe and discuss with physical therapy, speech therapy and social work to create a role for them in the clinic and advocate for their place as well.

Growth occurred every day throughout this experience both for myself as an individual and for the IU Health North team. For myself, I was able to use leadership opportunities and experiences that will make me a better occupational therapy practitioner and team member. I was

able to create a comprehensive program that will increase the opportunities offered to the families that leave the NICU. The services that are offered to these families will expand as will the roles of the interdisciplinary team. This experience makes me feel like I contributed something meaningful and important to a large population of people and as an individual, I will take away more than I could have ever anticipated.

References

- American Academy of Pediatrics. (2004). Follow-up care of high-risk infants. *Pediatrics*, 114(5), 1377-1397.
- Ballantyne, M., Stevens, B., Guttman, A., Willan, A.R., & Rosenbaum, P. (2012). Maternal and infant predictors of attendance at neonatal follow-up programmes. *Child: Care Health and Development*, 40(2), 250-258.
- Bayley, N. (2006). *Bayley scales of infant and toddler development: Administration manual* (3rd ed.). San Antonio, TX: Harcourt Assessment, Inc.
- Bayley, N. (2006). *Bayley scales of infant and toddler development: Technical manual* (3rd ed.). San Antonio, TX: Harcourt Assessment, Inc.
- Bockli, K., Andrews, B., Pellerite, M., & Meadow, W. (2014). Trends and challenges in United States neonatal intensive care units follow-up clinics. *Journal of Perinatology*, 34, 71-74.
- Bos, A.F. (2013). Bayley-II or Bayley-III: What do the scores tell us? *Developmental Medicine & Child Neurology*, 55(11), 978-979.
- Case-Smith, J., & O'Brien, J.C. (2015). *Occupational therapy for children and adolescents* (7th ed.). St. Louis, MO: Elsevier Inc.
- Cole, M. & Tufano, R. (2008). *Applied theories in occupational therapy: A practical approach*. Thorofare, NJ: SLACK Incorporated.
- Cronin, A., & Mandich, M. (2016). *Human development and performance: Throughout the life span* (2nd ed.). Boston, MA: Cengage Learning.
- Crozier, S. C., Goodson, J. Z., Mackay, M. L., Synnes, A. R., Grunau, R. E., Miller, S. P., & Zwicker, J. G. (2016). Sensory processing patterns in children born very preterm. *American Journal of Occupational Therapy*, 70(1), 1-7.
- Greene, M. & Patra, K. (2016). Part C early intervention utilization in preterm infants:

- Opportunity for referral from a NICU follow-up clinic. *Research in Developmental Disabilities*, 53-54, 287-295.
- Greene, M.M., Patra, K., Nelson, M.N., & Silvestri, J.M. (2012). Evaluating preterm infants with the Bayley-III: Patterns and correlates of development. *Developmental Disabilities*, 33, 1948-1956.
- 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.
- Jacobs, K. & McCormack, G.L. (2011). *The occupational therapy manager* (5th ed.). Bethesda, MD: American Occupational Therapy Association, Inc.
- 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, 293-298.
- Lipner, H.S., & Huron, R.F. (2018). Developmental and interprofessional care of the preterm infant: Neonatal intensive care unit through high-risk infant follow-up. *Pediatric Clinics Of North America*, 65, 135-141.
- Logan, B.A., Brown, M.S., & Hayes, M.J. (2013). Neonatal abstinence syndrome: Treatment and pediatric outcomes. *Clinical Obstetrics and Gynecology*, 56(1), 186-192.
- Nwabara, O., Rogers, C., Inder, T., & Pineda, R. (2016). Early therapy services following neonatal intensive care unit discharge. *Physical & Occupational Therapy in Pediatrics*, 1-11.
- Pearson Education, Inc. (2008). Bayley-III technical report 2: Factors contributing to differences between Bayley-III and BSID-II scores. Retrieved from:

https://images.pearsonclinical.com/images/Assets/Bayley-III/BayleyIII_TechReport2.pdf

Rath, T. (2007). *StrengthsFinder 2.0*. New York, NY: Gallup Press.

Scaffa, M.E. & Reitz, S.M. (2014). *Occupational therapy in community-based practice settings* (2nd ed.). Philadelphia, PA: F.A. Davis Company.

