BOSTON UNIVERSITY

SARGENT COLLEGE OF HEALTH AND REHABILITATION SCIENCES

Doctoral Project

ENGAGING FAMILIES:
A CONTINUING EDUCATION COURSE ON
FAMILY CENTERED CARE PRINCIPLES AND PRACTICE

by

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B.S., Georgetown University, 2013
M.S., Boston University, 2016

Submitted in partial fulfillment of the
requirements for the degree of
Doctor of Occupational Therapy
2017

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DEDICATION

I dedicate my doctoral project to my amazing family who have unconditionally supported and encouraged me through every step of my academic and personal life.

Mom, thank you for teaching me long ago to imagine the possibilities rather than see the limitations in differently abled children. Your continued passion for our field of occupational therapy and compassion for the families you work with, inspires me. Without your example, I would not have become an occupational therapist.

Dad, you encouraged me to chase my dreams, push myself, and to never stop believing in myself. Your love and faith in me, as well as your kindness towards others, has helped to mold me into the woman I am today.

Greg and Caitlin, as the youngest, I have always looked up to both of you. You are not only my siblings, but also my best friends. You have helped guide me through every milestone of my adult life with love, patience and humor. Your hard work, kindness, dedication and passion for what you do motivates me every day.

I love you all with all of my heart.

ACKNOWLEDGMENTS

First and foremost, I would like to thank Dr. Wendy Coster. Without her immense knowledge, patience and encouragement I could not have completed my doctoral project. It was a tremendous opportunity to work under her guidance and learn from her research expertise. Dr. Coster was also an incredible mentor to me personally as she encouraged me to believe in myself as a researcher and as an occupational therapist. I will be forever grateful for the wealth of knowledge and confidence Dr. Coster has given me and will greatly miss her mentorship.

I would also like to express my sincere gratitude to Dr. Karen Jacobs for her unwavering support and encouragement throughout the doctoral process. Her faith in my abilities sustained me, especially when I questioned my competency to complete this project. Dr. Jacobs' passion for the field of occupational therapy and commitment to the education of new therapists serves as a role model for me. I will continue to set only high goals for myself, both professionally and personally.

I would also like to thank my fellow doctoral candidates. Your positive and constructive feedback on my work, as well as the stimulating discussions about your projects, were instrumental in motivating and supporting me through this process.

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ABSTRACT

Research has shown that Family Centered Care (FCC), or a partnership between parents and health care professionals, has a positive impact on child outcomes when a child is hospitalized and post discharge as well as on psychosocial wellbeing for the family as a whole (Glang, McLaughlin, & Schroeder, 2007; Harrison, Romer, Simon, & Schulze, 2007; Bamm & Rosenbaum, 2008; An & Palisano, 2014; Foster, Whitehead, & Maybee, 2010). However, throughout the literature it is evident that FCC principles, including parent participation, are not being implemented effectively in pediatric inpatient rehabilitation, leading to a disparity between what theory and evidence supports and what is seen in actual practice (An & Palisano, 2014; Aarthun & Akerjordet, 2012; Foster et al., 2010; Arcuri, McMullan, Murray, & Silver, 2015). The aim of this doctoral project was to better understand the factors that are influencing this problem as well as explore evidence-based solutions to this problem. A literature review on these topics was used to develop an educational program for pediatric occupational therapists called *Engaging Families: A Continuing Education Course on Family Centered Care Principles and Practice*. *Engaging Families* is a two-day training course educating pediatric occupational therapists on FCC strategies and implementation of these strategies in order to effectively incorporate parents in their child’s inpatient occupational therapy process.

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Chapter 1: Introduction

The problem guiding this doctoral project is decreased parent participation in their child's inpatient rehabilitation. Pediatric inpatient rehabilitation centers provide critical intensive occupational therapy for children who have recently sustained a traumatic injury requiring hospitalization for an extended period of time. The extent and nature of parent participation in their child's inpatient rehabilitation, as well as relevant theory and evidence to address the problem of limited parent participation, was examined through a literature review. A continuing education course, *Engaging Families: A Continuing Education Course on Family Centered Care Principles and Practice,* for pediatric occupational therapists working in inpatient rehabilitation settings, was developed based on guidelines derived from the review of the literature. The desired outcome for this program is to enhance practitioners' knowledge and skills in strategies to effectively engage parents in their child's inpatient rehabilitation program.

Parents play a large role in their child's development as they are the principal people with whom a young child and even more developmentally mature children interact on a regular basis, over an extended period of time (Bronfenbrenner & Morris, 2006). Urie Bronfenbrenner's bioecological model, an extension to his ecological systems theory, emphasizes a need to look at human development not just in terms of the person's characteristics but also in relation to the entire ecological system surrounding the individual, which for a child who has sustained a traumatic injury includes the family, the therapists, and the hospital (Bronfenbrenner, 1994). It is through increasingly more complex interactions between a child and his or her parents that the child increasingly becomes an agent of their own development and develops self-efficacy, or belief in their own ability to succeed (Bronfenbrenner & Morris, 2006). It is because of this role of the environmental context of the child, which intimately includes the child's parents in the microsystem, that Bronfenbrenner stresses the importance of including the immediate family when working with children (Bamm & Rosenbaum, 2008). Children with traumatic injuries make better gains during occupational therapy and have a better outcome post discharge from the hospital if their parents play an integral role in the therapeutic process through participation and decision-making, as parents are those drivers of development in the child's microsystem (Glang, McLaughlin, & Schroeder, 2007; Harrison, Romer, Simon, & Schulze, 2007; Bamm & Rosenbaum, 2008).

Research into this problem of decreased parent participation in their child's rehabilitation has led to evidence regarding Family Centered Care (FCC), which can be operationally defined as "the innovative approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients and families" (Schrieber, Benger, Salls, Marchetti, & Reed, 2011, p. 225). While there is ample evidence to support that FCC and its principles improve parent participation and self efficacy, have a positive impact on parental satisfaction with their child's care, and improve child outcomes post discharge, there is still confusion within the health care community over the benefits, burdens, and realities of effectively implementing FCC (Glang, McLaughlin, & Schroeder, 2007; Harrison et al., 2007; Bamm & Rosenbaum, 2008). Therefore, FCC is not sufficiently nor effectively implemented in clinical settings leading to clashes that can affect the family-provider relationships and lead to families feeling guarded around the providers (An & Palisano, 2014; Aarthun & Akerjordet, 2012; Foster, Whitehead, & Maybee, 2010; Arcuri et al., 2015).

Studies have shown that the main factors that limit the implementation of parent participation and other FCC principles include: decreased provider knowledge and skills for effective communication; decreased knowledge or poor understanding of FCC principles and implementation of these principles; and health care providers perceptions of parents' role in the decision making health care process (Harrison et al., 2007; Arcuri et al., 2015; Foster et al., 2010; An & Palisano, 2014; Aarthun & Akerjordet, 2012). These antecedents lead to poor communication and lack of informational exchange between the parents and the providers, which in turn leads to decreased parental understanding of their child's diagnosis, prognosis, and plan of care as well as unclear roles and responsibilities for parents within the rehabilitation process (Aarthun & Akerjordet, 2012; Power & Franck, 2008; Kirk, Fallon, Fraser, Robinson, & Vassallo, 2014; Foster et al., 2010; Arcuri et al., 2015; Roscigno, Grant, Savage, & Philipsen, 2013). With these factors impacting the parent-child-provider triad, parents begin to feel incompetent, afraid, and unsure of their abilities and roles and ultimately demonstrate decreased self-efficacy for participating in their child's occupational therapy sessions (Power & Franck, 2008).

Advancing parent participation, in spite of the barriers outlined above, is a problem that is relevant throughout pediatric inpatient rehabilitation settings. The field of occupational therapy seeks to provide evidence based, client centered care. Occupational therapists work to identify the needs of the client by looking at client factors, environmental and cultural contexts, and performance skills and patterns. Included in this profile of the client is the client's family; this is especially true in pediatric care because of the major role that parents play in their child's development. Therefore, when working with children, occupational therapists need to not only provide client centered care but also family centered care through the incorporation of the child's parents within the rehabilitation process. Looking at ways to optimize the outcomes of interventions with pediatric clients in the hospital, by addressing parent participation, falls well within the occupational therapy domain of practice.

Based upon the available research, *Engaging Families: A Continuing Education Course on Family Centered Care Principles and Practice* was created to address the aforementioned challenges with incorporating parents in their child's inpatient rehabilitation. The program will focus on effective communication skills, evaluation of parental characteristics and needs for individualized education to each parent, skills training through occupational performance coaching, and collaborative goal setting. All of these program components have been shown in the literature to be important aspects of FCC and effective strategies to incorporate parents in their child's inpatient rehabilitation. *Engaging Families* will be a two-day training course, for seven hours per day. It will consist of didactic portions—PowerPoint, lecture, and videos—and practice portions—simulations and role plays—to enhance occupational therapists' learning and carryover of information into daily practice.

The remainder of this project will discuss the theoretical and evidence basis for the proposed problem and solutions to the problem as well as detailed information on the proposed program, *Engaging Families: A Continuing Education Course on Family Centered Care Principles and Practice*. Remaining chapters outline the evaluation, funding, and dissemination plans for *Engaging Families.*

Chapter 2: Theoretical and Evidence Base to Support the Project

This chapter consists of two main sections. In the first section, details regarding the theoretical basis for the doctoral project will be discussed. In the second section, a synthesis of the evidence to support the design of the program, *Engaging Families,* is detailed.

Family-centered care (FCC), or partnership between parents and health care professionals, has been shown to have a positive impact on hospitalized children's outcomes by increasing parent engagement in their child's care and increasing psychosocial wellbeing for the family as a whole (Glang et al., 2007; Harrison et al., 2007; Bamm & Rosenbaum, 2008; An & Palisano, 2014; Foster et al., 2010). Unresolved family stress has been shown to have a negative impact on the child's rehabilitation outcomes. Therefore FCC is recognized as critical when serving children with disabilities as a way to decrease parental strain and promote child outcomes through parent participation in the decision making and care processes (Braga, Da Paz Junior, & Ylvisaker, 2005).

Family centered care can be operationally defined as "the innovative approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients and families" (Schrieber et al., 2011, p. 225). FCC interventions operate on the main principle that parents know their children best, therefore, to promote the optimal functioning of a child with a disability, one must foster family involvement by treating families with dignity and respect; providing information; having open communication; allowing parent participation and shared decision making; and taking into consideration the family's beliefs, values, needs, and preferences (Egilson, 2011; Schrieber et al., 2011; An & Palisano, 2014; Bamm & Rosenbaum, 2008). Despite the evidence to support FCC principles, there is often a disparity between what theory and evidence supports and what is seen in actual practice; FCC principles of parent participation and a mutually beneficial partnership are more often not implemented within pediatric inpatient rehabilitation hospitals (An & Palisano, 2014; Aarthun & Akerjordet, 2012; Foster et al., 2010; Arcuri et al., 2015).

The Scope of the Problem

Approximately 17–26% of children, or around 1 in 4 families, are affected by chronic health conditions that require care; 8% of these cases are severe (McAnuff, Boyes, & Kolehmainen, 2014; Kolehmainen et al., 2012). A 2009/2010 National Survey of Children with Special Health Care Needs showed that approximately 23% of households in the United States had at least one child living with a chronic health care need (NSCSHCN, 2010). The Centers for Disease Control and Prevention (CDC, 2016) state that between 2010 and 2014 there were 46,122,273 nonfatal injuries leading to hospitalizations for children of all races and sexes, ages 0–19, totaling approximately 11.2% of children in this age group. The leading causes of nonfatal injuries during this time were unintentional falls, unintentional motor vehicle accidents with the child as an occupant in the car, self harm by poisoning, and being struck by a car as a pedestrian, in this order from most prevalent to least prevalent (CDC, 2016). In 2013 the number of inpatient stays was 5,620,416 for children ages birth – 17 years old (HCUP, 2015).

Framework to Understand the Problem

In order to frame this problem regarding limited parental participation in their child's inpatient rehabilitation, a contextual approach was taken. Urie Bronfenbrenner's bioecological model, an extension to his ecological systems theory, emphasizes a need to look at human development through not just the human characteristics but also the entire ecological system surrounding the individual (Bronfenbrenner, 1994). The bioecological theory has four key components all of which are dynamic and interactive. They are as follows: proximal processes or the interaction between the organism and the environment, operating over time to produce human development; the person or the characteristics of the individual that play a role in development; the immediate or remote contexts that will be described below; and the time periods in which the processes are taking place, framed both by the developmental age of the individual and the historical timeframe (Bronfenbrenner & Morris, 2006).

Keeping these four components in mind, the bioecological theory has two propositions. The first proposition states that throughout the life course, especially in early development, development occurs through processes that involve progressively more complex reciprocal interactions between the individual and the people, objects and symbols in his or her immediate environment; these interactions occur over an extended period of time and on a regular basis and are considered the proximal processes, or the primary drivers of development (Bronfenbrenner & Morris, 2006). Proposition II states that the systematic variance in the form, power, content, and direction of these proximal processes that affect development is a joint function of the characteristics of the developing individual, the immediate and remote environment in which development is taking place, the nature of the developmental outcome at hand, and the social continuities and changes that occur over the life course (Bronfenbrenner & Morris, 2006). Based on these propositions, the characteristics of the developing person function as a “product of development” and the “indirect producer” of development (Bronfenbrenner & Morris, 2006, p. 798).

