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Supporting Parent and Infant Transition from the Neonatal Intensive Care Unit to Infant Clinic Follow-Up

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Under the direction of the faculty capstone advisor:

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A Capstone Project Entitled

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Section I: Abstract

Follow-up care for infants after discharge from the Neonatal Intensive Care Unit (NICU) is essential as infants who have had a stay in the NICU are at an increased risk of having developmental delays. Infants have improved long-term outcomes if early intervention services are provided in the first year of life. A common problem in NICU follow-up clinics is high no-show rates, resulting in a gap in developmental care for infants with serious medical needs. The occupational therapy doctoral capstone student identified barriers that parents living in a metropolitan area, with diverse cultural backgrounds, faced in accessing and receiving developmental care for their infants. Common barriers included: limited understanding of the details of the Infant Clinic appointment, complete lack of knowledge about the existence of the Infant Clinic appointment and confusing the Infant Clinic appointment, with the well-child primary care visit after NICU discharge. In order to reduce these barriers and to streamline the process from NICU discharge to outpatient occupational and speech therapy follow-up at the Infant Clinic, several strategies were put into place. These strategies included: increased education and reiteration of importance of attending the Infant Clinic appointment by NICU staff, development of educational materials about the Infant Clinic written at appropriate reading levels in order to comply with health literacy guidelines, development of incentives to increase parent motivation to attend the appointment, and increased interdisciplinary collaboration between NICU staff and Infant Clinic staff in order to improve continuity of care across the two settings.

Supporting Parent and Infant Transition from Neonatal Intensive Care Unit to Infant Clinic Follow-Up

Survival rates for infants of young gestational age and low birth weight have increased in recent years, while the length of stay in the Neonatal Intensive Care Unit (NICU) has decreased (Brachio et al., 2018; Bockli, Andrews, Pellerite, & Meadow, 2014; Santos, Pearce, & Stroustrup, 2015). Due to these trends, infants being discharged from the NICU are more likely to have unresolved medical issues continuing at home, making access to follow-up care after NICU discharge a necessity (Bockli et al., 2014; Santos et al., 2015). Some of the common medical complications after NICU discharge include: feeding problems, issues with growth, and neurodevelopmental disabilities (Bockli et al., 2014). NICU follow-up clinics serve to provide parents with access to practitioners who specialize in the care needed for their infants, and to provide support for parents (Bockli et al., 2014). Multidisciplinary medical care after NICU discharge from professionals who specialize in premature infants is essential (Bockli et al., 2014). A study on follow-up clinics showed that pediatricians are concerned that they do not have the training needed to provide such specialized care and rely on specialists who are trained in infant care (Brachio et al., 2018; Bockli et al., 2014).

Another important function of follow-up clinics is to establish ongoing specialized care for the infant if necessary (Bockli et al., 2014; Greene & Patra, 2014). Infants who are discharged from the NICU are at increased risk for long-term neurodevelopmental impairment, which necessitates evaluation by occupational therapy (OT), speech therapy (ST), and physical therapy (PT) (Orton et al., 2018). Evaluation by these disciplines in the first year of the infant's life is needed in order to identify developmental delays and to make referrals to early intervention services (Greene & Patra 2016; Orton et al., 2018).

Though the importance of follow-up after NICU discharge may be obvious to health care providers, there is often a disconnect in parents following through with referrals made for follow-up care (Bockli et al., 2014). A common struggle among various NICU follow-up clinics is a high "no-show" rate, with many patients not coming to these appointments (Bockli et al., 2014). In a study exploring the difficulties faced by NICU follow-up clinics, a majority of respondents stated the no-show rate for their clinic was as high as 20% (Bockli et al., 2014). The factors related to the high no-show rates were not discussed in the study (Bockli et al., 2014). However, other researchers have highlighted the importance of identifying barriers that patients face in accessing health care; factors that could be contributing to no-show rates (Betancourt, Green, Carrillo, & Ananeh-Firempong, 2016; Batterham et al., 2016).

There are disparities in health care access especially among racial and ethnic minorities (Betancourt et al., 2016). These disparities include: differences in patient recognition of symptoms, ability to communicate symptoms with practitioners, ability to understand recommendations made by practitioners, and compliance with recommendations and medications (Betancourt et al., 2016). These factors can also be referred to as a person's health literacy level (Batterham et al., 2016). Health literacy is defined as: "the personal and relational factors that affect a person's ability to acquire, understand and use information about health and health services" (p. 3, Batterham et al., 2016). Individuals with lower health literacy levels have a lower utilization of health services and have poorer health outcomes as compared to individuals with high levels of health literacy (Batterham et al., 2016). It is the responsibility of health care providers to assess the health literacy of the patient population being served in order to provide better support to patients, to increase health care access, and to improve health outcomes (Batterham et al., 2016).

In addition to potential socioeconomic and health literacy barriers, parents who have sick infants in the NICU face many stressors on top of stressors already associated with having a newborn (Williams et al., 2018). Due to this increased level of stress, it is crucial that NICU staff become more aware of the needs that NICU parents have (Williams et al., 2018). After barriers and stressors specific to the patient population have been identified, health care providers must utilize their increased awareness by developing strategies to increase ease in service activation (Batterham et al., 2016).

The Doctoral Capstone Experience & Project Introduction

This purpose of the OT doctoral capstone experience (DCE) is to streamline inpatient therapy services in the NICU, which includes OT and ST, with the outpatient OT and ST services in the infant follow-up clinic at Eskenazi Hospital. There is a high no-show rate in the Infant Clinic, which results in a gap in follow-up care for infants with immediate developmental needs. The barriers that patients face in regard to accessing health care services and coming to the Infant Clinic need to be identified, and strategies must be developed to reduce these barriers in order to provide care appropriate to the health literacy level of Eskenazi's patient population (Betancourt et al., 2016; Batterham et al., 2016). Additionally, there is a need for a written discharge guidelines that can be utilized by the IP and OP therapy teams to ensure consistency in the Infant Clinic referral process, and thorough, multidisciplinary education about details and importance of the appointment.

Section II: Literature Review

The role of OT in the NICU

OT practice in the NICU is a specialized and emerging practice area and requires the occupational therapist to have additional training and skills beyond entry level in order to

provide services to infants and parents (Borges et al., 2018; Vergara et al., 2006). Knowledge of the varying medical diagnoses, conditions, developmental variability, and potential abnormalities that neonates experience is necessary in order to provide proficient care in this setting (Vergara et al., 2006). It is important as a NICU therapist to have an awareness of the fragility of the neonates as they are at risk for harm if exposed to inappropriate environments (Aita et al., 2017; Altimier & Phillips, 2016; Santos et al., 2015; Vergara et al., 2006). The occupational therapist often focuses intervention priority on protecting the infant from being exposed to inappropriate environmental conditions by modifying sensory aspects of the environment such as lighting, noise, and temperature of the nursery (Aita et al., 2017; Altimier & Phillips, 2016; Santos et al., 2015; Vergara et al., 2006). Besides sensory integration and modulation, other areas of intervention may include addressing neurodevelopment and feeding skills (Borges et al., 2018; Vergara et al., 2006).

Establishing relationships with families. Aside from providing direct care to neonates, occupational therapists are expected to establish therapeutic relationships with the families of the neonates as many families are under high amounts of stress and facing uncertainty regarding their infant's outcomes (Vergara et al., 2006; Dudek-Shriber, 2004). These relationships serve to equip and empower the family members to contribute to the infant's optimal development (Vergara et al., 2006). Occupational therapists are also viewed by other NICU professionals as being primary providers of parent education, which occurs through these established relationships (Caretto, 2000).

Facilitate transfer to follow-up care. Though discharge planning begins upon admission to the NICU, the role of OT with neonates does not end at NICU discharge (Caretto, 2000; Hall, Phillips, & Hynan, 2016). Occupational therapists are not only also responsible for

preparing parents to take their infant home, but also for directing parents to appropriate follow-up care. These infants often have developmental delays that impact their long-term cognitive, social/behavioral, physical, and emotional development and require outpatient OT or early intervention after discharge (Bockli et al., 2014; Hall et al., 2016; Santos et al., 2015). However, there are barriers that impact parents' abilities to access the developmental care that their infants need after discharge (Betancourt et al., 2016; Batterham et al., 2016; Purdy et al., 2015).

Parental Barriers to Providing Care after Discharge

Parent anxiety. Researchers have studied parents' experiences after NICU discharge, and have found themes relating to parent fear and anxiety of leaving the safe environment of the NICU and having to care for the infant independently at home (Aloysius et al., 2017; Caretto, 2000; Forsythe & Willis, 2008; Hummel, 2003; Williams et al., 2018). Anxiety is increased in parents of infants in the NICU as compared to parents of typically developing infants (Hummel, 2003). Some research has shown that these concerns persist even up to 18 months after NICU discharge (Aloysius et al., 2017).

Limited access. Aside from stress and anxiety, parents face additional barriers to accessing and receiving services after discharge (Purdy et al., 2015). Some of these barriers include: limited access to health insurance, insufficient administrative procedures for transferring care to outpatient or community resources, difficulty obtaining specialized equipment needed to care for their infant, limited access to medications, lack of access to specialized or emergency services in isolated areas, and poor discharge follow-up guidelines for families (Betancourt et al., 2016; Batterham et al., 2016; Purdy et al., 2015). Resources to reduce these barriers specific to discharge guidelines include: pre-established discharge plans, parent training check lists, and NICU follow-up programs (Purdy et al., 2015).

Cultural barriers. Cultural barriers can also make it more difficult for patients to access and receive necessary and appropriate health care services (Betancourt et al., 2016). Individuals who are part of a minority ethnic population tend to be more socioeconomically disadvantaged, and have lower education levels compared to their majority population counterparts (Betancourt et al., 2016). Due to these disadvantages, those in the minority group tend to have difficulty communicating with their health care providers about symptoms, understanding the prescribed instructions for health management, and adhering to recommendations (Betancourt et al., 2016). According to researchers who studied this topic, it is important for health care providers to identify the sociocultural barriers specific to various minority groups and to identify which ways these sociocultural barriers have not been addressed by the health care organization (Betancourt et al., 2016).