Appendix A

1. What is the basic process of your follow-up clinic?
2. What services are provided through the follow-up clinic?
3. How was this program started and when did it start?
4. Who is on your follow-up team and what are the roles of these people involved?
5. How does reimbursement work for services?
6. What is the frequency of your clinic and what ages do you see the infants?
7. Who attends follow-up clinic?
8. Does a physician need to staff the clinic? If so, what does their participation need to be?
9. What are the strengths of your program? What would you change about the program if you could?
10. How many a month from your NICU do you discharge and how many follow-up at clinic?
11. How many do you see during a clinic session?
12. Do you provide services for the parents?
13. How did you sell this program to the decision makers?
14. How long did it take for the program to start?
15. How is the program funded?
16. How does documentation occur?
17. What assessment do you use and why? Who administers it?
18. How do you evaluate your program?
19. What are the days and times your clinic is open and where is it located?
20. How does the discharge process work from the NICU and from clinic?

Appendix B

Program Development Plan-NICU Follow-Up Clinic

1. Background and Trends of the Service Sector

a. Nature of the Service Sector

- i. The current process of NICU discharge from IU Health North includes the required parent education by nursing with the provision of resources and appointments at that time. If therapies were involved, they also provide parent education and may make referrals for First Steps (early intervention) or outpatient therapies. If child was determined high risk during their stay and met the requirements, they may receive referral to Developmental Pediatric Clinic at Riley. After discharge, they are not followed.
- ii. Social Work recently noted multiple infants who received referrals for First Steps but were never contacted. First Steps has been overwhelmed and it is taking an extended amount of time before the infant is even evaluated. The infant may not be picked up for services initially, but they may need services later in their development.
- iii. The literature review went over the development of NICU infants, early intervention, and current follow-up programs to identify the evidence that supports the need and value of a follow-up clinic.
- iv. Data were collected from follow-up clinics from all over the country and were used to make recommendations for the program proposal. The data

collection provided information on existing programs that serve the population that would be targeted.

b. Problem Statement

- i. The neonatal intensive care unit (NICU) at Indiana University North Hospital (IU Health North) provides interdisciplinary services to infants and their families who require specialized care after birth. One long-term goal of this team was to create a follow-up clinic for infants and their families after they are discharged to make sure that no infant falls through the gaps of the healthcare system. When the infants from the NICU are discharged, they typically are not seen again or followed by the hospital to ensure they are receiving the services they need to thrive and develop along with their peers.
- ii. The mission of IU Health is, “We are guided by the vision that we will lead the transformation of healthcare through quality, innovation and education, and make Indiana one of the nation’s healthiest states.” This mission is not fully meeting its potential for this population. Infants who discharge from the NICU in other facilities locally are being followed and are receiving services to ensure they are healthy and developmentally appropriate. If IU Health North started the follow-up clinic, they would be able to take that leadership role providing quality services for these infants and their families through a unique and innovative program that improves their quality of life.

- iii. A needs assessment was conducted with the various disciplines (occupational therapy, physical therapy, speech therapy, neonatology, nursing, social work, and management) of the staff at IU Health North to identify specific needs that need to be addressed through this program and the roles they believe individuals could play to improve the quality of life in infants who are discharged from the NICU.
- iv. Topics and questions that were identified by NICU and rehabilitation staff that would need to be answered included; services provided by follow-up clinic, staffing and roles, space in facility, reimbursement, cost and equipment, evaluation tools used, documentation, frequency of clinic, and requirements for referral to clinic.

c. Market Factors and Future Trends

- i. The number of infants who are discharged from the NICU are increasing as outcomes are improving with technology and care. This will increase the amount of infants who survive and will need to be followed during their early development. This could also increase the number of infants who will be referred for outpatient services in the hospital.

2. Services

a. Description of Services

- i. The follow-up clinic will provide developmental evaluations, parent education and resources, feeding assessments, and appropriate referrals for specialty services to the infants seen after discharge.