The immediate and remote contexts or ecological systems that Bronfenbrenner postulates as important drivers of human development consist of the microsystem, the relationship of the immediate environment to the person, such as family and schools; the mesosystem, the linkages and processes that take place between two or more settings; the exosystem, the processes that occur between two or more settings, with one of those settings not directly containing the developing person, but rather influencing them, such as the parent’s work place or the child’s neighborhood; the macrosystem, the overarching patterns of the aforementioned systems that are characterized by culture and society; and the chronosystem, the effects of time on the aforementioned systems (Bronfenbrenner, 1994; Bronfenbrenner & Morris, 2006).

Applying this framework, the current problem can be understood as involving the proximal contextual forces of the microsystem, the roles that the parents play in their child’s development and recovery process and the health care system or hospital setting that the child now has an immediate connection to because of their injury. Parents play a large role in their child’s development, as they are the principal people with whom a young child and even more developmentally mature children interact on a regular basis, over an extended period of time (Bronfenbrenner & Morris, 2006). Through increasingly more complex interactions between a child and his or her parents, that child increasingly becomes an agent of their own development. This interactive process between parents and the child helps to generate the "ability, motivation, knowledge, and skills to engage in such activities both with others and eventually on the child's own" (Bronfenbrenner & Morris, 2006, p. 797). Additionally, self-efficacy, or one's belief in their own ability to succeed, is not only influenced by the characteristics of the child, but also directionally influenced by the interaction of the features of the child's environment, including their parents (Bronfenbrenner & Morris, 2006).

It is because of this role of the environmental context of the child, which intimately includes the child's parents in the microsystem, that Bronfenbrenner stresses the importance of including the immediate family when working with children (Bamm & Rosenbaum, 2008).

> " In order to develop—intellectually, emotionally, and morally—a child requires…the same thing: participation in progressively more complex reciprocal activity, on a regular basis over extended periods of time with one or more other persons with whom the child develops a strong, mutual, irrational attachment, and who are committed to that child's development, preferably for life…The establishment and maintenance of patterns of progressively more complex interaction and emotional attachment between caregiver and child depend in substantial degree on the availability and active involvement of another adult who

> assists, encourages… and expresses admiration and affection…"
> (Bronfenbrenner & Morris, 2006, p. 816).

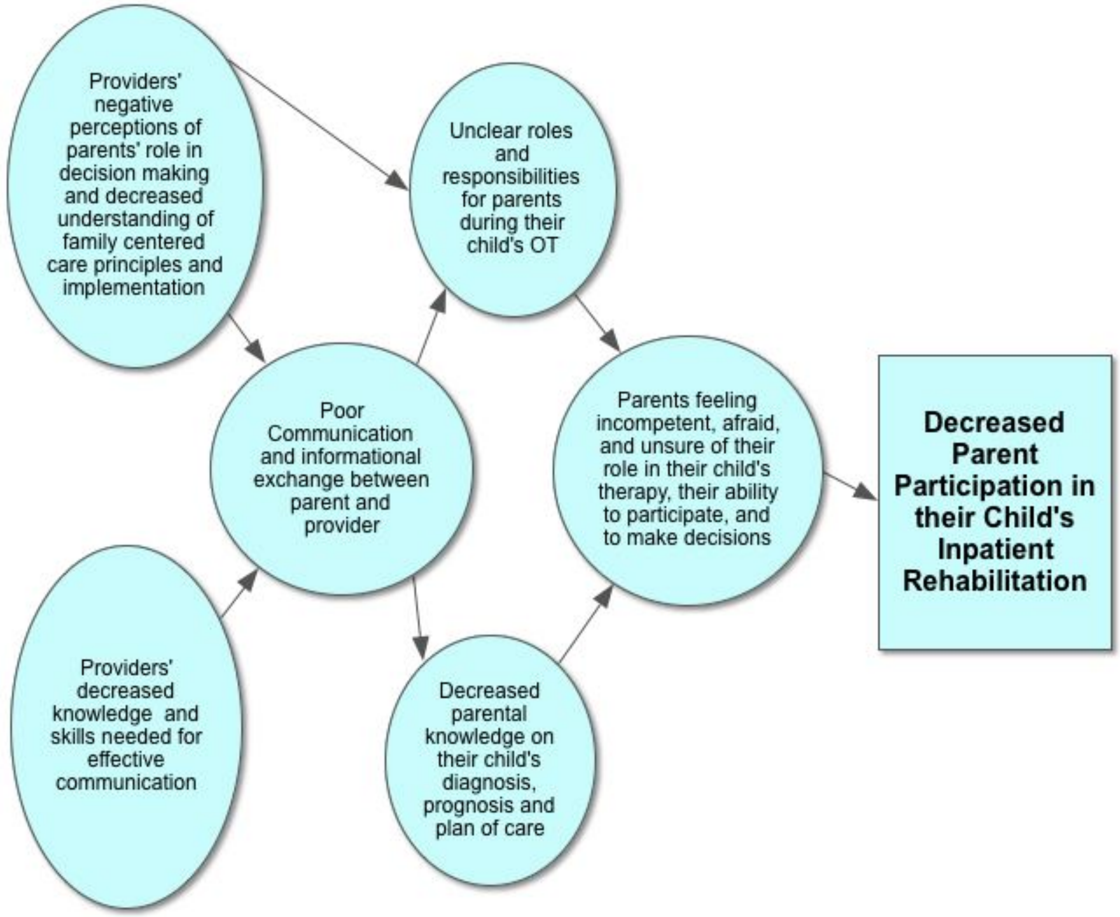
Applying Bronfenbrenner's perspective, the focus of this project extends beyond the child who sustained a traumatic injury that has placed them in the hospital, to the parents and the occupational therapists that comprise the child's microsystem. Parents arguably are the people with whom the child has the strongest mutual attachment, while the therapist can become an additional active support who not only encourages and assists the child to regain the functional skills lost due to the injury, but also enables the parents to continue to play a participatory role in their child's development. Children with traumatic injuries make significantly better gains during occupational therapy and have a better outcome post discharge from the hospital if their parents play an integral role in the therapeutic process through participation and decision-making, as parents are those drivers of development in the child's microsystem.

Proposed Explanatory Model of Identified Problem

Since research suggests that FCC can have a positive impact on child outcomes post injury, there has been a paradigm shift in rehabilitative care from the parents playing a passive observational role to a more active partnership role (Glang et al., 2007; Harrison et al., 2007; Bamm & Rosenbaum, 2008). Despite this ideological paradigm shift, there still remains a significant disparity between what theory and evidence supports and what is seen in actual pediatric inpatient rehabilitation hospitals (An & Palisano, 2014; Aarthun & Akerjordet, 2012; Foster et al, 2010; Arcuri et al., 2015).

Studies have shown that the main factors that limit the implementation of parent participation and other FCC principles include: decreased provider knowledge and skills for effective communication; decreased knowledge or poor understanding of FCC principles and implementation; and health care providers perceptions of parents' role in the decision making health care process, which can be influenced by clashing cultural differences between the family and the provider (*Figure 2.1*) (Harrison et al., 2007; Arcuri et al., 2015; Foster et al., 2010; An & Palisano, 2014; Aarthun & Akerjordet, 2012). All of these antecedents lead to poor communication and lack of informational exchange between the parents and the providers, which in turn leads to decreased parental understanding of their child's diagnosis, prognosis, and plan of care as well as unclear roles and responsibilities for parents within the rehabilitation process (*Figure 2.1*) (Aarthun & Akerjordet, 2012; Power & Franck, 2008; Kirk, Fallon, Fraser, Robinson, & Vassallo, 2014; Foster et al., 2010; Arcuri et al., 2015; Roscigno et al., 2013). With unclear roles and responsibilities as well as decreased understanding of their child's prognosis and plan of care parents begin to feel incompetent, afraid, and unsure of their abilities; they lose their self-efficacy for participating in their child's occupational therapy program (*Figure 2.1)* (Power & Franck, 2008).

Figure 2.1: Explanatory Model of the Problem



The aforementioned factors affecting parent participation are ones of concern and importance. Providers' lack of effective communication skills, decreased understanding of how to implement FCC principles in everyday practice, and providers' own perceptions of parents role in the rehabilitative care of their child, lead to parental loss of control and ability to actively make decisions for their child's plan of care and to participate in every step of the therapeutic process (An & Palisano, 2014; Foster et al., 2010). In the end, this can diminish functional gains for the child as well as diminish psychosocial wellbeing of both the child and the family post discharge (An & Palisano, 2014; Foster et al., 2010).

Evidence for the Problem

In order to assess the proposed explanatory model outlined above, four main questions were used to guide the literature search on parent participation in children's inpatient rehabilitation care and communication between family members and the rehabilitation team. They are as follows:

1. How many families are faced with their child having traumatic injuries that require long-term rehabilitation stays?
2. What is the current evidence regarding parent participation in their child's inpatient rehabilitation program?
3. What are parents' perceptions of their child's therapy services?
4. What are the main challenges with communication between parents and their child's rehab team?

Since there is a relatively small amount of literature on parent participation and communication within occupational therapy literature specifically, research included all disciplines within the rehabilitation process, including physical therapy, speech therapy, and nursing. Databases searched were CINAHL, PsychInfo, Pub Med, and AJOT using key terms of "rehabilitation," "potential role," "inpatient OR hospital OR unit OR clinic," "parental involvement OR parental participation," " parental attitude OR parental perception," "injuries," and "professional family relations."

Despite ample evidence supporting the benefits of implementing FCC principles in pediatric rehabilitation settings as well as factors that influence patient and family satisfaction with care, there is still confusion within the health care community over the definition, benefits, burdens, and realities of effectively implementing and operationalizing FCC (Harrison et al., 2007). While FCC and family-professional collaboration has become best practice for pediatric rehabilitation, both families and professionals have reported challenges in the important FCC process of collaboration, specifically with sharing information, addressing family needs and concerns, and determining the roles of the professional versus the family (An & Palisano, 2014; Aarthun & Akerjordet, 2012; Foster et al., 2010; Arcuri et al., 2015). Therefore, FCC is not sufficiently nor effectively implemented in clinical settings leading to clashes that can affect the family-provider relationships and lead to families feeling guarded around the providers (An & Palisano, 2014; Aarthun & Akerjordet 2012; Foster et al., 2010; Arcuri et al., 2015).

One commonly used indicator of the extent to which services provided have met family needs is through measures of satisfaction (King, Cathers, King, & Rosenbaum, 2001). However, the construct of satisfaction is difficult to measure and define (King et al., 2001). King and colleagues have defined the construct as the parents' and child's judgment of their care at each stage of the process (King et al., 2001). It has been shown that satisfied clients and parents adhere more strongly to treatment recommendations and demonstrate decreased distress and depression (Law et al., 2003). Parents most often report that their dissatisfaction with services is related to the services not meeting the needs of the child and family, being in a setting that was not welcoming, not having information shared or provided, and having professionals that did not listen to parent concerns, accept or involve parents as part of the team, allow parents to have final say regarding decisions, and treat parents as knowledgeable **(**King et al., 2001).

Parent participation is a cornerstone for FCC however wide variability in implementation has been observed in clinical practice, as participation can range from passive presence to the parent having total care (Power & Franck, 2008; Brewer, Pollock, & Wright, 2013). Parent participation, to varying degrees, is generally something that parents want during their child's care as well as something that has been shown to increase parent satisfaction with their child's rehabilitative care (Aarthun & Akerjordet, 2012; Power & Franck, 2008; Hallstrom & Elander, 2007; Glang et al., 2007; Harrison et al., 2007). Many parents want to participate in their child's care by helping their child perform activities of daily living that they would usually help the child perform at home. However, often times this is done solely by the nursing staff or during occupational therapy sessions during which the parents are unsure of how to and when to participate (Power & Franck, 2008). Despite the varying roles parents want to take, health care providers find it hard to balance including the families in the decision making and intervention process while maintaining important communication skills of listening, understanding, and responding to families' needs, values, and perspectives. They tend to focus more on the quantity of participation of the parents, in the process losing sight of the importance of both aspects of FCC, participation and communication (McAnuff et al., 2014; Teal & Street, 2008).