Importance of addressing barriers. There are risks involved in leaving the socioeconomic and cultural barriers unaddressed, specifically related to the long-term outcomes for infants (Nwabara et al., 2017). It is crucial for many of the infants discharged from the NICU, to be evaluated by therapy services in the first year of their life to test for potential developmental delays, and so they can be referred to the appropriate discipline if needed for ongoing services (Orton et al., 2018; Greene & Patra 2016). Early intervention for infants who spent time in the NICU is also related to better long-term outcomes for the child (Benzies, Magill-Evans, Hayden, & Ballantyne, 2013; Landsem et al., 2015; Ma et al., 2015). In addition to the issue of high no-show rates seen in NICU follow-up clinics, there is also a delay in the activation of therapy services post NICU discharge, and some infants who need follow-up services are not receiving them altogether (Bockli et al., 2014; Nwabara et al., 2017). Identification of the barriers that contribute to high no-show rates and delayed activation of

services, is the first step in providing more accessible health care for patients of diverse socioeconomic and cultural backgrounds (Betancourt et al., 2016; Batterham et al., 2016).

Experience of NICU Parents

The fears that parents had about taking their infant home, were found to be manageable if parents were given support from NICU professionals during the NICU stay and after discharge (Aloysius et al., 2017; Caretto, 2000). Other factors that influence the degree of parent anxiety include: degree of parent involvement in the NICU and parents staying with their infant in the NICU (Aloysius et al., 2017; Davidson et al., 2017). One study found that mothers who were present and involved during their infant's stay in the NICU, had increased maternal satisfaction as compared to those who were not (Davidson et al., 2017). Other researchers have found that parents who participate in the care of their newborn, are better prepared to transition home (Aloysius et al., 2017; Larsson et al., 2015; Osorio et al., 2017). Mothers who were provided with information about their infant's condition, taught how to look for signs of pain or discomfort, and taught how to respond by providing learned soothing strategies for their infant had increased maternal satisfaction (Davidson., et al, 2017). Some other contributors to parent stress and frustration were related to rules and regulations present in the NICU (Williams et al., 2018). Researchers suggest that having clear and empathetic communication with parents regarding reasoning and significance behind rules may also decrease parent anxiety (Williams et al., 2018).

Strategies to Decrease Parental Barriers

Education. Though some sort of parent education is common across NICUs, there is variation in how parent education is provided by occupational therapists in the NICU (Caretto, 2000). Researchers found that the majority of therapists scheduled education sessions with

families at the times the family was present in the NICU (Caretto, 2000). Additionally, there was a variety of teaching methods reported, including: demonstration, discussion, handouts, and hands-on practice (Caretto, 2000). Some even reported that parents "rooming-in," or staying the night in the hospital to practice providing all necessary care for their infant, was a standard parents needed to meet prior to discharge (Caretto, 2000). However, not all parents were provided with resources at discharge (Caretto, 2000). Out of all the participants in the study, 86% reported that written discharge plans were provided at discharge, and 81% reported that some type of follow-up with parents was required after discharge (Caretto, 2000). According to researchers, there is still a need for continued research on parent education and discharge criteria in order for occupational therapists to provide more effective parent education programs (Caretto, 2000).

Strategies to Decrease Parental Barriers

Sensitivity to patients' diverse cultural backgrounds. When working with patients of diverse cultural backgrounds, researchers emphasize the importance of developing cultural competence (Betancourt et al., 2016). Cultural competence has been defined by researchers as "understanding the importance of social and cultural influences on patients' health beliefs and behaviors; considering how these factors interact at multiple levels of the health care delivery system; and, finally, devising interventions that take these issues into account to assure quality health care delivery to diverse patient populations" (p. 297, Betancourt et al., 2016). Some of the interventions identified by researchers included: developing interpreter services, language-appropriate education resources, and providing education to health care professionals on cross-cultural barriers (Betancourt et al., 2016).

Interdisciplinary collaboration. It is the responsibility of NICU professionals to work

together to develop patient-specific and realistic, discharge plans in order for parents and infants to have a smooth, supported, and healthy transition to home (Hall et al., 2016; Hummel, 2003; Purdy et al., 2015). Additionally, NICU professionals who are responsible for referring parents to community and outpatient resources, need to be up-to-date on guidelines for recognizing potential barriers and strategies to overcome those barriers in order to properly care for NICU families (Purdy et al., 2015). A strategy for further providing a seamless discharge to follow-up services, is to integrate interdisciplinary collaboration into the process for follow-up referrals (Welch, Check, & O'Shea, 2017).

Difference between multidisciplinary and interdisciplinary teams. There is a significant difference between multidisciplinary and interdisciplinary teams (Choi & Pak, 2006). A multidisciplinary team uses each professional's expertise to accomplish individual goals, staying within their own boundaries (Choi & Pak, 2006). An interdisciplinary team searches for opportunities to link various processionals' skills to work coherently towards a group goal (Choi & Pak, 2006). Interdisciplinary collaboration has also been defined as: "an effective interpersonal process that facilitates the achievement of goals that cannot be achieved when individual professionals act on their own" (p. 299, Bronstein, 2003). A study comparing multidisciplinary and interdisciplinary teams, found that interdisciplinary teams had significantly better teamwork and team effectiveness than multidisciplinary teams (Korner 2010).

One study found that having scheduled multidisciplinary meetings regarding patient care in the NICU resulted in improved team collaboration, continuity of care for patients, and improved patient outcomes (Welch et al., 2017). Those in attendance included: neonatologists, pediatric surgeons, a physical therapist, an occupational therapist, a speech therapist, social worker, family support coordinator, the NICU Nurse Manager, and others (Welch et al., 2017).

After one year of implementing weekly multidisciplinary team meetings, the average hospitalization duration decreased by 6.5 days, showing a significant improvement in patient outcomes, thus, highlighting the effectiveness of implementing interdisciplinary collaboration into existing multidisciplinary teams (Welch et al., 2017).

Another study highlighted the importance of interdisciplinary collaboration in providing psychosocial support and continuity of care to NICU parents (Chorna et al., 2016; Hynan & Hall, 2015). This study also emphasized that psychosocial support should begin in the antepartum phase, continue during the NICU admittance, and into the post-NICU discharge phase (Hynan & Hall, 2015). An important aspect of collaboration among practitioners is providing communication to parents with a focus on clarity and continuity especially during transitions in care and "handoffs" to new providers, such as NICU to NICU follow-up (Chorna et al., 2016; Hynan & Hall, 2015). Other research has specifically discussed the necessity of collaboration between developmental pediatricians and rehabilitation services, like OT, PT, and ST, in NICU follow-up clinics (Brachio et al., 2018; Smyser, et al., 2016).

NICU follow-up clinics serve a crucial role in providing multidisciplinary care to infants and parental support after discharge in many ways: acting as a connection between primary care physicians and specialists, early identification of developmental delays and disabilities, and referral to other appropriate services (Brachio et al., 2018). However, in order for these follow-up clinics to be successful there not only needs to be interdisciplinary collaboration within settings, but also between the professionals in the NICU and those in the NICU follow-up clinics (Chorna et al., 2016; Hynan & Hall, 2015).

Theoretical Basis

Theoretical Framework: Model

The NICU Developmental Care model will guide this DCE (Altmier & Phillips, 2016). This model consists of seven neuroprotective family-centered developmental core measures and is commonly used to guide practice within NICUs (Altimier & Phillips, 2016). Though the NICU Developmental Care model is not a traditional occupational therapy practice model, it is highly specific to providing care within the NICU and has a focus on providing family support, which is a focus of this DCE. All seven of the core measures outlined in this model can be applicable to OT, however, some of the most applicable for this project are: healing environment, partnering with families, positioning and handling, safeguarding sleep, and minimizing stress and pain (Altimier & Phillips, 2016). This model also has guidelines that serve both the infant and the parent as clients, which is important for this setting as intervention often involves parent education to increase self-efficacy in the ability to care for their newborn (Altimier & Phillips, 2016; Davidson et al., 2017). Neuroprotective family-centered developmental care includes ensuring the whole family is involved in the infant's care. Several researchers have identified the importance of involving family in patient care (Altimier & Phillips, 2016; Davidson et al., 2017).

The effect that the environment has on infant stress and development is emphasized in the NICU Developmental Care Model (Altimier & Phillips, 2016; Painter, Lewis, & Hamilton, 2019). This aspect of the model is highly applicable to the role of OT for providing intervention in the NICU (Altimier & Phillips, 2016; Vergara et al., 2006). Many OT interventions in this setting are prioritized on modifying the environment especially as related to sensory modulation (Altimier & Phillips, 2016; Vergara et al., 2006).

Though this model primarily serves to provide policies and guidelines for infant care during time at the NICU, its core guidelines are also applicable after NICU discharge and align with the intervention areas for OTs working with infants after NICU discharge (Vergara et al.,

2006; Aloysius, Kharusi, Winter, Platonos, Banerjee, & Deierl, 2017). According to researchers, discharge planning and preparation should begin upon an infant's admission to the NICU in order to adequately prepare parent's to be their infant's primary caregiver (Aloysius et al., 2017). Due to the focus of the DCE being on providing parental support before NICU discharge, in order to improve consistency with therapy post-discharge, a model that focuses on family support with discharge in mind will be an excellent framework for this project.

Theoretical Framework: Frame of Reference

The frame of reference that will guide this project is the Sensory Integration and Processing frame (Cole & Tufano, 2008). Not only is sensory integration a standard approach for OT in the pediatric setting, but this frame can be also applied to clients with a variety of occupational difficulties including difficulties with: hypersensitivity and hyposensitivity to sensory stimuli, postural control, motor control, and cognition (Cole & Tufano, 2008; Mohapatra & Rani, 2016; Smith, Mruzek, & Mozingo, 2015). These difficulties are commonly addressed by OT in the NICU and NICU follow-up settings as premature infants are at an increased risk of having developmental challenges identical to those listed above (Vergara et al., 2006; Aloysius et al., 2017). This frame views therapeutic changes as occurring as a result of sensory interaction within the infant's environment (Cole & Tufano, 2008; Mohapatra & Rani, 2016). These sensory interactions are adjusted based on the infant's ever-changing needs; the adjustments are made by the occupational therapist who makes decisions based off of the infant's cues (Cole & Tufano, 2008). Controlling and modifying these environmental interactions are again, a priority for OT intervention in the NICU, and there has been research that highlights the major impact that the NICU environment has on neurodevelopmental outcomes of infants in the NICU (Aita et al., 2017; Altimier & Phillips, 2016; Santos et al., 2015). According to this frame, the client is the

one who knows what kind and how much sensory input they need (Cole & Tufano, 2008; Mohapatra & Rani, 2016). How these adjustments are made by the occupational therapist, will be further discussed in the following section. This frame will not only be helpful with guiding program development and the creation of educational parent resources for NICU discharge, but it will also guide the secondary DCE focus, which is clinical practice skills. These interventions and interactions with direct patient care include sensory integration principles with all clients especially those who come to the clinic for feeding groups.