- ii. Infants who received therapy services in the NICU or those that were identified to be followed, will receive a referral from the neonatologist at discharge along with a scheduled appointment for their two months corrected age.
- iii. Infants will be seen at 2 months, 14 months and 20 months corrected age and clinic will occur one time a month. Each appointment will last approximately one hour. A breakdown of the recommended schedule is included as an attachment to the proposal. There will be approximately 7-8 appointments a clinic day.
- iv. At two months, the appointment will include the social worker, dietitian, occupational therapy, physical therapy, and speech therapy. All other appointments will include occupational, physical and speech therapy. The roles of the staff will be further addressed later in this proposal plan.
- v. The standardized developmental tool that is recommended to administer is the Bayley Scales of infant and Toddler Development-III and information regarding cost and training are discussed later. Evidence that supports the use of this tool is in the literature review and evaluation portions of the student report.
- vi. Documentation will be completed on a template used by all disciplines and the report will be given to the parents and primary care provider. An example of the template is attached to the proposal.
- vii. The recommendation for start date is to start scheduling appointments when the Bayley-III is purchased and received at IU Health North. This

will give therapists two months to train on it prior to the first scheduled appointment.

b. Unique Program Services or Features

- i. The infants will be seen in the same hospital they were discharged from.
- ii. The infants will receive comprehensive evaluations by an interdisciplinary team all in one appointment.
- iii. They could be seen by the same therapists who treated them in the NICU or if they are referred to outpatient services, they could be seen by the therapist who will follow them.
- iv. If they were not picked up by First Steps, they can be followed regularly to make sure they do not fall behind their peers developmentally. They can be seen and evaluated prior to First Steps evaluation if the process is delayed.
- v. Parents can receive resources and education that will assist them between appointments.

3. Market Analysis

a. Target Market and Analysis

- i. The initial goal of the follow-up clinic is to see between 7-8 infants a month. With the inclusion of all infants that were followed by therapy services in the NICU, assuming approximately 12-15 infants a month, that will ensure the schedule is full for follow-up clinic each month. This has the potential to grow to more than once a month as the appointments evolve later in the first year.

- ii. The follow-up clinic will be at IU Health North and it is assumed that it is closer to the families' residences and other doctors' offices that may be following the infants.

b. Competitors: Comparing Strengths and Weaknesses

- i. Locally, other hospitals have follow-up programs and if IU Health North develops this program, they will not be a threat due to referrals occurring at discharge within the hospital network.
- ii. Data were collected from hospitals locally and outside of the state to provide a framework for the development of this follow-up clinic considering both the strengths and weaknesses they have.
- iii. Strengths that local programs demonstrated were the limited amount of space that they needed to have clinic at their site and that feeding assessments and interventions were provided.
- iv. Weaknesses of the local programs were the need to improve times of administration of the standardized assessment, two of the clinics only had two therapy disciplines, and one clinic did not follow the infants regularly after their first appointment.

4. Marketing

a. Promotion

- i. Promotion will occur starting during the discharge process in the NICU. Parents will be educated on the purpose of the follow-up clinic, the benefits of attending, and the roles of the team members that provide services to promote compliance and attendance.

- b. Marketing Strategy
 - i. The follow-up clinic can serve as a marketing strategy for the outpatient therapy clinic at IU Health North if the infant is appropriate. It can be marketed to the family as they are discharged from the NICU. There also is the potential to market to primary care physicians if they believe a child is appropriate.
- 5. Management and Ownership
 - a. Key Players' Qualifications and Experience
 - i. Neonatal and Nursing staff will provide the referral, education and appointment information during the discharge process prior to leaving the NICU.
 - ii. Outpatient office coordinators will assist with pre-authorization for insurance and appointment reminders to help with compliance and reimbursement.
- 6. Staffing
 - a. Staffing Patterns
 - i. Social Work: The role of this individual will be to participate in the two-month appointment and provide resources to the parents based on their needs. This will allow for the parents to get home and settled to identify needs they may have.
 - ii. Dietary: The role of this individual will be to participate in the two-month appointment and discuss feeding with the parents and provide consultative services.