Despite the desire for parents to be in a joint partnership, as individually defined by the parents, health care professionals consistently apply their technical expertise and take a more dominant role in the decision making process, with a lack of role negotiation occurring between the groups (Aarthun & Akerjordet, 2012; McAnuff et al., 2014). Professionals' interpretations of and attitudes towards parents' role in health care influences the parents' participation, with many professionals defining parents' role in health care rather than negotiating the level of parent involvement (Aarthun & Akerjordet, 2012; Foster et al., 2010). Providers also demonstrate difficulty giving parents a role in the decision making process due to challenges with balancing parent involvement with evidence based practice (Aarthun & Akerjordet, 2012; Foster et al., 2010). Parents often reported that this poor definition of roles and responsibilities for their participation led to feelings of uncertainty regarding when and how to participate; fear led to decreased participation as they felt they would make a mistake or do something that the health care professional would disapprove of (Egilson, 2011; Power & Franck, 2008). Because of the varying nature and degree with which parents want to participate in their child's care, role negotiation through effective communication is extremely important. In fact, a negative quality of communication between the health professional and the parent has been shown to have a direct negative effect on the parents' level of confidence in taking on an active participatory role (Aarthun & Akerjordet, 2012; Roscigno et al., 2013; Teal & Street, 2008).

Communication, or a mutual partnership based on providers respect and understanding that parents know their child best and will act in their child's best interest, and dissemination of important information so that parents can make informed decisions in their child's care, are additional important aspects of FCC (Foster et al., 2010; Arcuri et al., 2015; Kirk et al., 2014; Roscigno et al., 2013). However, the two principles of communication and providing information are consistently absent from the provider-parent relationship as many health care professionals lack in depth skill training in communication, leading to ineffective informational and partnership encounters (Kirk et al., 2014; Foster et al., 2010; Arcuri et al., 2015; Roscigno et al., 2013). Research has shown that therapists need to acquire and expand their communication skill set so that effective partnership building and teaching can occur in their client and family interactions (Harrison et al., 2007; Arcuri et al., 2015; Foster et al., 2010).

Having information provided to the parents is a cornerstone to enabling them to make informed decisions and be active participants in their child's therapy (Aarthun & Akerjordet, 2012; Roscigno et al., 2013; Teal & Street, 2008; Kirk et al., 2014; Foster et al., 2010; Arcuri et al., 2015). Unfortunately, parents have unmet informational needs across the care trajectory because of a lack of information communicated to them or poor presentation of the information making it hard to understand and absorb (Aarthun & Akerjordet, 2012; Kirk et al., 2014). This can lead to a decrease in parent participation and self-efficacy in decision making in their child's care because of a lack of understanding of their child's illness, plan of care, and ways to actively participate (Hallstrom & Elander, 2007; Aarthun & Akerjordet, 2012).

The process through which the diagnosis and plan of care information is presented relates directly to the effectiveness of the communication exchange between the parents and the professionals. Parents report that the language used throughout this process can be at times difficult to understand because of the unfamiliar medical terminology used during the communication exchange (Arcuri et al., 2015; Kirk et al., 2014; Foster et al., 2010; Roscigno et al., 2013). Additionally, when the language and explanations were vague, unclear, or incomplete, parents were caught off guard by their child's plan of care and had feelings of uncertainty about the future and their role within the rehabilitative care of their child (Roscigno et al., 2013; Kirk et al., 2014).

In summary, while many healthcare professionals report wanting to implement FCC principles, many are unsuccessful, leading to parents feeling, ignored, powerless, or insignificant in the care of their child (Foster et al., 2010). The main reasons for decreased family participation in their child's inpatient rehabilitation, specifically in occupational therapy, stem from health care providers having decreased communication skills, decreased knowledge of FCC principles and how to effectively implement them during care, failure to provide adequate and easily accessible information regarding the child's care, and biases or perceptions of parents role within the decision making and health care process (Harrison et al., 2007; Arcuri et al., 2015; Foster et al., 2010; An & Palisano, 2014; Aarthun & Akerjordet, 2012; Power & Franck, 2008; Kirk et al., 2014; Roscigno et al., 2013).

Results of an investigation of the evidence on current methods and strategies to address the outlined problem are reviewed in the next section.

Evidence Base to Support the Project

FCC has been shown to have a positive impact on child outcomes when the child is hospitalized for a traumatic injury and post discharge (Schrieber et al., 2011; Glang et al., 2007; Harrison et al., 2007; Bamm & Rosenbaum, 2008). The effectiveness of pediatric rehabilitative interventions depends on a multitude of factors extending beyond the intervention, client and therapist to also include the environment and the interactions between the practitioners and the child as well as the practitioners and the parent (Levassuer & Carrier, 2010). Successful implementation of FCC theoretical principles relies strongly on positive parent–provider relationships (Levassuer & Carrier, 2010).

To determine current approaches and methods for addressing the proposed problem, a review of the literature was conducted. The following questions guided the search:

1. What are effective methods to engage parents in collaborative interventions for their child?
2. What are critical elements of effective communication in health care encounters with parents?
3. What methods have been used to help parents understand their child's diagnosis and intervention? Which methods appear to be most effective?
4. What are effective interventions to teach effective communication skills to practitioners?
5. What parent characteristics are most important to consider in designing effective education methods?

In order to address each question, CINAHL, PsychInfo, PubMed, and AJOT databases were searched using a variety of key terms including “communication,” “interventions,” “occupational therapy OR occupational therapists,” “parents of disabled children,” “parent education,” “professional family relations,” and “family centered care.”

Successful service provision, as perceived by parents of children with disabilities, requires a distinct commitment by the therapist or health care provider to put the family’s needs and desires at the forefront (Egilson, 2011). Parents’ satisfaction with their child’s rehabilitation services appears to be directly related to how family based they are (Egilson, 2011). Studies have shown that the primary categories of family needs while their child is hospitalized include: optimizing the child’s health and development through parent participation and parent-provider communication; providing support for the family, both emotional and physical; meeting the parents’ personal needs, such as the need for confirmation and feedback; allowing the parents to be with their child throughout the care process; having ample and clear flow of information provided about their child’s care; and having respectful and supportive professionals who are willing to listen and be available for questions (Egilson, 2011; Power & Franck, 2008; Foster et al., 2010; Teal & Street, 2008; Hallstrom & Elander, 2007). To increase parental satisfaction, organizations can formally adopt a FCC approach to services, train staff in FCC, and provide a more welcoming environment (Law et al., 2003).

Many parents see themselves as closely connected with their child and their child’s experiences; therefore, they want to be able to be present and/or participate in some or all situations that their child is dealing with post injury, including helping to plan the child’s care and treatment (Hallstrom & Elander, 2007). In order to enhance FCC, the therapist must respect a client and their family's wishes around their desired involvement in the therapeutic process, as appropriate levels of family responsibility can range from simply listening to a discussion about patient care all the way to leading the discussion with the level of participation being dynamic throughout the rehabilitation process (Brewer et al., 2013).

While parents' desired level of participation may be unique for each family, collaborative goal setting is a common and important component to FCC because it engages families more actively in their child's therapeutic process and has been associated with positive child and family outcomes (Brewer et al., 2013; An & Palisano, 2014). Effective implementation of true family-provider collaborative goal setting begins with creating a culture that supports and values collaborative goal setting, educating providers on the importance of collaboration in the goal setting process, and creating time in the therapeutic process to engage in structured and systematic goal setting and review (Brewer et al., 2013). Parents report that goals need to be concrete, context oriented, and observable in order to be effective and useful for the family (Brewer et al., 2013). Additionally, the parents valued having the goals written and displayed for everyone to see (Brewer et al., 2013).

Collaboration on goals begins with the therapist discussing the family's needs related to the child's development, daily routines, and preferences through a client-centered interview process; this then leads to a determination of mutually agreed upon goals for occupational therapy (An & Palisano, 2014; Baldwin et al., 2013). Additionally, having parents visualize a preferred future in which the therapist guides the parents to identify what positive changes they want to see in the immediate future and what will be different when the intervention is successful, has been shown to be an effective strategy for health care providers to use when engaging in collaborative goal setting with parents (An & Palisano, 2014; Baldwin et al., 2013; Kolehmainen et al., 2012). Adopting an explicit goal setting process helps clinicians engage in collaborative goal setting by creating goals that are understandable and truly collaborative in nature. The process can be completed using validated and systematic measures such as the Canadian Occupational Performance Measure (COPM) and the Goal Attainment Scale (GAS) (Brewer et al., 2013; Graham et al., 2010; An & Palisano, 2014). Once goals have been created and clarified, the therapist works on increasing child and family awareness and integrated knowledge as well as providing opportunities to practice the new skills (Baldwin et al., 2013).

Parental skills training, to improve the parents' ability to care for their child post discharge, is another FCC intervention that can be used during rehabilitation (Cole, Paulos, Cole, & Tankard, 2009). Skills training can involve teaching the parents' coping skills, stress management skills, or developing problem solving skills. In fact, family oriented problem solving interventions have been shown to reduce not only family stress and strain, but also problem behaviors in children post traumatic injury, more specifically brain injury (Cole et al., 2009; Kreutzer et al., 2002). Family problem solving interventions that focus on concrete skills training to increase self-monitoring, self-regulation, and social problem solving skills have been shown to improve parent-child relationships, parents' sense of injury-related burden, and parental stress post injury (Cole et al., 2009; Wade, Michaud, & Brown, 2006).

Parents report that learning the aforementioned skills from their child's therapist is most effective with observation, practice of therapeutic techniques with the therapist scaffolding and providing feedback, having the ability to ask questions and have them answered, and obtaining reading materials and information from the therapist regarding their child's development and treatment plan (Harrison et al., 2007). Utilizing a multimodal or multimedia component to skills training was seen as beneficial; parents reported improved self-efficacy in carrying over therapeutic techniques when techniques were demonstrated and visually represented for parents to refer back to (Braga et al., 2005). Additionally, parents report that a successful partnership with their therapist was the key not only to facilitating learning, but also to increasing the willingness of the parents to learn from the therapist (Harrison et al., 2007).

Another effective therapeutic approach to help parents with skill acquisition is coaching, which has been widely tested with parents of children with occupational performance challenges (Graham, Rodger, & Ziviani, 2014; Baldwin et al., 2013; Kessler & Graham, 2015). Coaching can be operationally defined as a method of "collaboratively identifying challenges, setting goals, and working towards the goals," with the coach offering feedback on occupational performance to help support achievement towards the goal (Kessler & Graham, 2015, p. 160). Coaches facilitate change through creating environments that are conducive to client awareness of their strengths as well as facilitating client discovery of goals, plans and strategies (Graham et al., 2014; Baldwin et al., 2013; Kessler & Graham, 2015).

One type of coaching, Occupational Performance Coaching (OPC), is a family centered and strengths-based intervention in which the therapist works with the parents to achieve occupational performance goals for themselves and their child (Graham et al., 2014). OPC is a way for the occupational therapists to enact principles of FCC. The therapist takes on the role of the informant, guide and coach while partnering with parents to develop meaningful goals, identify the desired performance for their child, and problem solve difficult situations within a supportive partnership (Graham et al., 2009). Throughout the whole parent-provider interaction and therapeutic process, positive reinforcement is used to affirm parents' strengths and self-efficacy for caring for their child with a traumatic injury (Baldwin et al., 2013).

In order for coaching and skills training to be effective, parents need to actively participate in their child's therapy sessions. Parents generally report that good communication with their child's healthcare provider would increase their participation in their child's care, help them make more informed decisions, and have more control over the care (Hallstrom & Elander, 2007; Aarthun & Akerjordet, 2012). Concepts of FCC and parents' needs during their child's care are inter-related: when parents received information that helped to increase their knowledge of their child's illness, they in turn participated more actively (Hallstrom & Elander, 2007; Aarthun & Akerjordet, 2012). In general, there are six types of interpersonal communication modes that should set the foundation for the therapist's approach to talking with parents: 1) advocating, in which the therapist uses statements that normalize a client's experience; 2) collaborating, in which there is an emphasis on the parents' equal role in setting goals with the therapist and their child; 3) empathizing, in which the therapist tries to understand the child's and parents' experiences through using gentle inquiry, summarizing statements, validation, and mirroring; 4) encouraging, in which the therapist uses positive reinforcement and hope building statements to build confidence; 5) instructing, in which the therapist educates the parents on the therapeutic process and how to perform tasks or explain the rationale for a therapeutic activity; and 6) problem solving, in which the therapist asks strategic questions to help the parents reason through a challenge that has arisen (Kreutzer et al., 2002; McAnuff et al., 2014; Hart, Drotar, Gori, & Lewin, 2005). When engaging in these effective interaction styles with parents, health care professionals should be cognizant of the perspectives of the patient and their family and the social context of the family in order to effectively communicate with each parent and reach a shared understanding of the child's diagnosis and treatment (Teal & Street, 2008; King et al., 2001).

In addition to verbal communication, parents express the desire to have written medical information communicated to them in a way that matches the parents' needs and preferences with respect to the timing, manner, and context of the information provided, believing that without this information they would be unable to be involved and unable to make informed decisions regarding the care of their child (Power & Franck, 2008; Aarthun & Akerjordet, 2012; Roscigno et al., 2013; Teal & Street, 2008; Kirk et al., 2014; Foster et al., 2010; Arcuri et al., 2015). Health care professionals need to provide information to parents that is easily understandable and meets each family's individual needs (Arcuri et al., 2015; Egilson, 2011; Harrison et al., 2007; Schrieber et al., 2011; An

& Palisano, 2014; Cole et al., 2009).