Section III: Screening and Evaluation

Needs Assessment

Needs assessment for the site. The needs assessment was completed through several informal meetings with the site mentor prior to, and in the first week of the DCE. After these meetings, the project focus was identified as: developing discharge guidelines for NICU and Infant Clinic staff in order to provide increased parent support during and after NICU discharge. The questions that guided the needs assessment were related to what was going well with existing NICU discharge processes, and what needs to be improved with those discharge processes (Appendix A). A theme that emerged from the discussion was the high incidence of "no-shows" at the clinic. The site mentor explained that not only are no-shows detrimental to productivity rates, but parents failing to bring their infants to the Infant Clinic, often leads to lack of developmental care for these babies as they "fall through the cracks," and are at risk for not receiving the developmental care they desperately need. The Infant Clinic is run by the site mentor, who is an occupational therapist, and a speech therapist who specializes in infant feeding. The majority of infants who come to the follow-up clinic are referred by NICU doctors and residents, and many of the infants had either an extended stay in the NICU, a diagnosis of

Neonatal Abstinence Syndrome (NAS), or premature birth that resulted in developmental delays related to feeding, reflexes, and emotion regulation. Infants can also be referred to the Infant Clinic through community referrals such as primary care physicians, though these referrals are not as common. The occupational therapist and speech therapist complete an evaluation which assesses: infant reflexes, emotion regulation, and feeding and eating skills. Based on the assessment, the therapists work together to determine whether the infant should continue to receive care at the Infant Clinic, receive a home-based early intervention referral, or be discharged from care. Therefore, if the parents do not bring their infant to the appointment, they are at risk for not receiving home-based early intervention services either.

The site mentor identified several factors she believed contributed to barriers for parents in understanding the purpose and importance of following through with NICU follow-up care. Some barriers included: patient demographics, limited education and/or emphasis on the importance of the Infant Clinic appointment at the time of referral, limited patient motivation to go to the appointment, health literacy, and other parent-specific factors that might make it difficult for parents to come to the appointment (e.g. other kids, lack of transportation, foster care, etc.). She also acknowledged her efforts to provide patient information at the appropriate health literacy level at the Infant Clinic but was unsure if health literacy level was addressed by inpatient staff.

In addition to naming potential barriers that parents face in accessing the Infant Clinic, the site mentor also described the impact that the no-show rate has on the therapists. When there are several no-shows to the Infant Clinic, the occupational therapist and speech therapist fall behind productivity standards as they are obviously unable to complete evaluations if there are no babies present. Also, the waitlist for infants to be scheduled in the Infant Clinic continuously

grows as the parents who "no-show" their evaluations are often tacked back onto the waitlist at the next available date. Not only would increasing the show-rate benefit the infants' ongoing development, but it would also help to increase the productivity rates for the therapists and shorten the waitlist for the Infant Clinic.

Needs assessment for the parent. In pediatric settings, the parents are also considered the client, especially when the patient is an infant and unable to voice his or her opinions, concerns, and goals. (Stoffel et al., 2017). In an effort to understand the experiences of parents who have had infants in the NICU, one-on-one interviews were conducted with two mothers of current pediatric clients at the outpatient clinic, whose children spent time in the NICU or hospital after birth. Questions were focused on the NICU experience specifically related to what aspects contributed to increased parent support and confidence at discharge, and what areas needed to be improved (Appendix B). Some common themes arose from the two interviews, including: education and training on providing medical and developmental care for the infant at home, need for psychological and emotional support, a desire for communication with other parents with similar experiences, and feeling overwhelmed about what to expect with their infant's future. The mothers that were interviewed both spoke English and were of a higher socioeconomic status as compared to the typical patient population at Eskenazi. The reason they were chosen to be interviewed, was because the site mentor identified them as willing participants who were far enough removed from the NICU experience, that it would not be upsetting for them to share about the hardships they endured during that time. However, due to the difference in these mothers' socioeconomic status as compared to the typical Eskenazi patient demographic, there will still be a patient questionnaire given to parents at Infant Clinic appointments to understand the experiences of the patients who represent the majority of the

patient population at the hospital. See tables 1-4 for Infant Clinic patient demographics, the data represents patients from February 2017 to February 2019. The patient questionnaire will be developed utilizing the feedback from the one-on-one interviews with past NICU mothers. These questionnaires be given during the implementation phase of the project, as the goal of this project is to identify the barriers that parents face in the transition from NICU discharge to outpatient developmental care services, and then to develop strategies to increase the show-rate to Infant Clinic appointment.

Table 1

Payor Mix (n = 200)

Payor Source	*n*	%
Medicaid	176	88.0
Health Advantage	1	0.5
Commercial	12	6.0
Uninsured	11	5.5

Table 2

Ethnicity (n = 200)

Ethnicity	*n*	%
Hispanic or Latino	68	34.0
Not Hispanic, Latino/a, or Spanish origin	125	62.5
Unreported	7	3.5

Table 3

Race (n = 200)

Race	*n*	%
White	61	30.5
Black or African American	66	33.0
Unreported	58	29.0
Asian	5	2.5
More than one race	9	4.5
Other Pacific Islander	1	0.5

Table 4

Preferred Language (n = 200)

Language	*n*	%
English	142	71.0
Spanish	49	24.5
Other	9	4.5

Parental Barriers to Follow-up Care

Health literacy level. One of the primary barriers identified by the site mentor was the level of health literacy of the patient population. According to researchers, it is important to diagnose health literacy strengths and weaknesses of the patient population being served and to develop specific strategies for responding to the common health literacy limitations relevant to the target population (Batterham et al., 2016; (Betancourt, Green, Carrillo, & Ananeh-Firempong, 2016). The site mentor further identified the need for the educational resources that are distributed at discharge or distributed upon referral to the Infant Clinic to be adjusted to a

Flesch-Kincaid 6th grade reading level (Badarudeen & Sabharwal, 2010; Betancourt et al., 2016). Researchers have also described health literacy to include a person's level of motivation to understand and use information in ways that contribute to good health (World Health Organization, 1998). According to the site mentor, it seems that a lack of patient motivation to attend follow-up appointments contributes to the no-show rate. For this reason, it may be useful to advertise and offer incentives for attending the follow-up appointment.

Lack of NICU parent support. Additionally, both the mothers with NICU experience who were interviewed during the needs assessment phase, and researchers, have described the impact having an infant in the NICU has on overall levels of stress and anxiety and the need for support for NICU parents (Aloysius et al., 2017; Caretto, 2000; Forsythe & Willis, 2008; Hummel, 2003; Williams et al., 2018). One mother from the needs assessment specifically identified a desire for emotional support during her time in the NICU. Research has shown that support from NICU professionals during and after time spent in the NICU, decreased parent anxiety (Aloysius et al., 2017). Therefore, there is a need for emotional support for parents during and after time spent in the NICU, and presence of this type of support could lead to better long-term outcomes for both parents and infants (Aloysius et al., 2017; Caretto, 2000; Forsythe & Willis, 2008; Hummel, 2003; Williams et al., 2018). The type of support that would be most utilized by Eskenazi's patient population will be identified during the implementation phase.

Application to Current and Existing Practice Areas

The settings of the infant follow-up clinic and the NICU are both emerging practice areas for OT (Borges et al., 2017; Lammers, 2018; Vergara et al., 2006). However, the value of identifying the barriers that an organization's patients face in accessing health care, is highly applicable to both existing and emerging practice areas. In order to provide patient-centered care

in any setting, an understanding of patient demographics and barriers patients face must be achieved (Badarudeen & Sabharwal, 2010; Betancourt et al., 2016). However, depending on patient demographics in a particular setting, the barriers that patient's face to showing up for appointments may differ. For example, if the patient demographic consists of patients with higher education levels, higher socioeconomic status, and higher levels of health literacy, there may not be as much of a focus on providing patient incentives due to higher patient motivation levels (World Health Organization, 1998). If the patient population has a higher employment rate and patients have less availability to attend appointments during the work day, a strategy for increasing patient access may be scheduling appointments during evening hours, for example. On the other end of the spectrum, for Eskenazi's patient population, transportation to and from appointments is a barrier many patients face in attending appointments at the Infant Clinic. Therefore, a strategy specific to this patient population could be to provide transportation vouchers for patients.

Overall, the concepts of this project are clearly applicable to any OT practice setting due to OT's emphasis on providing patient-centered care (Stoffel et al., 2017). The varying factors among practice settings are simply the actual patient demographic characteristics. According to researchers, it is the role of all health care organizations to identify how demographic and cultural factors impact patients' access to health care, and to respond by developing strategies to reduce those barriers (Badarudeen & Sabharwal, 2010; Betancourt et al., 2016).

Section IV: Implementation

Data Collection and Identification of Barriers

The implementation phase of this DCE project includes two major foci: identifying the barriers that parents face in coming to their Infant Clinic appointments and developing strategies

to reduce those barriers. The barriers were identified through a parent questionnaire related to the NICU stay, NICU discharge experience, and Infant Clinic appointment (Appendix C). The surveys were written at a 6th grade reading level per the Flesch Kincaid readability standard for medical information (Badarudeen & Sabharwal, 2010). Surveys were completed at Infant Clinic appointments with parents who met the following criteria: parents of infants who had a NICU stay, parents who were present and involved during the infant's NICU stay, and parents who had custody of their infant. Foster parents and parents of infants who came from community referrals (i.e. primary care clinics) were not surveyed due to lack of NICU experience. Due to the high no-show rates and the high number foster parents who come to the Infant Clinic, not many surveys were able to be administered in-person, and those parents who did complete surveys did not answer all of the questions. In order to gather more data, and to gather data from the perspectives of parents who did not come to the Infant Clinic, the survey was also administered over the phone to parents who "no-showed" their Infant Clinic appointments over an eight-month time period. The reasons parents gave for missing the Infant Clinic appointments had moderate variability. Some common responses included: not ever knowing they had an appointment, going to the well-baby visit after NICU discharge thinking it was interchangeable with the Infant Clinic appointment, loosing appointment information, and forgetting about the appointment altogether.

Infant Clinic data collection. In addition to completing the parent surveys, Infant Clinic appointment data from a year-long period was analyzed for number of no-shows. Over a year-long period, ninety-three referrals were made to the Infant Clinic from the NICU. Of those ninety-three, thirty-six no-showed their Infant Clinic appointments, without ever re-scheduling or coming to the clinic for evaluation, resulting in a 38% no-show rate for the Infant Clinic. Forty-five came to their Infant Clinic appointments, with thirteen of those no-showing at least one

time, but often more than one-time. Of the twelve remaining referrals, a few called and cancelled their appointments without rescheduling, and some had upcoming appointments scheduled for evaluation (Appendix D). Data was also collected to track how many infants were actively receiving in-home early intervention services by the time of the Infant Clinic appointment in order to assess for possible gaps in developmental care. Of the forty-five infants who were seen in the Infant Clinic, only nine had activated First Steps services by the time of the Infant Clinic Evaluation.