- iii. Speech Therapy: The role of this individual will be different based on the age of the infant. At the two-month appointment they will participate with dietary in the feeding assessment. They will also complete the receptive and expressive language sections of the Bayley-III during all three appointments.
- iv. Occupational Therapy: The role of this individual will be to complete the fine motor and cognitive portions of the Bayley-III with the infant at all ages. The two-month appointment will be done with physical therapy and the 8- and 14-month appointments will be in conjunction with speech therapy.
- v. Physical Therapy: The role of this individual will be to complete the gross motor portion of the Bayley-III with the infant at all ages. At the two-month appointment, it will be in conjunction with occupational therapy, in and the remainder of appointments will be completed independently.
- vi. All of the staff members will complete documentation on the template with the results of the Bayley sections and their assessment and plan for their discipline.

b. Staff Training

- i. Staff training will be minimal for social work and dietary as they will be in more of a consultative role for the two-month appointment.
- ii. Therapies will have to be trained in the administration of the Bayley-III and documentation. They will otherwise have little training.

7. Finances

- a. Funding Requests/Investments
 - i. Funding that would be required would be for the Bayley-III and all of the record forms to replace. The comprehensive kit is \$1248.00 and includes 25 forms to start. Packages of 25 for the forms are \$134.70. All other equipment needs are already available in the outpatient clinic. A more detailed reference sheet will be provided with the proposal.
 - b. Assumptions
 - i. Reimbursement will occur with evaluation codes for all therapy disciplines.
8. Facilities
- a. Location
 - i. IU Health North Outpatient Rehabilitation in a therapy room.
 - b. Building and Space Requirements
 - i. It would only need to be a small room for the majority of the appointment and an area with a mat for the gross motor portions at the 8- and 14-month appointments.
 - c. Equipment and Supplies
 - i. The Bayley-III kit will have all of the equipment required to perform the assessment.
 - ii. An open crib or mat table could be used for the two-month appointment and a table will be needed for the 8- and 14-month appointment.
 - iii. A mat will be needed for the gross motor portion of the assessment.

- iv. Social Work and Dietary may require handouts for their portion of the appointment.

9. Program Evaluation

- a. A doctoral candidate in the occupational therapy program could complete the program evaluation in the future.
- b. The first component could include data collection that could look over appointment compliance, results and referrals, documentation, and other continuous quality improvement items.
- c. The second component could be related to billing and reimbursement, examining the financial side of the follow-up clinic.

10. Risks

- a. Having available space for the follow-up clinic long term.
- b. Assuming services will be reimbursed for the evaluations of therapy services.
- c. Completing a three-discipline evaluation in an hour with ease and documentation.

Appendix C

Children's Hospital and Medical Center Omaha: <https://www.childrensomaha.org/nicu-follow-up-clinic2>

Children's Hospital at Vanderbilt:

<http://www.childrenshospital.vanderbilt.org/services.php?mid=2085>

Children's Hospital of Philadelphia: <http://www.chop.edu/centers-programs/neonatal-follow-program>

Children's Hospital of Pittsburgh: <http://www.chp.edu/our-services/newborn-medicine/neonatal-follow-up-clinics>

Children's Hospital of Richmond at VCU:

<https://www.chrichmond.org/Services/Cardiology.htm>

Cincinnati Children's Hospital: <https://www.cincinnatichildrens.org/service/n/nicu-follow-up>

Cleveland Clinic: <https://my.clevelandclinic.org/pediatrics/departments/nicu-follow-up>

Cone Health: <https://www.conehealth.com/services/pregnancy-and-childbirth/nicu/follow-up-clinics/>

Connecticut Children's Medical Center: <https://www.connecticutchildrens.org/search-specialties/neonatology/neonatology-programs-services/neonatal-neurodevelopmental-follow-up-program/>

Golisano Children's Hospital: <https://www.urmc.rochester.edu/childrens-hospital/neonatology/follow-up.aspx>

Gundersen Health System: <http://www.gundersenhealth.org/services/pediatric-care/neonatal-follow-up/>

Eastern Carolina University: <http://intranet.ecu.edu/cs-dhs/neonatology/followup.cfm>

Kalispell Regional Healthcare: <https://www.krh.org/krhc/services/neonatal-intensive-care-unit/follow-up-clinic>

Lurie Children's Hospital: <https://www.luriechildrens.org/en-us/care-services/specialties-services/neonatology/programs/Pages/neonatal-and-cardiac-intensive-care-follow-up-clinic.aspx>

Lutheran Health Network: <http://www.lutheranchildrenshosp.com/interior.php?t=93>