The information that parents indicated they wanted included: diagnosis, prognosis, medical complications and side effects, risks, the child's treatments and tests, how they can best care for their child, how to cope with painful and difficult situations, and the child's therapy goals and activities that occurred during therapy (Hallstrom & Elander, 2007; Egilson, 2011). Additionally, comprehensive education regarding the child's injury, the therapeutic process, FCC, and what it will mean for the family during their child's stay in the hospital should be provided to parents at the initial session (Law et al., 2003). This information will help increase the parents' knowledge of their child's condition and the rehabilitation process, decrease the anxiety that parents may be experiencing, and alter parents' beliefs about FCC, which is important in determining their perception and satisfaction with services (Law et al., 2003). This educational material needs to provide clear information, be repeated several times throughout the therapeutic process, and be related to where the child is in the recovery process (Cole et al., 2009; Conoley & Sheridan, 1996; Kreutzer et al., 2002). Providing educational materials that are accessible to the parents has been associated with reducing parents' stress, burden, and fears for the future (Cole et al., 2009; Conoley & Sheridan, 1996).

Since many practitioners have not been educated in FCC principles and practice, there is a need for a professional development, continuing education course that can help prepare occupational therapists to apply FCC approaches in everyday practice. Evidence was reviewed in order to determine the most effective way to develop this type of course in order to enhance learning and carry over of knowledge to everyday practice.

Studies have shown that effective ways to educate providers in order to improve both their verbal and written communication skills, include the use of written materials to increase awareness and knowledge and the use of interactive and interpersonal approaches to increase the potential for facilitating change in practice (Law et al., 2005; Hart et al., 2005; Nikendei et al., 2011). Therefore, when problem based learning and interactive workshops are used in conjunction with written materials, there is an improvement in knowledge and understanding of that material (Law et al., 2005). Utilizing an interactive and educational program that focuses on research linking interpersonal communication skills with positive outcomes of care and then provides strategies to improve providers' communication skills with the parents of their patients has been shown to positively change how providers communicate with the families they work with (Hart et al., 2005; Nikendei et al., 2011). Additionally, providing the therapists opportunities to practice using these communication strategies in a simulated, role-play setting with peer feedback has been shown to improve the provider's communication skills (Hart et al., 2005; Nikendei et al., 2011). Simulations within an educational program have been shown to provide a safe environment for the program participants to bridge theory and practice and to allow the practitioner to explore their own actions, construct meaning through discussion with other participants, and trial new ways to problem solve common communication barriers (Zubairi, Lindsay, Parker, & Kawamura, 2016). Breaking down each component skill of communication through the continuum of care (e.g. "exploration of problems," "understanding parents' perspectives," "providing structure to consultation," and "building relationship") has also been used to tailor the education to providers (Nikendei et al., 2011).

Throughout the entire continuum of care and when using different strategies such as collaborative goal setting, OPC, skills training, and providing educational materials, health care practitioners need to be aware of parents' level of health literacy, in order to tailor the education to optimize learning (Levassuer & Carrier, 2010; Levassuer & Carrier, 2012). Health literacy can be operationally defined as the ability of the person to "access, understand, evaluate, and communicate information as a way to promote, maintain and improve health" (Levassuer & Carrier, 2010, p. 757). Health literacy allows the provider and parent to engage in a dialogue that fosters common perspectives on how to solve a problem, mutual learning, listening and an environment filled with trust and partnership (Levassuer & Carrier, 2010).

Adequate health literacy of parents is necessary for management of their child's health care needs during not only acute illness but also long-term management of chronic conditions, such as traumatic injuries (Betz, Ruccione, Meeske, Smith & Chang, 2008). In fact, poor health literacy in parents can lead to incorrect performance of care for their child once home (Betz et al., 2008). A recent national survey showed that ninety-two million Americans have below an eighth grade level reading ability (Badarueen & Sabharwal, 2008). Unfortunately, the readability and comprehension of educational materials is often overlooked (Badarueen & Sabharwal, 2008).

Experts recommend that when creating patient education materials, the readability level should be less than a sixth grade level (Badarueen & Sabharwal, 2008). There are standardized ways for those creating health education to determine the grade level or readability of those materials, with the most widely used being the Flesch Kincaid Grade level and Reading Ease, which look at sentence length and word length (Badarueen & Sabharwal, 2008). Both of these scores can be ascertained from a typical Microsoft Word document, making it easy to determine the readability of health education materials that occupational therapists provide their clients. One can use the *spelling and grammar* option and click on *show readability statistics*. At the end of the spelling check, the Flesch Kincaid Ease and Grade Level will be provided (Jacobs, 2016).

There are multiple ways for practitioners to increase the readability of the information they present including: organizing information in chunks, limiting the length of lists to seven points, defining technical and unfamiliar words, prioritizing need to know information at the beginning and using topic headings, making pages un-crowded, and using basic and realistic visual aids such as carefully captioned pictures (Jacobs, 2016). In addition to determining the readability of printed educational material, there are six identified ways to integrate health literacy into occupational therapy practice: be informed, standardize practice to health literacy, make information accessible, strengthen interactions, intervene, and collaborate (Levassuer & Carrier, 2012). Practitioners need to communicate in clear, simple and culturally competent language (Levassuer & Carrier, 2012).

In addition to parents' health literacy, occupational therapists should always match the intervention to the family (Cole et al., 2009). Individually tailoring each intervention to the family's needs and level of functioning should always be done during the therapeutic process (Cole et al., 2009). Giving parents the opportunity to be active in the design and implementation of the FCC services and providing time for them to feel comfortable about its implementation will lead to improved ease of FCC (Law et al., 2003). Since post-injury challenges that the child and family face after the child has sustained a traumatic injury are unique to each family based on their pre-existing family structure, values, and beliefs, it is important to consider the family's pre-injury functioning, presence of siblings, the family's readiness for change, and the family's perceptions regarding the demands they now face having a child with a traumatic injury and the resources they may or may not have for meeting these demands (Cole et al., 2009).

While there is ample evidence to support that FCC and its principles have a positive impact on parental satisfaction with their child's care, improve parent participation and self-efficacy, and improve child outcomes post discharge, application of the research needs to be done carefully to be effective in the pediatric inpatient occupational therapy setting (Glang et al., 2007; Harrison et al., 2007; Bamm & Rosenbaum, 2008). Many of the studies in this area focus on strategies for general health care practitioners and are not specific to OT. Studies included parents of children with developmental disabilities, not just traumatic injuries; therefore the context and nature of the disability may influence how the evidence can be applied to the present project. Additionally, many of the aforementioned research studies were conducted in different countries; cultural differences and health care system differences should be considered when applying this research. Finally, as with much occupational therapy and therapy related research, many of the studies cited had small sample sizes, making it hard to generalize findings to a larger population.

Table 2.1 presents a list of important FCC strategies and elements that will be addressed during the continuing education program, *Engaging Families: A Continuing Education Course on Family Centered Care Principles and Practice.* Each element of the intervention is described in terms of its application for this project with the evidence literature to support its use.

Table 2.1: Summary of the Guidelines for the Purposed Program

Element of Intervention	**Research Study**	**Application**
Parent- Provider Communication: 6 Interpersonal Communication Strategies	(Aarthun & Akerjordet, 2012) (Hallstrom & Elander, 2007) (Hart et al., 2005) (Kreutzer et al., 2002) (McAnuff et al., 2014)	Provides content for the educational program - effective communication strategies to teach OTs so that they can effectively implement FCC principles into their practice
Provider's cultural sensitivity and awareness of the environmental and personal factors contributing to their communication with parents (e.g. parents perspectives, social context of the family)	(Aarthun & Akerjordet, 2012) (Brewer et al., 2013) (Hallstrom & Elander, 2007) (King et al., 2001) (Kirk et al., 2014) (Kuo, et al., 2011) (Power & Franck, 2008) (Teal & Street, 2008)	Provides content for the educational program- taking into consideration the family culture and needs when communicating and implementing FCC principles
Continuing education program for OTs: Didactic (educational) Portion Simulated Role Play Portion	(Hart et al., 2005) (Law et al., 2005) (Nikendei et al., 2011) (Zubairi et al., 2016)	Structure of the program- provides a framework for the composition of and strategies to use during the creation of the continuing education program for the OTs
Parental Skills Training – Problem Solving	(Cole et al., 2009) (Kreutzer et al., 2002) (Wade et al., 2006)	Content for the educational program- Provides a strategy for OTs to use when educating parents on therapeutic techniques to improve child and family functioning

Occupational Performance Coaching: Family centered and strengths based	(Baldwin et al., 2013) (Graham et al., 2014) (Graham et al., 2009) (Kessler & Graham, 2015)	Content for the educational program - Provides strategy for OTs to use when educating parents on therapeutic techniques to improve child and family functioning
Collaborative Goal Setting	(An & Palisano, 2014) (Baldwin et al., 2013) (Brewer et al., 2013) (Graham et al., 2010) (Kolehmainen et al., 2012)	Content for the educational program Provides strategy for OTs to use to incorporate parents into care
Providing easily accessible and pertinent written and visual information to parents on their child's prognosis, diagnosis, plan of care, treatment strategies	(Aarthun & Akerjordet, 2012) (Arcuri et al., 2015) (Cole et al., 2009) (Conoley & Sheridan, 1996) (Egilson, 2011) (Foster et al., 2010) (Harrison et al., 2007) (Hallstrom & Elander, 2007) (Kirk et al., 2014) (Kreutzer et al., 2002) (Law et al., 2003) (Power & Franck, 2008) (Roscigno et al., 2013) (Schrieber et al., 2011) (Teal & Street, 2008)	Content for the educational program- Provides the basis for educational materials to help parents understand the care and their child's needs better
Matching the intervention to family	(Aarthun & Akerjordet, 2012) (Brewer et al., 2013) (Cole et al., 2009) (Egilson, 2011) (Hallstrom & Elander, 2007) (Kuo et al., 2011) (Power & Franck, 2008)	Content for the educational program- Provides a basis for understanding the family so that education and intervention can be tailored to their needs
Consideration of Parents' Health Literacy	(Badarueen & Sabharwal, 2008) (Betz et al., 2008) (Jacobs, 2016) (Levassuer & Carrier, 2010) (Levassuer & Carrier, 2012)	Content for the educational program- Provides a basis for understanding the family so that education and intervention can be tailored to their needs- specifically related to written materials and explaining the child's condition and the therapeutic process

In the next Chapter, *Engaging Families*, will be described in detail.

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Chapter 3: The Proposed Program

Description of the Proposed Program

The field of occupational therapy seeks to provide evidence based, client centered care. Parents play a central role in their child's growth and development and are integral parts of a child's environment, therefore, when working with children, occupational therapists need to not only provide client centered but also family centered care through the incorporation of the child's parents within the rehabilitation process. Despite the evidence supporting the use of Family Centered Care (FCC), or a partnership between parents and health care professionals in pediatric rehabilitation, there still remains a significant disparity between what theory and evidence supports and what is actually seen in practice (An & Palisano, 2014; Aarthun & Akerjordet, 2012; Foster et al., 2010; Arcuri et al., 2015; Glang, McLaughlin, & Schroeder, 2007; Harrison et al., 2007; Bamm & Rosenbaum, 2008). This project focuses on developing, implementing, and evaluating a continuing education course provided to occupational therapists on FCC, its principles, and how to effectively incorporate parents into their child's therapeutic process.

Program Description. The proposed continuing education program, *Engaging Families: A Continuing Education Course on Family Centered Care Principles and Practice,* focuses on educating pediatric occupational therapists on FCC and strategies to use during every day practice in order to increase parent participation and self-efficacy in caring for a child with a recent change in functional status secondary to a traumatic injury. The program will focus on effective communication skills, evaluation of parental characteristics and needs for individualized education to each parent, skills training through occupational performance coaching, and collaborative goal setting. All of these program components have been shown in the literature to be important aspects of FCC and effective strategies to incorporate parents in their child's inpatient rehabilitation.

Goal and Outcomes. The overall goal of *Engaging Families* is to help educate pediatric occupational therapists on the importance of incorporating parents into their child's therapeutic process and to provide the occupational therapists with the knowledge and skill set to know how to do so. It is the hope that by increasing the occupational therapists' skills in implementing FCC strategies with parents of children with a recent traumatic injury, parents will be able to become active participants in their child's therapeutic process, improving not only child outcomes post discharge, but also parental level of self efficacy and knowledge for caring for a child with a recent change in functional status secondary to a traumatic injury.

Program Participants. The continuing education program will be offered to inpatient occupational therapists who work in pediatric rehabilitation settings. Groups will remain small with a maximum number of participants per groups of 10–12 in order to allow ample opportunities for role-play scenarios and gaining feedback from peers.

Program format: Engaging Families will be a two-day training course, for seven hours per day. It will consist of seven overall topics: general overview of FCC, its principles, and why it is best practice; parent-provider communication; written informational exchanges with parents; collaborative goal setting; skills training using occupational performance coaching; and matching intervention sessions to the family. A detailed outline of the program can be found below in *Table 3.1* and *Table 3.2* with summaries of each component below the tables.