Minor Process Adjustments

Aside from the focus on data collection, strategies were also developed with the goal of improving the show-rate to the Infant Clinic by increasing communication and continuity of care between the inpatient NICU staff and the outpatient Infant Clinic staff. In order to understand the roles of various NICU staff related to Infant Clinic referrals, several meetings were held with the following NICU team members: social worker, family care coordinator, OTs, STs, nursing manager, and other lead nursing staff. Some small changes that were made based off of those discussions included: updating discharge letters in EPIC (electronic medical documentation system) to use consistent terminology of "Infant Clinic" as the title of the clinic varied among various documentation between NICU staff, causing confusion.

A few of the other minor changes made to the existing referral process included: education about the purpose of the Infant Clinic and importance of attending the appointment, included in the Baby Boot Camp class content. Baby Boot Camp is a class that covers basic newborn care, safety, and information about follow-up appointments. This class is available and encouraged for all parents who deliver their babies at Eskenazi, but it is often mandatory for high-risk parents such as young parents, first time parents, parents lacking social support, or

parents who abused substances or engaged in other risk-taking behaviors throughout their pregnancy. The nursing team will also begin showing parents the location of the Infant Clinic when they walk families out at discharge, in order to increase accessibility of the clinic.

Creation of Resources

Infant Clinic handout. An Infant Clinic handout was created which included details about the appointment, importance of the appointment, what to expect at the appointment, photos of the OT and ST who staff the clinic, and how to prepare for the appointment. This handout will be given to parents at the time of referral to the Infant Clinic by the inpatient NICU therapist who makes the referral. The handout will available for other NICU staff to give to families as necessary (e.g. if parents lose their copy, if nursing thinks a family might benefit from having information about the appointment if a future referral might be needed, etc.). In addition to the NICU, the handouts will be distributed in the newborn unit, where Infant Clinic referrals are occasionally made, and at primary care clinics that often refer to the clinic. These handouts were also sent to the marketing department at Eskenazi for approval and branding prior to distribution (Appendix E). A change that occurred with all resources created, including ensuring that all information given about the Infant Clinic is written at a 6th grade reading level or below in order to meet appropriate health literacy standards for medical information (Badarudeen & Sabharwal, 2010).

Therapy team posters. Due to the feedback received from parent surveys—that parents did not know what the Infant Clinic was, or often could not recall their infant having therapy in the NICU—posters were also created for all NICU baby rooms. The posters provided education on the role of the inpatient therapy team and the outpatient therapy team in the Infant Clinic. These posters were created in collaboration with the family care coordinator in the NICU

(Appendix F).

NICU journal pages. The family care coordinator was in the process of creating a "NICU Journal" to be given to all families with infants in the NICU to be used as a method for tracking their infant's successes, discharge checklists, and notes from the treatment team. As a strategy to increase continuity of care and interdisciplinary collaboration, a few additional journal pages were created in collaboration with the family care coordinator that were focused on a checklist for after discharge (Appendix G). The checklist included various activities such as: attending the well-baby visit, attending the Infant Clinic appointment, completing tummy time, and baby-proofing the home, in order to reinforce the importance of follow-up after discharge. There were also educational pages created in collaboration with the both therapy teams for skills that parents can work on with their infant after discharge. The third page included an interactive feeding worksheet where parents could fill out their infant's feeding plan at discharge, with help from the speech therapist, in order to ensure parents were on the same page as NICU staff at discharge, and to hopefully prepare parents for the Infant Clinic appointment, where a feeding evaluation takes place and parents are expected to know the details of their infant's feeds (i.e. bottle system, nipple size, type of formula, volume per feed, frequency of feeds, etc.).

Establishment of Incentives for the Infant Clinic Evaluation

Due to the aspect of health literacy that is related to level of patient motivation to access appropriate health care, incentives were also developed in an effort to increase parent motivation to attend the Infant Clinic evaluations, as Eskenazi's patient population has on average, low health literacy levels (World Health Organization, 1998). The Marion County Health Department has a program titled the "B.A.B.E." coupon program. This program allows low-income parents who live in Marion County to receive B.A.B.E. coupons for attending their prenatal, post-

partum, and primary care appointments for their infant. B.A.B.E. coupons can be "cashed-in" at the B.A.B.E. store for various essential and non-essential baby items. These coupons were not previously being distributed in the Infant Clinic, and Infant Clinic staff were not aware the program existed, so the application process was completed and the Infant Clinic was approved for B.A.B.E. coupon distribution.

Several local charities and other baby companies were also contacted in search of donations for the Infant Clinic. Project Linus, a charity organization that donates baby blankets to sick children, agreed to provide ongoing baby blanket donations to the Infant Clinic. Aside from the two ongoing donations, several one-time donations were received from baby companies and staff members who had unwanted baby items. These gifts, along with one B.A.B.E. coupon, will be given to parents by the therapists at the initial evaluation, with a note that reinforces the importance of attending these appointments. Moving forward, NICU staff will be telling parents that they will receive a free gift and B.A.B.E. coupon at the Infant Clinic evaluation, in order to increase parent motivation to show-up for the appointment.

Leadership

There were many opportunities for leadership skills development throughout the DCE. Making changes to an existing program is a very sensitive and complex project to take on as the student must gain a comprehensive understanding of how the existing program was run prior to attempting any change. Also, managing communication between therapy teams in two different settings is complicated. In order to build positive working relationships with all staff members, the student spent a lot of time meeting with the team members involved in NICU discharge and Infant Clinic referrals to gain their feedback on areas of strength and weakness with the existing process. Additionally, the student made effort to incorporate every related staff member's

feedback into all aspects of the project. At times there were miscommunications or need for clarification, and the student took additional time to meet with those individuals in order to make sure everyone was on the same page and agreed with any potential changes. All of these experiences provided the opportunity for the development of flexibility, openness, and patience when leading this type of project. Also, due to some tension between the teams, the student was served as a liaison between the two teams and facilitate positive conversations in order to initiate change.

Additionally, these experiences required that the student take initiative to contact and collaborate with professionals outside of the therapy team in order to develop a program that had a holistic approach. This resulted in an increased comfort level with meeting with and presenting in front of various staff members about process changes. It also allowed for change in the referral process in areas that would not have been reached if the project was kept within the therapy department, which will make the program more effective in the long run (Bronstein, 2003).

Staff Development

Due to the extremely busy schedules that both the inpatient therapy team and outpatient therapy team have, there was not time for any one staff member to make quality improvement adjustments to the Infant Clinic referral process. This project involved a lot of time spent in meetings and required being present at both the outpatient campus and the main hospital downtown. Prior to this project, there was limited communication between the inpatient and outpatient therapists, and throughout this project, the student was able to meet with several staff members on both teams in order to gain insight and make changes. This facilitated increased communication and clarity between the teams which will improve continuity of care related to NICU discharge and follow-up in the Infant Clinic. This project also allowed for more

interdisciplinary collaboration as the student involved staff in the NICU in the Infant Clinic referral process, who were not previously involved. Some of these staff members included: Baby Boot Camp leaders, nursing, and the family care coordinator. There was a lack of understanding of the roles that each member played in the NICU and in the Infant Clinic, so the student created a discharge guidelines resource that summarized every team member's role in making Infant Clinic referrals or other roles related to NICU discharge (Appendix H). This resource will be used to further staff development after the DCE ends, as NICU and Infant Clinic staff may refer to it in order to know who to reach out to when needed regarding specific aspects of the discharge process. There was also a statement released in the Eskenazi staff newsletter over a span of several days, in order to inform all staff about the Infant Clinic and how referrals are made as many staff members did not even know it existed. Specific information about the changes to the process will also be presented to the NICU staff that is involved in making referrals to the Infant Clinic during a lunch and learn. The goal is that this project will impact staff development long-term, not only related to the Infant Clinic, but also by increasing interdisciplinary collaboration moving forward.

Section V: Discontinuation & Outcomes

Project Outcomes

A goal attainment scale (GAS) was created by the student in order to measure project outcomes (Case-Smith & O'Brien, 2014). The GAS was focused on goals specific to the program development and was scored by the site mentor. All four project goals met at least "more than the expected outcome," with three of the four goals meeting "much more than expected outcome" (Appendix I).

Discontinuation

There are several strategies in place for ensuring this project can be sustained after the student completes the DCE rotation. The identification of barriers to the Infant Clinic show-rate and the development of strategies to reduce barriers, can be easily sustained by NICU and Infant Clinic staff. For example, the survey given to parents to identify barriers faced in accessing developmental care during and after NICU discharge, will be left with the site mentor for distribution in the future as desired. The initial survey that was developed for identification of parental barriers was rather lengthy and would not be easily utilized by the site mentor due to time constraints during Infant Clinic appointments. To address this problem, a simplified version was created that will be more realistic for the site mentor to administer during Infant Clinic appointments. The data collected from these surveys was provided to the site mentor on a shared computer folder so that she may complete further data analysis if desired in the future. The appointment data that was gathered by the student including: number of Infant Clinic referrals from the NICU versus Newborn Unit or community referrals, no-show rate, cancellation rate, and First Steps referral rate versus infants receiving First Steps services at time of the Infant Clinic evaluation, will also be available for the site mentor to access as desired on the shared computer folder. The student focused data analysis on no-show rate, but also tracked other data that the site mentor may utilize for future program development.

In order to guarantee continued utilization of the strategies that were developed by the student, the student held a “Lunch and Learn” presentation for related staff that will be responsible for maintenance of these strategies. The Lunch and Learn included presentation of the data that was gathered during the implementation phase, as well as the many strategies that were put into place to hopefully reduce barriers. The student developed a written discharge protocol resource that outlines each related NICU and Infant Clinic staff members’ specific roles

related to the discharge and Infant Clinic referral process. The staff members included in the discharge guidelines included: the NICU social worker and case manager, the family care coordinator, NICU speech and occupational therapists, NICU nursing staff, Infant clinic speech and occupational therapist, outpatient therapy managers, and registrars responsible for scheduling Infant Clinic appointments. In addition to the clarification of staff roles related to discharge, each staff member description also included roles related to the new Infant Clinic referral process. The resource was originally titled "NICU Discharge and Infant Clinic Referral Protocol/Staff Roles," however, at the lunch and learn, the therapy manager clarified that the term "protocol" cannot be used unless the guidelines are mandated by the hospital managers, so the term "guidelines" was used instead.