Mayo Clinic: <https://www.mayoclinic.org/departments-centers/childrens-center/overview/specialty-groups/newborn-intensive-care-unit-follow-up-clinic>

Mercy Health: <https://mercyhealthsystem.org/parents-guide-nicu/nicu-follow-clinic/>

Nationwide Children's: <https://www.nationwidechildrens.org/nicu-followup-clinic-visits>

Peyton Manning Children's Hospital: <http://www.peytonmanningch.org/medical-genetics-neuro-development/>

Riley Children's Hospital: <https://www.rileychildrens.org/departments/developmental-pediatrics>

Rush University Children's Hospital: <https://www.rush.edu/kids/services-conditions/neonatal-intensive-care-unit/follow-care-nicu>

Wake Forest School of Medicine: <http://www.wakehealth.edu/School/Neonatal-and-Perinatal-Medicine/Neo-Assets/NICU-Follow-Up-Clinic---Amos.htm>

Sacred Heart Children's Hospital: <https://washington.providence.org/hospitals/sacred-heart-childrens-hospital/services/neonatal-intensive-care/neonatal-developmental-follow-up-clinic/>

San Antonio Regional Hospital:

https://www.sarh.org/our_services/healthy_beginnings/maternity_services/nicu_follow-up_clinic/

Saint Joseph Health System: <http://www.sjmed.com/nicu-follow-up-clinic>

St. Louis Children's Hospital: <http://www.stlouischildrens.org/women-and-infants/newborn-medicine>

University of Kentucky HealthCare: <https://ukhealthcare.uky.edu/kentucky-childrens-hospital/services/neonatal-intensive-care-unit>

Appendix D

Two Month Appointment Example:

8:00-8:15: Dietary & Speech Therapy perform feeding evaluation and consultation (OT & PT frontload templates for the documentation with history and the Bayley-III).

8:15-8:50: Occupational Therapy and Physical Therapy perform the fine motor, cognitive and gross motor portions of the Bayley-III (Speech Therapy observes for language and documents during this time).

8:50-9:00: Score the Bayley-III and provide parents with results and recommendations.

9:00-9:15: Dietary & Speech Therapy perform feeding evaluation and consultation (OT & PT document from previous appointment).

Cycle through

8 & 14 Month Appointment Example

8:00-8:30: Occupational Therapy administers the fine motor and cognitive portions of the Bayley-III while the Speech Therapist completes the language portions.

8:30-8:50: Physical Therapy administers the gross motor portion of the Bayley-III. (OT and ST score their sections and complete documentation.)

8:50-9:00: Finish scoring the Bayley-III and provide parents with results and recommendations.

9:00-9:30: OT and SLP administer Bayley-III. (PT completes documentation).

Appendix E

NICU FOLLOW-UP EVALUATION FORM

PATIENT
STICKER

Name:		Onset	Click here to enter a date.
Rehab Dx:		Parents:	
Date of Evaluation:	Click here to enter a date.	Total Time:	

The following evaluation was completed with parent/patient interview, interaction, and observation.

Standardized testing: Bayley-III (see attachment summary)

Contraindications/Precautions:

Patient Information and History:

Gestational Age:	Chronological Age:	Adjusted Age:
Medical Hx.		
Social Hx.		
Prior Therapies:		

Parent/Caregiver Goals and Concerns:**Subjective Information:****Social Work:****Dietary:****Results of the Bayley-III:**

Subscale:	Adjusted Age:	Score:	Developmental Age:
Gross Motor			
Fine Motor			
Cognitive			
Expressive Language			
Receptive Language			

Speech Therapy Assessment:

Occupational Therapy Assessment:

PATIENT
STICKER

Physical Therapy Assessment:

Education/Resources for Parents:

RECOMMENDATIONS:

PLAN:

Social work signature: _____

Date:

Dietitian signature: _____

Date:

Therapist signature: _____

Date:

Therapist signature: _____

Date:

Therapist signature: _____

Date: [Click here to enter a date.](#)

.....
PHYSICIAN CERTIFICATION: From: [Click here to enter a date.](#) To: [Click here to enter a date.](#)

Physician Signature (*stamped signature not acceptable*)

Date

Please sign and fax back to [317-688-2670](tel:317-688-2670)

Phone: 317-688-2021