Key Components

Engaging Families will consist of both didactic portions and practice portions to enhance occupational therapists' learning and carryover of information into daily practice. This combination has been shown to be an effective way to educate providers on their verbal and written communication skills, important aspects for all FCC strategies (Law et al., 2005; Hart et al., 2005; Nikendei et al., 2011). The presentations during the didactic portion of the program will be guided by Cognitive Theory of Multimedia Learning (CTML) in that videos and images will be provided to supplement text. CTML proposes that people learn more deeply from creating mental representations of words and pictures than they do from words alone; words and graphics presented together (multimedia) are more effective for a person's learning than just presenting one sensory experience because people attempt to build meaningful connections between the two types of information, in the process, making them more active learners (Sorden, 2012). In addition to the texts, images and videos, the presenter will verbally present the information. PowerPoint presentations will be printed and provided in a booklet format to allow the participants to be active listeners through taking notes during the didactic portion. Real world examples, as well as evidence based literature for the information presented will be provided to participants to demonstrate the clinical application of the information and the evidence basis to support its use in practice.

Simulations within an educational program provide a safe environment for the program participants to bridge theory with practice and allow the practitioner to explore their own actions, construct meaning through discussion with other participants, and trial new ways to problem solve common communication barriers (Zubairi, Lindsay, Parker, & Kawamura, 2016). Therefore, during the practice portions of the program, the practitioners will be able to implement learned knowledge in both an interactive and interpersonal way while providing and receiving peer feedback. This will allow participants to assess their level of understanding of the material recently presented and attempt to implement it in a way that is similar to everyday practice. It will be recommended to participants upon signing up for the course that they bring a personal laptop in order to participate in the simulation portions of the practice section of the course. Additionally, in the course pamphlet participants will be asked to think of a case scenario from their practice in which they had difficulty communicating with a parent so that discussion and problem solving can occur around this during the course.

Table 3.1: Schedule for Day 1 of *Engaging Families*

DAY 1	
Time	**Content**
7:45 – 8:00am	Sign in
8:00 – 9:00am	Overview a. What is Family Centered Care (FCC) and it's principles? b. Why is FCC considered best practice? What is the evidence for FCC?
9:00 – 10:00am	Parent- Provider Communication a. What are the 6 Interpersonal Communication Strategies and how can they be used effectively with parents? b. How to be culturally sensitive and aware of the environmental and personal factors contributing to provider- parent communication?
10:00 – 10:15am	**BREAK**

10:15 – 11:45am	Parent-Provider Communication – Practice a. Small group role play with partners using various communication strategies b. Scenarios provided- opportunity for each provider to practice being the provider and using the 6 communication strategies while a partner role plays the parent c. Entire group provides feedback after each scenario
11:45 – 12:30pm	**LUNCH**
12:30 – 1:15pm	Written Informational Exchanges with Parents a. How to provide easily accessible and pertinent written and visual information to parents on OT and their child's prognosis, diagnosis, plan of care, and treatment strategies? b. What is health literacy and how to take into consideration parents' health literacy during written and oral communication? c. How to use the Flesch Kincaid Reading Level when creating handouts for parents?
1:15 – 3:00pm	Written Informational Exchanges with Parents – Practice a. Participants practice determining the health literacy and accessibility of various medical handouts b. Given the opportunity to use a case example from work to create a handout that they could provide the child's parent c. Peer feedback is provided on each participants written handout

Table 3.2: Schedule for Day 2 of *Engaging Families*

DAY 2	
Time	**Content**
7:45 – 8:00am	Sign in
8:00 – 8:30am	Collaborative Goal Setting a. Why is collaborative goal setting important in pediatric inpatient rehabilitation? b. How to be truly collaborative when setting therapeutic goals for children and their families? **c.** What is the Canadian Occupational Performance Measure (COPM) and how can it be used to create collaborative goals?
8:30 – 9:45am	Collaborative Goal Setting- practice a. Provided the COPM- with a peer, practice the semi structured interview, scoring/documenting results, and creating goals from the assessment b. Practice using a semi-structured interview to gain

	information that could be used to create goals (See Appendix C)
9:45 – 10:00 am	**BREAK**
10:00 – 11:15am	Skills Training using Occupational Performance Coaching a. What is skills training and how to use it as a problem solving method with parents? b. What is occupational performance coaching and how to use it with parents as a way to teach skills during their child's OT sessions?
11:15 – 12:15pm	**LUNCH**
12:15 – 1:45pm	Skills Training Using Occupational Performance Coaching - Practice a. Small group role play- pick out of a hat an ADL/transfer to teach a family member i. One provider is the "child" and is told level of assistance that is needed to complete the ADL/transfer ii. One provider is the parent iii. One provider is the therapist b. Practice using the problem solving skills training approach and OPC c. Peer feedback provided after each role play (See Appendix C)
1:45 – 3:00pm	Conclusion: Matching the intervention sessions to the family a. How can the provider use all the information/ learning from this course to best match each family's needs? Summary of learning Remaining Questions

Summary of Each Component of the Program

Overview Section

During this introductory session, the course content and the overarching theoretical principles that guide the remaining topics discussed in the course will be outlined. Family Centered Care will be clearly and operationally defined so that participants gain a strong understanding of what FCC is and the main principles and assumptions of the theory. In addition, a summary of recent and pertinent research articles that discuss the importance of FCC in pediatric inpatient rehabilitation settings will be presented to help highlight the evidence basis supporting this theoretical framework and the remaining topics presented. Providing the evidence that supports FCC and its implementation into daily care will help participants appraise the importance of FCC with the hope that seeing the value of this approach will help increase their desire to learn the material and then implement learning into their own daily practice.

Parent Provider Communication Section

During the didactic portion of this session, the six interpersonal communication styles will be defined. They are as follows: 1) advocating, in which the therapist uses statements that normalize a client's experience; 2) collaborating, in which there is an emphasis on the parents' equal role in setting goals with the therapist and their child; 3) empathizing, in which the therapist tries to understand the child's and parents' experiences through using gentle inquiry, summarizing statements, validation, and mirroring; 4) encouraging, in which the therapist uses positive reinforcement and hope building statements to build confidence; 5) instructing, in which the therapist educates the parents on the therapeutic process and how to perform tasks or explain the rationale for a therapeutic activity; and 6) problem solving, in which the therapist asks strategic questions to help the parents reason through a challenge that has arisen (Kreutzer et al., 2002; McAnuff et al., 2014; Hart, Drotar, Gori, & Lewin, 2005). The presenter will provide short scripts that demonstrate each type of communication strategy to help enhance understanding and learning. Additionally, discussions will occur around how to analyze the social context of the family in order to effectively communicate with each parent and reach a shared understanding of the child's diagnosis and plan of care. Discussion of when in the therapeutic process and why to use each type of communication will be discussed in an open forum like discussion. Participants will be asked why they believe one communication strategy would be a better approach given a specific scenario. Brainstorming will occur as a whole group.

For the practice section of parent provider communication, the participants will be broken up into small groups (2–3 participants per group). They will be provided with real world scenarios in which one therapist takes on the role of the parent and one the provider. Each participant can practice using the six different communication strategies with feedback from peers in the group. At the end of the scenarios, the group will come together to discuss questions they have and to discuss which communication styles they felt were the best for each scenario and why. While there is not always a right or wrong answer for communication strategies in each scenario, an open discussion about which strategy appeared to be the most sensitive to the parents' current situation, family and social context, and time point in therapeutic process, will occur to help participants critically appraise how the types of communication and when they are used may have an impact, either positive or negative, on the parent-provider relationship.

Written Informational Exchange Section

In this section of the program, participants will learn how to provide written text and image information to parents regarding their child's prognosis, diagnosis, plan of care, and treatment strategies. Specific strategies of how to structure the page to be clear and easily readable will be discussed in detail, such as organizing information in chunks, limiting the length of lists to seven points, defining technical and unfamiliar words, prioritizing need to know information at the beginning and using topic headings, making pages un-crowded, and using basic and realistic visual aids such as carefully captioned pictures (Jacobs, 2016).

Additionally, this didactic section will address health literacy. The definition of health literacy will be provided as well as statistics that demonstrate the average health literacy in the United States to help highlight the importance of taking this factor into consideration when providing medical information to parents. Strategies will be discussed regarding how to take health literacy into consideration when communicating with parents via written materials as well as during oral communication. The six identified ways to integrate health literacy into occupational therapy practice (be informed, standardize practice to health literacy, make information accessible, strengthen interactions, intervene, and collaborate) will be discussed (Levassuer & Carrier, 2012). Finally, an introduction to the Flesch Kincaid Reading Level will be provided as well as a tutorial on how to determine the readability of provider created written material through the use of Microsoft word.

During the practice portion of written communication exchanges, participants will be provided with various online medical handouts to practice determining the health literacy and accessibility of materials. Group discussion on the readability level determined by each group and whether or not participants think, based on what they have learned, that it is a strong piece of written information to provide to a family, will occur during this section. After this, each participant will have the opportunity to think of a real world case example and create a one-page handout that meets health literacy needs and uses strategies for structuring the material. A peer review at the end will occur to help provide feedback to each therapist on their informational page, with the hopes that they will go home, edit the page and use it with the family from their case example.

At the end of the written informational exchange section, participants will be asked to provide a real world case example of a time that they had difficulty communicating with a parent, whether that was through written or oral communication. The group will help to brainstorm and discuss effective strategies, based on the principles learned in this section and the previous one, to communicate with this particular parent or parent personality type.

This concludes Day 1 of the continuing education course.

Collaborative Goal Setting Section

For the first topic of Day 2, a definition of collaborative goal setting will be provided along with research to support its use in the rehabilitation process. Discussion of how to use collaborative goal setting with parents and their children in a pediatric rehabilitation setting will be provided. One measure that helps to facilitate collaborative goal setting, the Canadian Occupational Performance Measure (COPM), will be introduced and instructions on how to implement it and score it will be provided. Research on its use in a pediatric setting will be provided to support its evidence basis for using it in this particular setting. Since this is a well known assessment, it is possible that many participants will be familiar with its use, therefore, prior to beginning this section, this therapist will ask for a raise of hands of people who know the COPM and have used it. If it appears that majority of the participants are familiar with the COPM, the presenter will pass through slides on the COPM to focus mainly on slides discussing the use of a semi-structured interview, not guided by a standardized assessment, to gain insight into parents' and children's priorities for care.

Similar to the didactic portion, the practice portion of this topic will also depend on the familiarity the participants have with the COPM. If participants state that they had not used the COPM in practice or were only somewhat familiar with the topic, then each of the participants will be provided with a copy of the COPM. With a peer they will practice engaging in the semi-structured interview, structured by the COPM, to gain information on what is important to that person. They will go through the whole process of documenting, scoring and creating goals from the results. Each participant will have a chance to be the therapist administering the COPM and the "client" to whom the therapist is administering this assessment. At the end of the interviews, peers will provide feedback to one another on their semi structured interview and their goal selection.

If participants express familiarity with the COPM, the above practice portion will not occur, only the practice section in which participants practice completing a semi-structured interview not guided by the COPM will occur. For this practice portion, participants will practice asking open-ended questions to families, exploring parents' and children's responses through asking follow up probing questions in order to gain more information, and taking this information and creating goals that have meaning for the parents and the child. Once again, one participant will practice being the therapist another participant the parent and a third participant the child. The parent and child will be given a sheet of paper that states their main goal, while the therapist will be given the child's clinical situation (i.e. type of traumatic injury and functional level). At the end of the practice portion, the participants will discuss whether the therapist was able to ascertain what the goals of the parent and child were. Each participant will have the opportunity to be the therapist, with three different clinical scenarios for each time. See Appendix C for details.

Skills Training Using Occupational Performance Coaching Section

In this section of the course, education will be provided on skills training, strategies used during skills training, and how to use it as a problem solving method with parents. Additionally, occupational performance coaching will be explained in detail as a skills training method to help teach parents the skills they need to take care of a child with a recent change in functional status secondary to a traumatic injury. The definitions of each will be provided along with how to effectively engage parents in the coaching method and what activities one can engage parents in and how. As with other topics outlined above, a few evidence based examples of how skills training and occupational performance coaching have been used in a pediatric setting to help parents learn the skills needed to take care of their child will be provided to demonstrate support for these strategies.

During the practice portion of skills training through occupational performance coaching, participants will have the opportunity to engage in small group role-plays, with one member being the child, one the parent, and one the therapist. The therapist will pick out of a hat an ADL or a type of transfer. The member who is playing the child will pick out of a hat the level of assistance to act out. The therapist will practice using the problem solving skills training approach and occupational performance coaching to help guide the participant playing the parent through the ADL or transfer shown. Feedback will then be provided by group members after each role play to help each therapist critical appraise their own role play in terms of the strategies and effectiveness of their performance to enhance their learning. Time will be provided for each participant to play each role. See Appendix C for details.

Conclusion Section

In the conclusion portion, the main discussion will be on how the provider can take all this information and new learning from the course and apply it to each individual family in order to best match each family's needs. A summary of each strategy and the main points from each will be reviewed and any remaining questions will be answered.