Another important aspect of the Lunch and Learn was the emphasis on addressing health literacy level of the patient population (Badarudeen & Sabharwal, 2010). Staff were shown how to assess the readability of educational resources and handouts given to families and given resources to utilize for identifying words related to higher reading levels in order to empower staff to address this independently moving forward. All resources that were created by the student were created at the appropriate reading level and will be available on a shared computer folder in order to staff to reprint as needed. The educational material published through the marketing department will be printed as needed through Eskenazi's printing department, Ricoh. The site mentor will be responsible for placing new orders.

In order to sustain the ongoing donations that were secured as incentives for parents to come to the Infant Clinic, the student trained the site mentor on the process for requesting more inventory when the supply in the Infant Clinic runs low. Further, the student transferred the necessary contact information for the charity organizations to the site mentor and left detailed

instructions in the shared computer folder for the site mentor's reference. The student also organized the donations and ensured they would be easily accessible by the site mentor for distribution (i.e. wrapped onesies and blankets together, ensured the site had needed stamps to authorize coupons, etc.).

An important emphasis of the project was on interdisciplinary collaboration, which was essential in the completion of this project and is required moving forward in order to sustain the strategies (Bronstein, 2003; Welch et al., 2017). The written discharge guidelines highlight the reliance that NICU and Infant Clinic staff have on one another in order for the new process to be successful. The strategies that were implemented would not have been possible without communication between all related NICU and Infant Clinic staff, which is why continued communication between inpatient and outpatient services is so important in order for the program to keep progressing. The collaboration between various disciplines allowed Infant Clinic education to be shared with patients and staff through avenues that would not have been identified or utilized without such interdisciplinary collaboration (Bronstein, 2003).

Response to Societal Needs

It is essential for infants discharged from the NICU to have access to developmental care as they are at a high risk for having a developmental delay and experience improved outcomes with early intervention services (Bockli et al., 2014; Santos et al., 2015). It is the responsibility of health care providers to assess the barriers that patient's face in receiving these services and to develop a plan to minimize or eliminate these barriers (Betancourt et al., 2016). This project addressed the barriers that Eskenazi's patients experience in accessing developmental care through parent-centered interviewing and development of strategies that met health literacy guidelines (Batterham et al., 2016). All resources given to parents about the Infant Clinic moving

forward, will meet the reading level requirement for medical information, and education about the Infant Clinic will be given consistently throughout the NICU stay through a variety of sources, including: NICU staff, Baby Boot Camp classes, NICU journal, posters in baby rooms, and Infant Clinic appointment materials given at time of referral (Batterham et al., 2016). Strategies will be continued on the outpatient side of services at the Infant Clinic through parent reinforcement of the importance of providing early developmental care to their infants (Greene & Patra 2016; Orton et al., 2018). In addition to targeting the low education levels commonly held by patients with low health literacy levels, the strategies also targeted patient motivation by offering incentives for coming to the Infant Clinic evaluation. Not only does this encourage parents to come to the appointment, but it also reduces the financial burden that many patients have, by providing free baby supplies to parents. These strategies will help the Infant Clinic therapists to provide necessary developmental care to a greater number of fragile NICU graduates, reducing the length of the wait list by increasing the first-time show-rate to evaluations. Most importantly, the increased ease in accessing the Infant Clinic will provide better long-term outcomes for infants (Nwabara et al., 2017; Greene & Patra 2016; Orton et al., 2018).

Section VI: Overall Learning

Communication Skills

Communication with parents. Communication was a fundamental part of this DCE project as the student served in a consultative role during a majority of the experience. One aspect of patient communication that has been thoroughly discussed, is the communication of important Infant Clinic information at the appropriate health literacy level of the patient population (Batterham et al., 2016). This included using terms that were simple and easy to

understand when providing verbal education to families and writing all printed information at a 6th grade reading level or below (Batterham et al., 2016). Due to the history of substance abuse during pregnancy that many of the parents coming to the Infant Clinic had, it was also important to approach all parent interactions without making assumptions or judgments about the parents' desires to love and care for their infant despite making unfavorable choices. It was also essential to show empathy while communicating with parents and acknowledge the difficult experiences they have endured having had an infant in the NICU. When the student made phone calls to parents who no-showed their Infant Clinic appointments, it was especially important to be sensitive to parent experiences, as being questioned about the reasoning behind not attending their infants' appointment, could be perceived as an attack. The student made increased effort to acknowledge the busy schedules and difficult experiences that parents had as well as thank parents for feedback while reinforcing the importance of their input in improving Eskenazi's services, with every parent interaction.

The student also gained experience with working with patients of diverse cultural backgrounds as many of the patients were Spanish-speakers. In order to facilitate communication, the student often used an interpreter, both live and over-the phone. However, there were times when interpreters were not available and the student was flexible in finding alternative means for communication. In order to provide client-centered care with use of an interpreter, it was crucial that the student maintained eye contact and receptive body language with the parent and/or patient while the interpreter was talking, and took additional time to confirm that the patient understood all aspects of education and recommendations.

Communication with staff. Communication with colleagues and staff was also completed with sensitivity as the student served as a liaison between the inpatient therapy team

and outpatient therapy team and was often communicating about changes to existing processes which can be difficult to do, not only as a student, but also as a person who is new to the organization. In order to make sure important information about changes to the existing processes were communicated correctly and carefully, the student planned time to be at the hospital in the NICU to have in-person meetings, as messages can often be misconstrued over email. Also, any time a new resource was created that involved information about various staff roles or collaboration with other professionals, the student asked for feedback from the involved staff members so that everyone was on the same page, and there were not any surprises with the new guidelines. All data regarding the Infant Clinic and additions to the existing processes were approved by NICU staff, then presented in-person to staff so that any needed clarifications could be provided immediately. Also, it was important for the student to keep an open, flexible mindset throughout all of these meetings so that staff felt free to offer concerns, opinions, and ideas.

The student took time to develop relationships with staff members who were not previously involved in the Infant Clinic referral process but were perceived by the student to be a good fit for delivering parent education about the importance of follow-up care after NICU discharge. These relationships resulted in collaboration on several different projects and allowed the Infant Clinic education to infiltrate more aspects of the NICU stay than previously anticipated (i.e. Baby Boot Camp in Newborn Unit, nursing staff showing parents the location of the clinic at discharge, etc.).

Other strategies were used in order to disseminate information about the Infant Clinic to a large group of people. A statement was released in the Eskenazi employee newsletter informing staff about the purpose, location, and schedule for the Infant Clinic, and publishing of informational materials about the Infant Clinic to be distributed to patients at all referral source

locations. Nursing staff was educated through an informational email about the purpose of the Infant Clinic and their roles in assisting with the referral process.

Communication with the public. Communication with the public and community took place in order to ask for and coordinate ongoing donations for the Infant Clinic. The student contacted dozens of companies and charities and shared the project purpose, while also sharing the plan for using any donated supplies to motivate parents to attend the Infant Clinic. The student also used strategic communication of researching the charities mission and specifically detailing how their mission aligned with that of the Infant Clinic's. All interactions were positive and the student followed up with every organization after receiving donations to express gratitude and to give specific examples of how the donation will positively impact patients' lives.

Leadership and Advocacy Skills

Leadership. The student utilized leadership skills by taking initiative at every phase of the project. The site mentor was occupied with a full caseload and also served in a leadership position at the outpatient clinic, working on program development of her own in other areas. Due to the site mentor's varied availability, it was important for the student to take initiative to contact other staff members in order to make connections and develop relationships with staff at all sites (i.e. outpatient clinic, Infant Clinic, NICU). Creating change in existing processes is difficult to do, so much of the student's initiative was demonstrated in forming positive working relationships across various inpatient and outpatient disciplines and spending extensive time observing other disciplines in order to learn about their roles and potential areas for collaboration. This allowed the student to inform other therapy staff about the roles that non-therapy staff play related to follow-up after NICU discharge and implement changes in areas that would have not otherwise been reached. This initiative also set an example for other staff about

the positive outcomes that occur with interdisciplinary collaboration. The multidisciplinary staff was already very collaborative with patient care during the NICU stay, however, the potential collaboration opportunities related to follow-up care post NICU discharge had not been addressed.

Advocacy. There were many opportunities for advocacy throughout the DCE. The student utilized advocacy skills through identification of barriers that patients face in accessing health care and by acting to reduce such barriers. Though the surveys questioned parents on the reasoning for no-showing the Infant Clinic appointments, questions were also included to gain feedback from parents on what would have made the NICU stay and discharge experience more successful. These questions were asked so that continued quality improvement takes place using feedback provided directly from past NICU families, ensuring the specific needs of patients are being addressed. Acknowledgement that Eskenazi's patient population consists of individuals with diverse cultural backgrounds, who require strategies designed specifically for them, is another form of patient advocacy (Betancourt et al., 2016). An example of strategies designed specifically for this patient population include the time that appointment reminders are sent to families. The registrars send families appointment reminders the day before their appointments, which may seem like late notice for individuals who come from a higher socioeconomic status and are working, requiring scheduling in advance, however, according to feedback given by parents, these appointment reminders come at a good time for them. Some parents commented that they would like reminders even closer to the appointments, such as day of the appointment. Also, the education that was provided to staff on the importance of creating resources that are at the appropriate reading level for the patient population being served, is another example of utilization of advocacy skills (Betancourt et al., 2016; Batterham et al., 2016).

In regard to the patient care aspect of this DCE, patient advocacy took place through documentation. Many of the parents from this patient population have had custody battles to keep their infants, either due to domestic violence, substance abuse, or other factors. When parents come to the Infant Clinic and it is obvious that they are playing an active role in providing appropriate care for their infant and are committed to making changes, it is always documented so that the parents have support from health care providers who have witnessed parents provide proper care to their infants.

Conclusion

The student met all goals set for the DCE as well as developed strong leadership and program development skills. With the newly implemented strategies in place, patient barriers to accessing the Infant Clinic will be reduced. More importantly, the strategies have facilitated increased staff sensitivity to health literacy levels and the strategies implemented have proven the effectiveness of an interdisciplinary team. The new guidelines will ensure that the Infant Clinic referral process consists of interdisciplinary collaboration, resulting in increased continuity of care and better long-term outcomes for infants and their families.

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Appendix A

Needs Assessment Questions for Site Mentor

1. What is currently going well for the Infant Clinic?
2. What is currently not going well for the Infant Clinic?
3. What factors do you think contribute to the “no show” rate?
4. What do you think is going well at NICU discharge that contributes to parents showing up for their appointments?
5. What do you think is not going well at NICU discharge that contributes to parents not showing up for their appointments?
6. How do you think cultural background impacts the follow through/show-rate with the Infant Clinic?
7. If you could make one change to the discharge process, what would it be?
8. Do you have any ideas for incentives that could be offered to parents when they arrive to the Infant Clinic for their first appointment?

Appendix B

Needs Assessment Questions for One-on-One Parent Interview

Reason for child stay in the NICU/hospital:

Length of stay in hospital:

1. What factors were helpful for you during time spent in the NICU?
2. What was most difficult about having your infant in the NICU?
3. Did you feel involved in the care of your infant while he/she was in the NICU?
4. Did you understand the medical needs of your infant while he/she was in the NICU?
5. What made you feel most supported when your infant was in the NICU?
6. Did you have contact with any other parents who had their baby in the hospital?
7. When/Where you contacted by First Steps after discharge from the NICU?
8. How long did it take for a First Steps therapist to get to your house after discharge from NICU?
9. Did your infant receive services at a NICU follow up clinic with OT/ST?
10. What was difficult about keeping track of appointments? What would make it easier to keep track of your baby's appointments?
11. How did you manage your schedule with doctor's appointments after discharge?
12. Did you feel equipped to participate in your child's development at home? (working on strategies taught by therapy?)
13. What would make you feel more supported/at ease when taking your child home from the NICU?
14. Would you be interested in a home program to "fill the gap" between discharge from NICU to waiting for either First Steps or outpatient services?
15. What information were you given in the NICU about how to support your child's development/available services?
16. Did you understand the purpose of the NICU follow-up appointment?

Appendix C

NICU Discharge Parent Survey (Implementation Phase)

1. What is your relationship to your baby?
    a. Birth mom
    b. Birth dad
    c. Foster mom
    d. Foster dad
    e. Other (Explain): _____

2. Why was your baby in the NICU?
    a. My baby was too small
    b. My baby came too early
    c. My baby was not eating enough
    d. My baby needed help breathing
    e. My baby needed medicine
    f. Other (Explain): _____

3. What/Who was helpful for you during time spent in the NICU?
    a. Employees in the NICU
    b. Educational papers given to me in the NICU
    c. Support from my family and friends
    d. Practicing with a therapist or nurse before I left
    e. I looked up things about the NICU online so that I could understand what was going on
    f. Other (Explain): _____

4. What was most difficult about having your baby in the NICU?
    a. Not understanding what was happening with my baby
    b. Having to see my baby upset or in pain
    c. Finding time to visit my baby because of work, or my other kids
    d. Trying to keep track of meetings about my baby's care
    e. Not being there to talk to my baby's doctors or nurses
    f. Not having an interpreter there to help me talk to my baby's doctors or nurses
    g. Other (Explain): _____

5. Did you feel involved in helping take care of your baby while he/she was in the NICU? (For example, involved in diaper changes, feeding, holding, comforting, etc.)
    a. Yes
    b. No

6. During your baby's time in the NICU, did you have contact with any other parents who currently or previously had a baby in the NICU?
    a. Yes
    b. No

7. Would you have used any of the following (circle if you would have):
    a. In-person parent support groups while your baby was in the NICU
    b. Online support group for parents of babies in the NICU
    c. Opportunity to talk to parents who have had babies in the NICU in the past

8. First Steps in a company that provides therapists to come to your house to help your baby get stronger and continue to grow. Before today, did you know what First Steps was?
    a. Yes
    b. No

9. Did First Steps call you?
    a. Yes
    b. No

10. When were you contacted by First Steps after discharge from the NICU?
    a. 1st week after discharge
    b. 1st month after discharge
    c. More than one month after discharge
    d. Other (Explain): _____

11. Was it hard to keep track of your baby's appointments?
    a. Yes
    b. No

12. Why was it hard to keep track of your baby's appointments?
    a. Too many other appointments
    b. My schedule is too busy
    c. No way to organize appointments
    d. Did not know when appointments were
    e. Did not know where appointments were
    f. Other (Explain): _____

13. What would make it easier to keep track of your baby's appointments?
    a. Reminder calls or texts
    b. Having a place to write it down
    c. Having support from a friend or family member
    d. Transportation to help me get there
    e. Other (Explain): _____

14. When it was time for your baby to be discharged from the NICU, how comfortable were you with changing his/her diaper?
    a. Completely uncomfortable
    b. A little bit uncomfortable
    c. I felt I could do it, but I was a little nervous
    d. Fairly comfortable

e. Completely comfortable
f. Other (Explain): _____

15. When it was time for your baby to be discharged from the NICU, how comfortable were you with feeding your baby?
    a. Completely uncomfortable
    b. A little bit uncomfortable
    c. I felt I could do it, but I was a little nervous
    d. Fairly comfortable
    e. Completely comfortable
    f. Other (Explain): _____

16. When it was time for your baby to be discharged from the NICU, how comfortable were you with holding and moving your baby?
    a. Completely uncomfortable
    b. A little bit uncomfortable
    c. I felt I could do it, but I was a little nervous
    d. Fairly comfortable
    e. Completely comfortable
    f. Other (Explain): _____

17. What would make you feel better about taking your baby home from the NICU?
    a. Having a phone number I can call to talk to someone from the NICU after discharge
    b. More training on (Check all that apply):
        i. NG tube _____
        ii. G tube _____
        iii. Feeding my baby _____
    c. Papers that remind me how to do exercises for my baby
    d. Papers that remind me about medicines for my baby
    e. Practicing feeding, diaper changes, and handling my baby before I go home with my baby
    f. Other (Explain): _____

18. Before your baby went home, did the occupational therapist meet with you to practice exercises with your baby?
    a. Yes
    b. No

19. Before your baby went home, did the speech therapist meet with you to practice feeding your baby?
    a. Yes
    b. No

20. Did you understand why you were scheduled for the NICU follow-up appointment you attended today?

a. Yes
b. No

21. Was it hard to make it to the NICU follow-up appointment today?
    a. Yes
    b. No

22. What was hard about coming to your appointment today?
    a. I have other kids I have to take places
    b. My baby has a lot of other appointments
    c. I do not have a car and I have to plan my transportation
    d. The time of the appointment
    e. I did not know where the was
    f. Other (Explain): _____

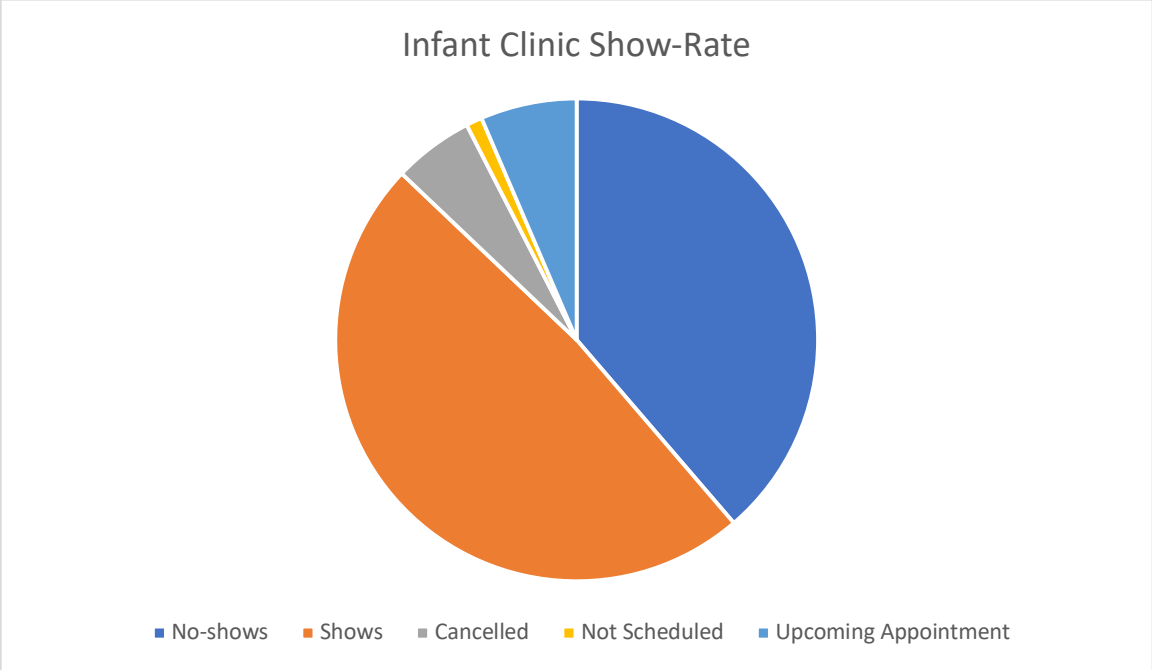
23. Did you ever use the handouts given to you at discharge?
    a. Yes
    b. No

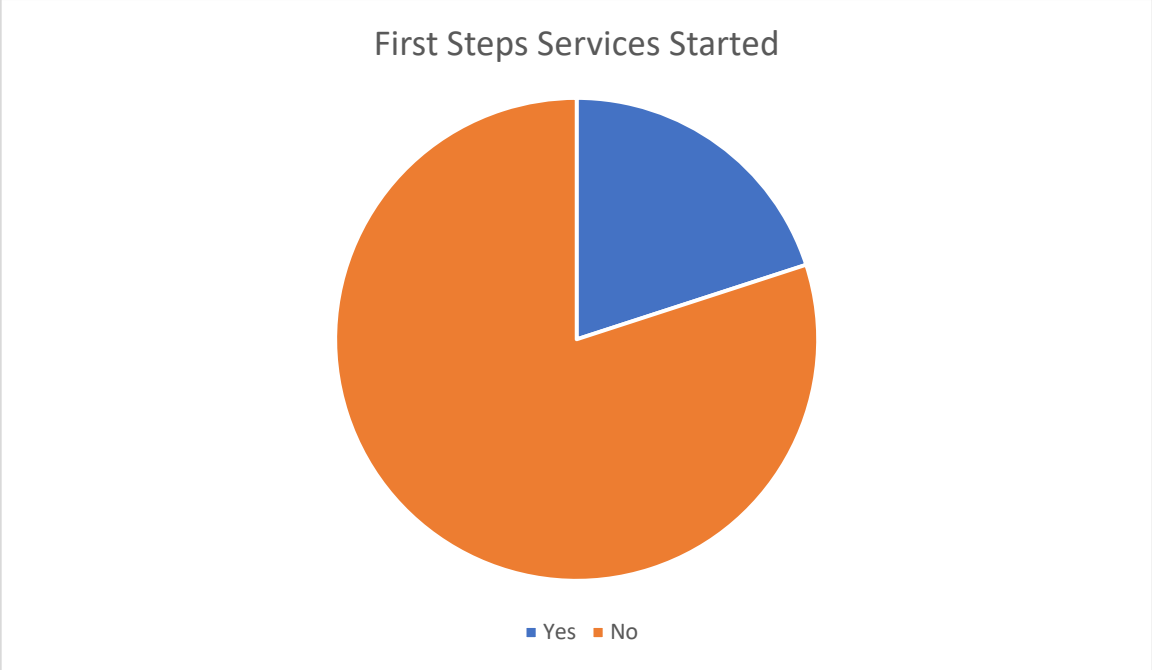
24. If no, why?
    a. Too many forms
    b. They were hard to read
    c. Did not understand what to do
    d. Not relevant to my baby
    e. Other (Explain): _____

Additional Comments:

Appendix D

Infant Clinic Data





Appendix E

Infant Clinic Resource

ESKENAZI HEALTH

Your Infant Clinic Appointment

What will happen at the appointment?