Program Objectives:

By the end of the program participants will…

- Be able to define Family Centered Care and its principles
- Effectively communicate with parents regarding their child's prognosis, diagnosis, and plan of care
- Engage parents in a semi structured goal setting interview and create family centered goals from this interview
- Understand and be able to implement Occupational Performance Coaching and Skills Training into daily practice

- Create written informational pages for parents that take into consideration health literacy

Barriers and Challenges for Implementation

The primary barrier for implementing this program is obtaining qualifications as an Approved Provider Program from the American Occupational Therapy Association (AOTA) in order to allow participants to be eligible to receive continuing education credits for the course. All continuing education courses undergo a rigorous qualification process in order to ensure quality of programs provided. A single course approval must be applied for in order to obtain AOTA's Approved Provider Program and award participants continuing education units that can be used towards renewal of their licensure (AOTA, 2016). In order to apply, a fee of $325 is required and the APP Single Course Approval application must be filled out in order to obtain the approval to run the course and provide the therapists continuing education credits (AOTA, 2016).

In addition to the primary barrier, another barrier to implementation will be getting a hospital to sponsor the course through offering boardroom space and an ADL suite on a Saturday/ Sunday schedule. This may require the hospital to hire staff for over time and will require that the required spaces are reserved for the course only. A pediatric hospital may be more willing to open their doors for this course if it can be shown that a course like the proposed one would provide a significant benefit to their own occupational therapy department. This will be a barrier that is targeted during the dissemination phase of the program.

The next Chapter will describe in detail how *Engaging Families* will be evaluated to determine the course's impact on occupational therapists' everyday use of FCC strategies and parent participation in their child's inpatient rehabilitation.

Chapter 4: Evaluation Plan

The proposed continuing education course focuses on educating pediatric occupational therapists on Family Centered Care (FCC), its principles, and how to effectively incorporate parents into their child's therapeutic process through the use of didactic and interactive based learning. The overall goal of the program is for practitioners to take this learned knowledge and implement it into their daily practice in order to improve parent participation in their child's therapeutic process as well as improve parent's self-efficacy and knowledge for caring for a child with a recent change in functional status secondary to a traumatic injury. The tertiary goal of the program is to improve child outcomes post discharge.

In order to evaluate the effectiveness of this program on primary outcomes, a pre-post test with six week follow up assessment schedule will be used to look at whether the occupational therapists gained knowledge and skills needed to implement learning from the program into practice. This will be done through assessing occupational therapists' knowledge of FCC principles and strategies and assessing their ability to implement them into daily practice. Additionally, assessment of parents' perceptions of the therapists' effectiveness with implementing these strategies will be obtained. Gaining parent insight will be a helpful tool for the therapists as a way to self check their implementation of their learning into practice as well as an additional tool for the evaluation to gain more insight into the effectiveness of this continuing education program.

In order to determine the effect the proposed program has on occupational therapists' and parents' outcomes listed above, the following research question was used to guide the design of the evaluation study: Does attending *Engaging Families: A Continuing Education Course on Family Centered Care Principles and Practice* lead to occupational therapists effectively implementing FCC strategies into their daily practice? The following sections detail the core purpose, context, scope, questions driving the evaluation, and data management plan utilized for this program evaluation.

Core Purpose

This formative evaluation would help to highlight whether the program is having its desired effects on the therapist, improving their knowledge and ability to include parents in their child's inpatient occupational therapy. Additionally, this evaluation will highlight which topics need to be expanded upon or which topics can be condensed. With the inclusion of the parent survey, the evaluation would highlight which, if any, strategies the therapists are implementing effectively into their daily practice and may show trends across therapists on which strategies are or are not implemented.

Context of Evaluation

The first dependent variable being measured is knowledge, which can be operationally defined as the facts and information acquired by the therapist through the continuing education course. This variable will be measured using a pre course and post course knowledge based assessment created by this therapist. There will be two to three clinical scenario questions per topic, in which the therapist will need to apply the knowledge acquired during the continuing education course to a real-world scenario. Additionally, for the post-test, one question will ask therapists, "Which of the following strategies do you believe you will implement in your day-to-day practice having taken this course?" At the six-week follow up, "Which of the following did you change in your day-to-day practice?" will be asked. Therapists will be able to select as many options as they want from the topics discussed in the course (i.e. written communication, health literacy, collaborative goal setting etc.).

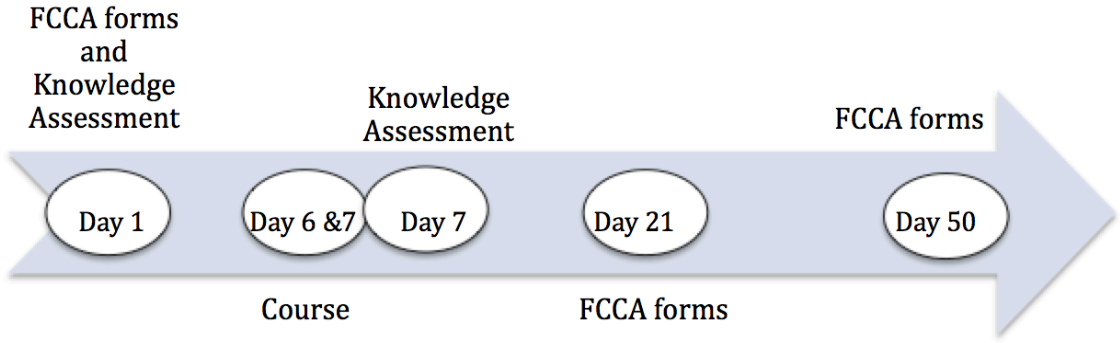
The second dependent variable is implementation of strategies; this can be operationally defined as therapists using strategies of collaborative goal setting, shared decision making, providing information in both written and oral forms to parents in a way that takes into account health literacy and the parents' needs, and educating parents on strategies to take care of their child with a traumatic injury. This variable will be measured through the Family Centered Care Assessment (FCCA), which assesses the family centeredness of health care practice (National Center for Family and Professionals, 2017). FCCA has a parent form and a provider form, both of which will be used for this evaluation at the designated pre, post, and six week follow up assessment periods (National Center for Family and Professionals, 2017). The measure assesses share decision making, health-promotion, strengths based care, family support, care setting practices, cultural competence, care coordination, and communication (National Center for Family and Professionals, 2017). Respondents are given statements that reflect family centered care and are asked to respond how often they received that care (parents) or provided that care (practitioners), with answer choices of *never, some of the time, most of the time*, and *always*. While the assessment does not provide standardized scores, it helps to highlight how often providers are implementing FCC principles into care based on self-report and parent-report. For this evaluation the categorical responses will be translated into quantitative scores for the sake of data analysis to determine significance with a score of 1 corresponding to the *never* category and 4 corresponding to the *always* category. This will be discussed more in the *Data Management Plan* section of this chapter.

Scope of Evaluation

The study would take place in a pediatric hospital that services children with complex and traumatic injuries. The participants would be the ten to twelve therapists who participated in the initial pilot of the continuing education course as well as two parents of hospitalized children, per therapist. The parent (mother or father) would be of a child (ages 8–12) with a recent (within one month) traumatic injury who has an OT who has gone through the FCC continuing education program and who will be in the rehabilitation hospital for long term, defined as greater than three months. Additionally, the parent would need to be present for at least 50% of the child's therapy sessions.

The program will take place over the course of two months. The first week, occupational therapists who have signed up for *Engaging Families* and the parents of two children for each of the therapists' caseload will complete the FCCA forms. Additionally, at this time point the therapist will complete the knowledge assessment. The course will take place over that weekend. Immediately after the course the therapists will complete the knowledge self-assessment. Two weeks post course, the therapists and parents will complete the FCCA forms again as well as the question about what strategies the therapists feel they were able to implement. Finally, one month later the therapists and parents will complete another FCCA assessment. Below, in *Figure 4.1* is a timeline of assessment measurement periods as outlined above.

Figure 4.1: Timeline of Program Evaluation



Quantitative data will be the primary form of data used to help determine significant changes in knowledge and implementation of Family Centered Care strategies into practice. While the FCCA information is in qualitative form currently, as mentioned, numbers will be assigned to each category of scores on the FCCA to allow for statistical analysis of this assessment.

<u>Evaluation Questions</u>

Table 4.1: Evaluation Questions

Stakeholders	Evaluation Questions
Program creators/ administrators Tipping Point Connectors (Hospital administrators)	Do parents report improvements in the family centeredness of their child's rehabilitative care after their occupational therapist attends the course?
	Do therapists implement the course content in their daily practice after attending the course?

Data Management Plan

The data management plan consists of an organized and coordinated approach to data collection. As previously mentioned, a knowledge assessment will be completed pre and post course by the occupational therapists, while the strategy implementation assessment (FCCA) will be completed pre, two weeks post course, and six weeks post course by both the providers and parents. Knowledge assessments will be scored immediately after each assessment period and documented in an Excel spreadsheet. FCCA parent and provider form scores will be converted from qualitative data to quantitative data and inputted into an Excel spreadsheet. Data will be stored on a secure database on this therapist's computer with a hard drive for back up. No personal information will be used, rather therapists and parents will be provided with a code so that confidentiality standards can be maintained.

The main author will complete data input and analysis. Scores on assessments for knowledge will be analyzed for improvements and statistical significance of change will be determined. Evaluation of whether therapists implemented topics they stated they would, on the knowledge post-test, will be looked at. Visual analysis of qualitative ratings on the FCCA will also be completed to determine where there were improvements in ratings for the providers with corresponding improvements in ratings from the parents. Additionally, the quantitative data from the FCCA will be computed with a total FCCA score. Statistical significance will be determined comparing total scores on pre, post and follow up FCCA assessments for providers and parents.

In the next Chapter, a two-year funding plan describing the creation and implementation of *Engaging Families*, including the evaluation plan outlined in this chapter, will be described.

Chapter 5: Funding Plan

Project Description

Engaging Families: A Continuing Education Course on Family Centered Care Principles and Practice focuses on educating pediatric occupational therapists on Family Centered Care (FCC) and strategies to use during every day practice in order to increase parent participation and self-efficacy in caring for a child with a recent change in functional status secondary to a traumatic injury. Topics included in the two-day, seven hour, FCC course include the following evidenced based intervention skills and strategies: effective communication skills, evaluation of parental characteristics and needs for individualized education, skills training through occupational performance coaching, and collaborative goal setting. The structure of the course will include both didactic and practice portions for each topic in order to enhance the occupational therapists' learning and carryover of information into daily practice. Simulations/practice scenarios within an educational program provide a safe environment for the program participants to bridge theory with practice and allow the practitioner to explore their own actions, construct meaning through discussion with other participants, and trial new ways to problem solve common communication barriers (Zubairi et al., 2016).

In order to create this continuing education program and successfully implement it in the pediatric occupational therapy community, expenses associated with its creation and implementation as well as funding sources to help offset these expenses must be taken into consideration. This chapter will help highlight those expenses and funding sources necessary for successful creation and implementation of the continuing education program, with a two-year outlook.

Expenses:

The first expenses to be discussed in this chapter will be around the creation of the program, which would occur during year one. This therapist will be creating the program and will need to take time off from her current job to create the continuing education program presentation. To create the program, one month will be taken off from work. Paid time off will be used for three weeks to cover the salary expenses, however one week unpaid will need to be taken. The therapist would take one week with no pay, which would be approximately $1,000, after taxes, based on her current salary rate. Benefits would continue to be provided through her current position.

In addition to the salary expenses, there are also expenses for supplies and materials. Rights to Microsoft will be needed in order to have access to Word, PowerPoint, Excel, and Outlook, all of which will be necessary for the creation, implementation, and evaluation of the program. This expense is $69.99/year; however this therapist currently owns Microsoft software, therefore this will not be an additional expense for the program. With the access to Word and PowerPoint, brochures can be created through this therapist’s home computer and then printed in large quantity at Office Depot or Staples in which the expense for 250 two sided brochures is $245. Stamps and envelopes will need to be purchased so that the brochures can be sent out. Stamps are $0.47 and flat rate envelopes that can have 20 brochures mailed in them are $6.65. It is the hope that for the dissemination plan, printed brochures will be provided to approximately five area hospitals the first year and ten the second year. They will be placed in staff rooms so that therapists can see the course offering and have the information needed to mail in the registration information. In order to receive the registration information for the course, a PO Box will need to be purchased. For a basic small PO Box, in the New York City area, the expense will be $90/year.

Additional expenses for the dissemination plan are outlined in Chapter 6. These expenses include New York State Occupational Therapy Association (NYSOTA) conference expenses, $325, and American Occupational Therapy Association (AOTA) conference expenses, including travel, $1,051.

After the first year of implementation, the hope is that with the evaluation plan and AOTA approval, Education Resources, Inc. will create an online post on their website (www.educationresourcesinc.com) for this course with a link to a digital version of the brochure in which there is no expense associated with it. With the digital version, participants can either mail in the registration information or complete it online.