- The therapists will ask you questions about your baby's birth and time in the hospital. They will also ask you how things are going at home.
- The therapists will hold and play with your baby to check his or her body, head and eye movement.
- The therapists will watch you feed your baby to make sure he or she is eating safely and comfortably.
- The therapists will tell you how your baby is doing and give ideas for helping him or her grow and learn at home. They will also answer any questions you have.
- The therapists may want to see your baby again to make sure he or she continues to grow normally and to support you.
- **Bonuses:** You will find out your baby's weight and receive a B.A.B.E. coupon and a small gift for you and your family.

What should I bring to the appointment?

- Any bottles and nipples you have been using or plan to use at home
- Formula or breast milk to use during the evaluation
- Breastfeeding supplies that have been recommended
- Pacifiers or special blankets that might help make your baby more comfortable
- Any paperwork you have been given after special tests or appointments
- At least one dry diaper
- Baby foods and spoons if your baby is eating these

Where is the appointment?

Your appointment will take place in the **Outpatient Rehabilitation Center**, located on the first floor of the Sidney & Lois Eskenazi Hospital, 720 Eskenazi Ave., Indianapolis, IN 46202. The center is located next to the Frank & Katrina Basile Gift Shop.

When you arrive, please check in at the front desk. The center can be reached at **317.880.0280** should you have any questions.

When is the appointment?
My appointment is on:

_____ at _____

Please note the appointment may last up to 60 minutes.

Why do I have this appointment?
Babies who are born early are at more risk for having developmental delays. Therapists are here to work with you and your baby so that he or she has better functioning later in life.

During the appointment, an occupational therapist and a speech therapist will complete a check-up on your baby and watch him or her eat. This will show what skills should be focused on to help your baby learn and grow. The therapists will teach you ways to help your baby at home.

Please bring your baby hungry

- Please bring your baby hungry, but not starving, to your appointment.
- This might be hard, but if your baby is hungry at the time of the appointment, it is more likely that he or she will eat while with the therapists.
- Watching your baby eat will help the therapists see how your baby is doing.
- You can give your baby a "snack" if he or she is fussy. A "snack" is 1 – 2 ounces. Please do not give the full feeding. You may also ask for an appointment time that is during your baby's normal feeding time.

Meet your therapists


Emily Faurote, OTD, OTR


KC Paez, MS, CCC-SLP

The Infant Clinic was established in 2016. Emily and KC have a lot of experience and special training in the care of children under 12 months of age.

Appendix F

Therapy Team Posters for Infant Rooms in NICU

Appendix G

NICU Journal Therapy Related Pages

*Photos were removed to preserve patient privacy. Patients gave consent to Eskenazi.

I'm a NICU graduate! Help me thrive!

Dear mom & dad, grandma, grandpa, aunts, uncles, and friends:

My care team asked me to tell you these important things that we can do together to help me learn and grow! Ask my pediatrician or my friends at the Infant Clinic if you have any questions!

Love,

_____

Play:

- ⇒ Do skin-to-skin (kangaroo care) with me every day. It boosts our bond!
- ⇒ Help me do 20 minutes of tummy time each day while I am awake and you are watching me. This helps me learn to crawl!
- ⇒ Talk, sing, and read quietly to me. Make eye contact and smile at me. The more the better. This all helps me learn to communicate!
- ⇒ Keep the lights low and avoid loud sounds. I'm still sensitive!

Sleep:

- ⇒ **ALWAYS** put me to sleep **A**LONE, on my **B**ACK, in my own **C**rib.
- ⇒ Use a sleep sack instead of a swaddle whenever possible.
- ⇒ NEVER use blankets, leave me on my tummy, or sleep with me. I could suffocate!
- ⇒ Please don't wake me up unless it is time for me to eat. My brain is developing!

Eat:

- ⇒ Follow my NICU feeding plan when we go home, and increase my feeds each week as directed. You can fill out my plan on the other side of this sheet!
- ⇒ NEVER prop my bottle. I could choke!
- ⇒ Feeding is a special bonding time! It should be a safe, happy experience.

Remember:

- ⇒ Keep all my appointments. In addition to seeing my pediatrician, I may need to be seen at the Infant Clinic to make sure I'm eating safely and growing the way I should. I might need other specialists, too. All are important to my health!
- ⇒ NEVER shake me. It could seriously damage my brain and I could die.
- ⇒ Please call my doctor if you have any questions about caring for me.
- ⇒ I can't wait to explore the world outside NICU with you!!

My Baby's Feeding Plan

This plan was created on _____ and should be followed until _____.
Please call your pediatrician if you have any questions about feeding your baby after discharge.

My baby's feeding schedule is: _____.

I will feed my baby with (circle the option that applies to you):

Breast Bottle Tube

I use a _____ nipple with _____ bottle to feed my baby.

My baby takes _____ ounces at every feed, for a total of _____ ounces per day.
(Remember: increase my feeds each week by _____).

I mix my baby's formula by adding _____ scoops of formula to _____ounces of water.

When I feed my baby, I should hold them in the following position
(circle the one that applies to you):

Back Side Side-lying Sitting up

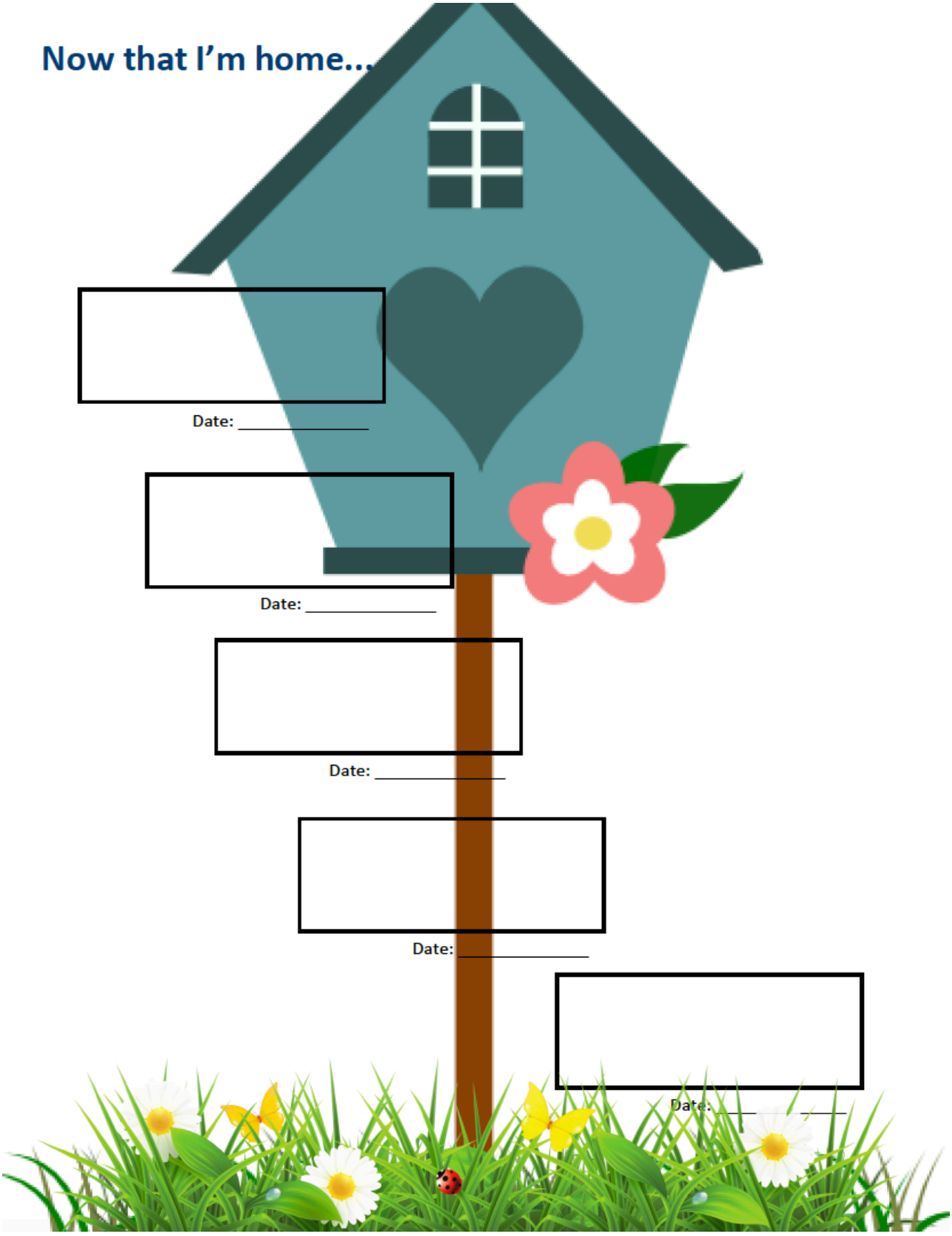
The other recommendations given to me for my baby include:

_____.

If I have questions about feeding my baby, I should call my pediatrician:

Pediatrician's name: _____

Pediatrician's phone number: _____


Now that I'm home...
Date: _____
Date: _____
Date: _____
Date: _____
Date: _____

Date: _____

Date: _____

Date: _____

Date: _____

Make your own stickers...	Road to home stickers	Now that you are home stickers
	My parents picked my pediatrician.	My parents added my first appointments to their calendar/phone!
	My parents attended Baby Boot Camp.	I went to my first well-baby visit!
	I have a crib and a car seat.	I went to my first Infant Clinic visit!
	My caregivers are all practicing the ABCs of safe-sleep.	My parents spoke with First Steps of Indiana!
	I passed my car seat study.	My parents taught all my caregivers the ABCs of Safe Sleep!
	I'm taking all my feeds and meeting nutritional goals set by my care team.	My parents do daily supervised tummy time with me!
	I'm brady/apnea free, or I passed my event countdown.	My parents protect me from dangers of secondhand smoke!
	My follow-up appointments are set.	My parents tested our smoke detectors and made an emergency exit plan.
	My parents roomed-in!	My parents "baby proofed" our home for me!
	My care team says I'm ready to go home from NICU!	

Appendix H

Infant Clinic Referral Guidelines and Staff Roles

Multidisciplinary Roles Related to NICU Discharge and Infant Clinic Follow-Up
*All Staff use the terminology: "Infant Clinic" when referring to this appointment

Sabrina Quigley- NICU Social Worker & Case Manager

- Collaborates with the multidisciplinary team to determine what type of follow-up may be needed for each infant after discharge such as: home nursing, enteral feedings, outpatient case management, and/or First Steps.
- Discusses follow-up recommendations with team and families and facilitates needed referrals to those agencies/providers as agreed upon by family.
- Makes community referrals for families based on individual case-by-case needs (e.g. Healthy Families, Healthy Start, referrals for baby supplies, WIC, counseling, employment, education, child care, peer-parent support, financial resources, or social security referrals for babies with qualifying medical needs).
- Coordinates with DCS when indicated to ensure safe and timely discharge of infants to their identified caregivers
    - Ensure the caregivers have access to appropriate services for baby after discharge
- Points out/reinforces importance of follow-up appointments to parents (including Infant Clinic)

Infant Clinic Specific Changes

- Name of Infant Clinic appointment changed in family Discharge Lists from "Outpatient Rehabilitation" to "Infant Clinic"

Angela Meyers- Family Support Coordinator, (NICU Nest)

- Provides support to new parents in the NICU through promoting parent-provider partnerships, helping parents navigate newborn Medicaid, selecting a primary medical provider for their infants, and teaching families how to use Medicaid cabs
- Hosts family support activities on the unit
- Assists with accessing community resources
- Offers free baby pictures to parents
- Promotes parent self-care (e.g. reminds parents to stay hydrated, eat regular meals, ensures breastfeeding moms know how to use their meal cards, share strategies for stress management, helps to facilitate needed referrals/services if parents express depression or anxiety, etc.)
- Collaborates with other members of the care team to develop resources that support education for families

- Created and manages NICU journal
- Provides education to parents during Baby Boot Camp (Mondays for Spanish speakers)

Infant Clinic Specific Changes

- NICU journal pages include parent education from a therapy perspective:
  - Eat, Play, Sleep page (ways to facilitate developmental after discharge)
  - Interactive feeding plan page (to promote parent understanding of their infant's feeding plan at discharge and to help prepare for potential Infant Clinic appointment)
  - Page for tracking progress after discharge home (writing appointments in calendar, attending Infant Clinic appointment, attending well-child visit, etc.)
- Collaboration for poster in NICU baby rooms which explains the purpose of Inpatient and Outpatient therapies (NICU and Infant Clinic)
- Notify Emily if posters need to be replaced or updated
- Inclusion of Infant Clinic education in Baby Boot Camp classes

Nursing Staff

- Ensure all discharge criteria have been completed (e.g. car seat study, pre/post O2 sats, NBN screen, etc.)
- Provide discharge education specific to patient (e.g. tube feeding, nutrition preparation, medication administration, newborn care, circumcision care, etc.)
- Lead Baby Boot Camp classes (only specific to some nursing staff, not all)
- Review of all follow-up appointments
- Review final discharge summary
- Observe car seat installation and infant positioning in car seat and provide education when needed
- Escort patient to discharge location

Infant Clinic Specific Changes

- Re-iterate importance of attending Infant Clinic appointment at discharge during family appointment review
- Show ALL parents/families the location of the Infant Clinic at discharge while walking them out

Inpatient NICU Occupational & Speech Therapists

Occupational Therapy Specific:

- Meet with caregivers during NICU stay to provide training on infant positioning and/or infant massage (as able)
- Provide parent education regarding infant progress
  - Developmental home program and or individualized home exercise programs
- Answer any questions parents have regarding recommendations

Speech Therapy Specific

- Meet with caregivers during NICU stay to provide coaching during a feeding, education, support about specific interventions and recommendations (as able)
- Establish a home feeding plan that is safe, promotes infant's growth, and is collaborative with the family's needs and culture (verbally or in writing) as appropriate
- Offer recommendations based on the infant's current skills and cues
- Answer any questions parents have regarding home feeding plan/recommendations

Both Therapies:

- Attend weekly discharge planning rounds for multidisciplinary collaboration in preparing for infant's discharge home
- Make recommendations or referrals for follow-up services or therapy as indicated (e.g. First Steps, Infant Clinic, outpatient video fluoroscopy swallow study, etc.)
- Assist infants and their families with smooth transition from NICU to home
- If an Infant Clinic referral is made:
    - Communicate with registrar to schedule appointment
    - Provide appointment reminder

Infant Clinic Specific Changes

- Provide parents with new Infant Clinic informational materials when providing appointment reminder and reinforce importance of appointment
- Notify Emily when stock of Infant Clinic informational materials needs to be replenished

Outpatient Infant Clinic Occupational & Speech Therapists

- Evaluate infant development and parent feeding infant
- Provide recommendations for exercises, positioning, feeding program, etc., at home
- Answer any questions parents have regarding home exercise plans/recommendations
- Determine need for further services and initiate First Steps referral, if needed
- Schedule needed return visits and provide family with an appointment reminder

Infant Clinic Specific Changes

- Maintain stock of Infant Clinic informational resources (reprint for NICU staff when notified)
- Provide parents with ongoing donations at time of 1st eval (Project Linus & B.A.B.E. coupons)
- Maintain stock of ongoing donations
- Administer parent survey as needed/desired

Registrars

- Schedule Infant Clinic evaluation after receiving order from NICU team
- Inform inpatient therapists via in-basket when appointment has been scheduled

- Call parents to confirm details of Infant Clinic appointment within 1 week of appointment
- If parents do not answer, leave a detailed message telling parents to call back to confirm
- Make at least one more attempt for contact with parents

Infant Clinic Specific Changes

- Read script for Infant Clinic appointment confirmation calls (includes updated info needed for Infant Clinic appointments, similar to information included on new Infant Clinic resource)

Appendix I

Goal Attainment Scale (Outcome Measure)

*Items in bold are the score given by the site mentor.

Goal 1: Identify the barriers that parents face in understanding information about their Infant Clinic appointment and barriers to coming to the Infant Clinic.

Much less than expected outcome	Less than expected outcome	Expected outcome	**More than expected outcome**	Much more than expected outcome
-2	-1	0	**+1**	+2
Receive feedback from less than 5 parents on barriers faced in understanding and accessing the Infant Clinic and the feedback is unclear/parent does not identify any external barriers that can be impacted by project	Receive feedback from less than 5 parents on barriers faced in understanding and accessing the Infant Clinic	Receive feedback from at least 5 parents about barriers faced in understanding and accessing the Infant Clinic	**Receive feedback from 10 or more parents on barriers faced when understanding and accessing the infant clinic (and feedback comes from parents who come to the clinic and parents who no-showed)**	Receive feedback from 20 or more parents on barriers faced when understanding and accessing the infant clinic (and feedback comes from parents who come to the clinic and parents who no-showed)

Goal 2: Complete data analysis in order to understand number of no-shows (NS) and number of patients receiving First Steps (FS) services by time of initial Infant Clinic Evaluation.

Much less than expected outcome	Less than expected outcome	Expected outcome	More than expected outcome	**Much more than expected outcome**
-2	-1	0	+1	**+2**
Complete data analysis for NS rate and FS rate for at least 5 weeks of Infant Clinic Appointments	Complete data analysis for NS rate and FS rate for at least 5 weeks of Infant Clinic Appointments	Complete data analysis for NS rate and FS rate for at least 10 weeks of Infant Clinic Appointments	Complete data analysis for NS rate and FS rate for at least 14 weeks of Infant Clinic Appointments	**Complete data analysis for NS rate and FS rate for 15+ weeks of Infant Clinic Appointments**

(during timeline of DCE) BUT there is some missing data	(during timeline of DCE)	(during timeline of DCE)	(during timeline of DCE)	**(including timeline of DCE) and complete additional data analysis relevant to project**

Goal 3: Meet with NICU staff to gain feedback about existing Infant Clinic referral process

Much less than expected outcome	Less than expected outcome	Expected outcome	More than expected outcome	**Much more than expected outcome**
-2	-1	0	+1	**+2**
Meet with at least 1 OT and 1 ST from the NICU to gain insight on Infant Clinic referral process (successes and barriers), but contact takes place 25% or less during DCE timeline	Meet with at least 1 OT and 1 ST from the NICU to gain insight on Infant Clinic referral process (successes and barriers), but do not maintain ongoing communication throughout DCE (contact takes place less than 50% but more than 25% of total weeks)	Meet with at least 1 OT and 1 ST from the NICU to gain insight on Infant Clinic referral process (successes and barriers) and contact takes place at least 50% of DCE timeline (7/14 weeks)	Meet with at least 1 OT and 1 ST from the NICU to gain insight on Infant Clinic referral process (successes and barriers) AND at least 1 other professional in the NICU related to the discharge process	**Meet with at least 1 OT and 1 ST from the NICU and 2 or more other NICU professionals, to gain insight on Infant Clinic referral process (successes and barriers) AND maintain communication on regular basis (~75% of DCE)**

Goal 4: Identify and implement strategies to increase parent/patient access to infant follow-up clinic.

Much less than expected outcome	Less than expected outcome	Expected outcome	More than expected outcome	**Much more than expected outcome**
-2	-1	0	+1	**+2**
Identify strategies to reduce barriers	Identify strategies to reduce barriers	Identify strategies to reduce barriers	Identify strategies to reduce barriers	**Identify strategies to reduce barriers**

related to infant clinic access, but implement less than 2 and do not involve multidisciplinary solutions (strategies impact therapy department only)	related to infant clinic access, but implement less than two during DCE timeline	related to infant clinic access (high no-show rate) and implement at least 2 strategies	related to infant clinic access and implement at least 2 strategies, involving interdisciplinary collaboration (NICU professionals outside of therapy team)	**related to infant clinic access and implement more than 2 strategies, involving interdisciplinary collaboration on an ongoing basis, and making strategies sustainability in a way that puts a minimal increase on staff workload after DCE**