Internet is needed to create the program in that the therapist needs access to online journals and email; this expense is currently split between three roommates and costs a total of $119.96/year each.

Finally, an additional expense, at the end of the creation phase, is an application fee for APP Single Course Approval through AOTA. This will be a one-time expense of $325. In order for therapists who participate in this program to be eligible for continuing education hours that go towards renewal of their license, AOTA will need to approve this course. Therefore this one time expense is an important expense for implementation of the program.

Expenses relating to the implementation of the program are outlined next. During the first year one course will be implemented with an evaluation of the course to be completed during this time; see Chapter 4 for more details. Many of the expenses for the implementation of the course are the same as the creation (i.e. rights to Microsoft, computer, internet, etc.). During the first year of program implementation, the program will be offered at a pediatric hospital in the greater New York City/tri-state areas, as this is local to the presenter's residence. During the second year, the course will be offered twice at two greater New York City/tri-state area pediatric hospitals. It is the hope that the hospitals will offer their boardroom space and ADL suites for the weekend course, with the ability to provide the educational course to their staff at a significantly discounted price.

Another expense for the implementation of the program is the salary for this therapist who will be presenting the course. The salary for continuing educators is on average $25.00/hour, with New York State paying slightly higher than the average. Therefore, the expense for salary for the presenter will be $30.00/hour with a total of $420 for the two day, seven hour training course. Expenses for salary will be $840 for the second year of program implementation. Since the course will be run during the weekends, as typical of many continuing education courses, the therapist will be able to continue with her current full time job.

In addition to the aforementioned implementation expenses, there will be expenses for bound copies of the PowerPoint/Handouts for the course. At Office Depot/Staples, square edge double-sided booklets, in black and white, with 100 pages, are $12.69/person. This would lead to an expense of $152.28/course since courses will be capped around twelve participants. The Canadian Occupational Performance Measure (COPM) will need to be purchased, since participants will be learning about and engaging in administering the COPM for one section of the continuing education course. The manual and 100 forms can be purchased for $225.45.

For the first course in year one, there will be no expense to the participants for attending the course. Participants will volunteer to take the course and agree to complete the evaluation assessments, see Chapter 4 for more details. The Family Centered Care Assessment (FCCA), provider and parent forms, is the assessment that will be completed by therapists and parents. It is seven pages total and the PDF versions are free to download. Two parents from each OT participant will complete the FCCA parent form. In addition to the FCCA, the occupational therapists will take a pre and post knowledge assessment that will be two pages in length. Evaluation assessment copies will expense approximately $0.11/ sheet. Copies of the assessments for each of the OT participants and parents as well as for each assessment measure time period will cost $83.16. While the FCCA is the current assessment utilized for the evaluation of this continuing education program, the Measure of Process of Care (MPOC) is a valid and reliable assessment that could be a better tool to use. If funds were available, an investigation into which assessment would be most effective to use as an evaluation tool would be completed. The MPOC parent and MPOC provider online assessments are $99.00 each.

Table 5.1: Expenses

Budgeted Item	**1st Year**	**2nd Year**	**Justification**
Salary	Creation Phase: $1,000 – (Donating Her Time) Implementation Phase: $30.00/hour *TOTAL:* $420	Implementation Phase: 30.00/hour *TOTAL:* $840	Therapist will need to take time off for creation of program. Three weeks are covered through PTO; one week would not be. During implementation phases therapist presenting will be paid at the average rate for continuing education providers in the state of NY. http://work.chron.com/much-paid-continuing-education-instructor-8741.html
Supplies	Microsoft Programs: $69.99 (already owned) PO Box: $90 Computer: $1500 (Already Owned) Internet: $29.99/mo for total of $119.96	Microsoft Programs: $69.99 (already owned) PO Box: $90 Internet: 119.96	The software has already been purchased and downloaded on computer. There will be no expenses associated with this for the program. https://poboxes.usps.com/poboxonline/search/landingPage.do www.apple.com Internet used currently is Xfinity. Since the work on this continuing education course will occur in this therapist's home, internet expenses are currently split 3 ways between the roommates. www.xfinityspecial.com/internet

	Mac Projector Connector: $10.99 *TOTAL: $220.95*	‘ *TOTAL: 209.96*	At Wal-Mart, expense for the connector for the Mac computer to a projector.
Materials	Dissemination Total: $684.35 Bound Booklets for the Course: $152.28 Copies of Assessments for Evaluation Plan: $0.11/sheet for total of $83.16 FCCA parent and provider form- Free MPOC Provider: $99 MPOC Parent: $99 COPM (12 Copies): $225.45 *Total without MPOC: $1,145.24* *TOTAL with MPOC: $1,343.24*	Dissemination Total: $1,692.2 Bound Booklets for the Course: $304.56 *TOTAL: $1,996.76*	http://www.officedepot.com/a/design-print-and-ship/ 12 Participants and 24 Parents (2 parents from each participating OT). FCCA Parent and Provider forms are each 7 pages. The knowledge assessment is 2 pages. 3 time periods for assessment. If funds were available, an evaluation into whether MPOC or FCCA would be a more effective measure to use would be completed. Therefore this is a potential extra cost. http://www.rehabmeasures.org/Lists/RehabMeasures/PrintView.aspx?ID=928
Other	Application for APP Single Course Approval through AOTA: $325 *TOTAL: $325*		In order for therapists who participate in this program to be eligible for continuing education hours that go towards renewal of their license, AOTA will need to approve this course.

Total Expense	**Total without MPOC: $2,111.19** **Total with MPOC: $ 2,309.19**	**$3,046.72**	

For the second year courses, there will be a fee to participate, as is typical with continuing education programs. This expense will be determined based on the total expenses for implementing and running the course minus the funds that are provided through in kind donations and grants. Available local resources, funds and grants that can help to offset the expense of the program will be discussed in detail next.

Available Local Resources and Grants

In order to fund this program, both in kind resources and grants will be used. One in kind resource that will be used is a local NYC hospital donating a conference room space and equipment, including ADL suite, for the program. Incentives of educating their staff for free or at a significant discount will be provided in order to increase the likelihood that a hospital will donate these resources for a weekend. The expense for this in kind resource is around $350/day with total cost of $700 for each course (Kitchen & Casazza, n.d.). In addition, this therapist will be seeking an OT volunteer who works at the hospital, in which the continuing education course is being held, to come to the course thirty minutes early to help people with signing in and out of the course. This expense would be around $15/course. These in kind resources, if needed to be purchased, would bring the total expense for year one to $2,826.19 and for year two to $4,476.72.

In addition to in kind resources, crowd source fundraising through GoFundMe.com will be created with the hopes of raising at least $500 from family, colleagues, and friends to help supplement the creation phase of the program since there are a lot of upfront expenses to this program.

In addition to the aforementioned funding sources, federal, state, and private grants are another avenue to obtain funds for programs. The Dudley Allen Sargent Research Fund: Doctoral Student Competition gives financial assistance to post professional doctoral students involved in research. In addition, the United Hospital Fund gives grants to those who are completing a project that has the potential to improve health care for New Yorkers, especially vulnerable populations, of which children with special needs fall into. These and other grants are outlined in Table 5.2.

Lastly, as mentioned previously, there will be a fee to therapists attending the program during the second year courses only. This is standard with the continuing education courses currently provided. It is the hope that with funding sources such as the ones mentioned above, that the fee for the therapists' participation would be minimal as compared to other continuing education courses.

Table 5.2: Grants

Grant Title:	**Criteria for Grant that makes it Applicable:**
Dudley Allen Sargent Research Fund: Doctoral Student Fund	• Gives financial assistance to post professional doctoral students involved in research • Any student enrolled in the Sargent College post professional doctoral degree can apply • Max award: $5,000 https://www.bu.edu/sargent/research/research-administration/dudley-allen-sargent-research-fund/
United Hospital Fund	• Provides grants to a project that has the potential to improve health care for New Yorkers, especially vulnerable populations • Encourage applications for programs that benefit not just a single organization but rather have a broader applicability and learning

	• Requires a dissemination plan • Awards range from: $50,000– $125,000 for up to a two year period https://www.uhfnyc.org/grants/criteria_and_instructions/
Agency for Healthcare Research Grant R03: Small Research Grant	• Given to support those undertaking small health service research that is completed in a short period of time (within two years) and has limited resources • Dissertation studies can be used if the work is within the scope of the award • Emphasis placed on research topics that address the Agency's mission of producing evidence that will improve health care quality and patient centered outcomes • Max award: $100,000 https://www.ahrq.gov/funding/process/grant-app-basics/appover.html
ED-GRANTS-022712-002 Community Parent Resource Centers CFDA #84.328C: Training and Information for Parents of Children with Disabilities	• Provides grants for programs that ensure that parents of children with disabilities gain training and information that will help improve results for their children • Max award: $100,000 http://www.grants.gov/web/grants/view-opportunity.html?oppId=146653
Department of Health and Human Services HRSA-17-100 Health Care Delivery System Innovations for Children with Medical Complexity	• Supports those developing innovative care models for children with chronic conditions, functional limitations, and high health care use • Those who are testing strategies and building evidence to optimize high quality, cost-effective, family centered care for children with complex medical needs • Total program funding for all awards: $3,250,000 (grant award based on scope of project) http://www.grants.gov/web/grants/search-grants.html
Department of Health and Human Services HRSA-17-060 Maternal and Child Health Research Network Program Children with Special Health Care Needs Research	• Supports those who are engaging in research addressing health care services for children with special needs • Total Program Funding for awards: $1,000,000 (grant award based on scope of project) http://www.grants.gov/web/grants/search-grants.html

Conclusion

Overall, the expenses to create and implement *Engaging Families: A Continuing Education Course on Family Centered Care Principles and Practice* contain salary for the therapist creating the program and providing the course, supplies, materials, and an application fee. The total expense for the first year is $2,111.19, with a potential total being $2,309.19, if funds are available to research if the MPOC should be used over the FCCA. For the second year total expenses are **$**3,046.72. In order to cover these expenses a GoFundMe.com account will be created in the hopes of raising money from family, friends and colleagues. Additionally, local in kind resources will be sought out and applications to federal, state and private grants will be completed. Finally, to cover the remainder of expenses, participants will be charged to attend the continuing education program for the second year courses only, as is customary. It is the hope that the fee to participate in the continuing education program will remain minimal as compared to the fee of other continuing education courses.

The next chapter outlines the dissemination plan including target audiences, activities and the goals of the dissemination, and their costs.

Chapter 6: Dissemination Plan

Introduction

Engaging Families, a Family Centered Care (FCC) continuing education program, is a two day, seven hour continuing education course offered to pediatric occupational therapists. The course focuses on educating pediatric occupational therapists on FCC and strategies to use during every day practice in order to increase parent participation in their child's rehabilitative care and their self-efficacy in caring for a child with a recent change in functional status secondary to a traumatic injury. The program will focus on effective communication skills, evaluation of parental characteristics and needs for individualized education to each parent, skills training through occupational performance coaching, and collaborative goal setting. The course will provide participants the ability to learn about the aforementioned strategies and principles and then practice these strategies in a simulated practice setting with peer feedback.

Dissemination goals

- *Long Term Goal:* The dissemination of the program to both the primary and secondary audiences will lead to major pediatric hospitals hosting the course and requiring their occupational therapists to take the course during the first six months of their job.
- *Short Term Goal 1:* The dissemination of the program to the primary audience will lead to at least two New York based pediatric hospitals hosting the course.
- *Short Term Goal 2:* The dissemination of the program to the secondary audience will lead to 10–12 pediatric occupational therapists registering for each of the

continuing education courses offered.

- *Short Term Goal 3:* The dissemination of the program to the primary and secondary audiences will lead to hospitals outside the New York region offering to host the course.

The dissemination plan will begin during the first year of the program after its creation. The dissemination plan outlined below provides information on the primary and secondary target audiences, key messages for each of these audiences, influential spokespeople, dissemination activities, and expenses for these activities.

Primary Target Audience

The primary target audience for the dissemination efforts will be the heads of rehabilitation and the clinical education coordinators at pediatric rehabilitation hospitals in NYC. Dissemination efforts will target this audience with the hopes that they will offer to host the course at their hospital.

Key Messages for Primary Target Audience

1. *Engaging Families: A Continuing Education Course on Family Centered Care Principles and Practice* provides pediatric occupational therapists with the knowledge and skill set to effectively implement FCC principles and strategies into their day-to-day practice in order to improve parent participation in their child’s inpatient rehabilitation process.
2. Parents’ satisfaction with their child’s rehabilitation services appears to be directly related to how family based they are (Egilson, 2011). In order to increase parental satisfaction with care, organizations can formally adopt a FCC approach

to services through training staff in FCC principles and strategies so that staff implements these in their day to day practice (Law et al., 2003). *Engaging Families* allows hospitals the opportunity to train staff on these principles and strategies at a reduced cost for hosting the program.

3. Family Centered Care or a partnership between parents and health care professionals has been shown to have a positive impact on child outcomes when hospitalized (Glang et al., 2007; Harrison et al., 2007; Bamm & Rosenbaum, 2008). *Engaging Families* educates therapists on how they can engage in an effective partnership with parents through didactic and practice based learning modules.

Primary Influential Spokesperson:

1. Wendy Coster, PhD, OTR, FAOTA given her extensive experience in research on children and youth with disabilities and her membership with the Academy of Research of the American Occupational Therapy Foundation (AOTF).
2. Later in the dissemination efforts, after one course has been conducted, occupational therapists and parents of children who are treated by these therapists will become influential spokespeople through providing testimonials.

Activities

Dissemination activities for the primary target audience will consist of written information, and person-person contact through telephone conferences. A cover page that introduces myself and the reason for the mail correspondence, the course brochure, and an executive summary will be mailed to the rehabilitation department heads and clinical education coordinators at ten major NYC and surrounding tri-state area pediatric hospitals; five hospitals will be contacted the first year with the hopes that one will sponsor the first course and five to ten hospitals will be contacted the second year with the hopes that two will sponsor the course. Within the cover letter, a sentence will be added about following up with a phone call. This therapist will place a call to the rehabilitation department heads and clinical education coordinators, after enough time has passed for the mail to have been received, in order to enhance the dissemination efforts and advocate for the program being implemented at their hospital and to their staff. After these dissemination activities occur, the dissemination activities for the secondary target audience will begin. This is outlined below.

Secondary Target Audience

The secondary target audience for the dissemination plan is pediatric occupational therapists who work in rehabilitation hospitals. Dissemination efforts will target this population with the hopes of increasing registration for the course.

Key Messages for Secondary Target Audience

1. *Engaging Families: A Continuing Education Course on Family Centered Care Principles and Practice* provides pediatric occupational therapists with the knowledge and skill set to effectively implement FCC principles and strategies into their day-to-day practice in order to improve parent participation in their child's inpatient rehabilitation process.

2. *Engaging Families* will provide pediatric occupational therapists with the tools to effectively implement collaborative goal setting and skills training through occupational performance coaching as well as develop effective written and verbal communication skills in order to improve parent participation and child's attainment of long- term discharge goals.
3. *Engaging Families* will offer program participants the opportunity for continuing education credits in their current area of practice that will improve their implementation of evidence based, client and family centered practice.

Primary Influential Spokespeople

1. Wendy Coster, PhD, OTR, FAOTA given her extensive experience in research on children and youth with disabilities and her membership with the Academy of Research of the American Occupational Therapy Foundation.
2. Former program participants through testimonials on the value the course added to their knowledge, skill set, and daily practice.
3. Parents of children treated by those participants through testimonials of the value of having their therapist engage in FCC principles during their child's care.

Activities

For the dissemination, targeted at the pediatric occupational therapists, written information and person-to-person contact will be used to encourage program registration. Course brochures will be created with a description, objectives and goals of the program as well information about the presenter's credentials. After the initial course in year one, testimonials will be added to the brochure in which previous occupational therapists provide testimonials about the course and the parents of children treated by these therapists provide testimonials about their child's care. Additionally, on the last page of the brochure, the registration form will be provided with information on who to make the check out to and where to mail the registration forms and checks. These brochures will be mailed to five NYC area pediatric rehabilitation departments during year one and ten greater NYC/tri- state areas during year two.

In addition to the brochures, presentations at the American Occupational Therapy Association (AOTA) conference and the New York State Occupational Therapy Association (NYSOTA) conference will occur. This author will present her doctoral project's research supporting the course and the course description, objectives and goals in order to reach a broader population of occupational therapists as well as rehabilitation heads. For Year 1, the presentation will occur at NYSOTA, as the initial course will hopefully occur in a NYC area hospital. For Year 2, the presentations will occur at NYSOTA as well as AOTA, as it is the hope that with AOTA's national recognition, not only will the short-term goals be met but also the long-term goal of major pediatric hospitals outside the tri-state area hosting the course will be met.

Table 6.1: Budget for Dissemination Plan

Audience	**1st Year**	**2nd Year**
Primary	Stamps: \$0.47 x5= \$2.35 Flat rate envelopes: \$6.65 x5=\$33.25 Brochure: \$1.18x5= \$5.90 Cover page (1 page): 0.11x5 = \$0.55 Executive summary (2 pages):	Stamps: \$0.47 x10= \$4.70 Flat rate envelopes: \$6.65 x10 =\$66.50 Brochure: \$1.18x 10 = \$11.80 Cover page: 0.11 x 10 = \$1.10 Executive summary: 0.11 x 20 = \$2.20

	0.11x 10= $1.10 *Total: $43.15*	*Total: $86.30*
Secondary	Stamps: $0.4 x10= $4.70 Flat rate envelopes: $6.65 x10=$66.50 Dissemination Brochures: $245 NYSOTA Conference Cost = $325 *Total: $641.20*	Stamps: $0.47 x10= $4.70 Flat rate envelopes: $6.65 x10 =$66.50 Dissemination Brochures: $245 AOTA Conference Cost = $451 Travel Cost = $600 NYSOTA Conference Cost = $325 *Total: $1,692.2*
Total Expense for 2 years of Dissemination= $2,333.4		

Evaluation of the Success of the Dissemination

In order to determine the success of the dissemination efforts on the primary target audience, the number of hospitals who agree to donate their space for the program will be used as criteria. Since the goal of the dissemination plan targeted at hospital rehabilitation department heads and continuing education coordinators is to have them volunteer hospital space for the course, then number of hospitals who volunteer this would be a measurable indicator of the success of the dissemination plan for this audience.

In order to determine the success of the dissemination efforts on the secondary audience, the number of occupational therapists who sign up for each course offered will be used as the criteria. The goal of the dissemination plan for the secondary audience is to encourage pediatric occupational therapists to sign up for the course. Therefore, the number of participants that sign up for the course, specifically looking at how full each course offering is, would be an effective measurement for the success of the dissemination plan on this audience.

Conclusion

The dissemination of *Engaging Families: A Continuing Education Course on Family Centered Care Principles and Practice* will target two audiences, first, the rehabilitation department heads and continuing education coordinators at major pediatric rehabilitation hospitals in the NYC and tri-state areas, and second, pediatric occupational therapists. The goals of the dissemination plan are to have hospitals host the course through providing the space for the course to be run and also having occupational therapists register for the course. Dissemination efforts will include written materials, person-to-person contact, and conference presentations in order to reach both the primary and secondary target audiences. The total expenses for the two-year dissemination plan will be $2,333.4.

Chapter 7: Conclusion

This project sought to develop a means to address the problem of decreased parent participation in their child's inpatient rehabilitation program. Based on a review of the literature on the nature of this problem and the potential solutions to this problem, *Engaging Families: A Continuing Education Course on Family Centered Care Principles and Practice* was created. This didactic and practice-based continuing education course will help pediatric occupational therapists learn about Family Centered Care (FCC) and strategies to more effectively incorporate parents into their child's rehabilitative care, as this has been shown to also improve child outcomes pre and post discharge (Glang et al., 2007; Harrison et al., 2007; Bamm & Rosenbaum, 2008).

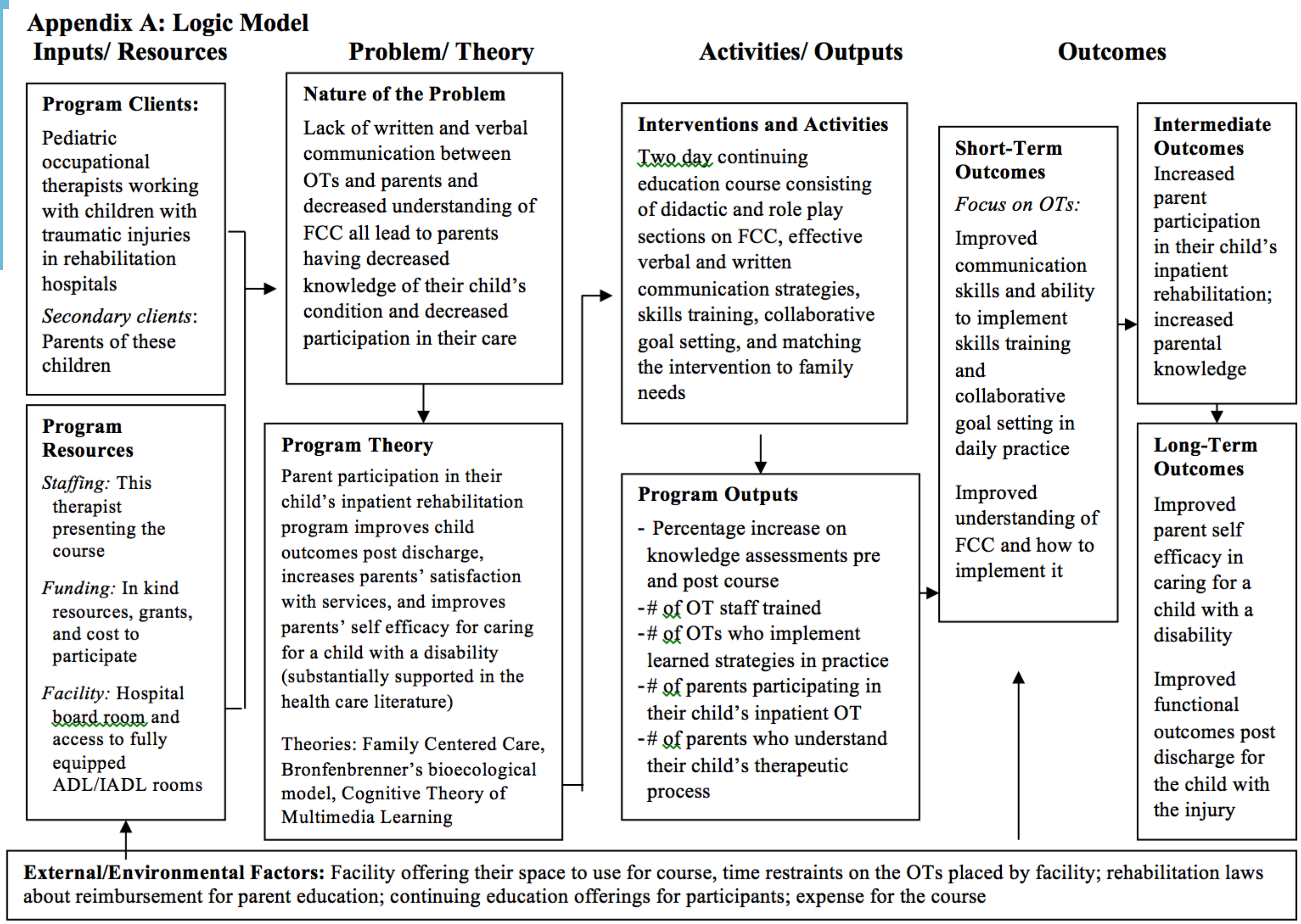
Engaging Families is a two day continuing education course that focuses on educating pediatric occupational therapists on FCC, effective verbal and written communication skills, evaluation of parental characteristics and needs for individualized education to each parent, skills training through occupational performance coaching, and collaborative goal setting. All of these program components have been shown in the literature to be important aspects of FCC and effective strategies to incorporate parents in their child's inpatient rehabilitation.

To determine if *Engaging Families* is having the desired effects on increasing practitioners' knowledge and use of FCC strategies in daily practice, an evaluation plan was included in this project. The evaluation will occur as a pre-post test with six-week follow up assessment using a knowledge assessment created by this author and the Family Centered Care Assessment (FCCA) parent and provider forms. The occupational therapists will complete all assessments and the parents of children being treated by those occupational therapists will complete the FCCA-parent form. These measurements will help to determine the effect of *Engaging Families* on the aforementioned dependent variables. See Chapter 4 for more details.

Lastly, this project addressed expenses, funding, and dissemination for *Engaging Families.* The total two-year expense for creating and implementing this course, one time in year one and two times in year two, is $5,157.91. Funding possibilities for these expenses include in-kind donations, government and private grants, and crowd source fundraising. The dissemination plan focuses on two target audiences. The first audience is rehabilitation department heads and clinical education coordinators at pediatric rehabilitation hospitals, with the hope that they will donate hospital space and resources to run the course. The second audience is pediatric occupational therapists with the hope that each course offering will have a full participant number of twelve. Dissemination activities include brochures, mail correspondence, phone correspondence and professional presentations. See Chapters 5 and 6 for more details.

Overall, *Engaging Families: A Continuing Education Course on Family Centered Care Principles and Practice* was created to educate pediatric occupational therapists on evidence-based best practice in pediatric rehabilitation. Through this course, occupational therapists will gain the knowledge and skill set to effectively incorporate parents in their child’s inpatient rehabilitation not only to improve parent self-efficacy for caring for a child with a recent change in functional status, but also to improve child rehabilitative outcomes.

APPENDIX A: Logic Model



Appendix A: Logic Model

Inputs/ Resources

Program Clients:

Pediatric occupational therapists working with children with traumatic injuries in rehabilitation hospitals

Secondary clients: Parents of these children

Program Resources

Staffing: This therapist presenting the course

Funding: In kind resources, grants, and cost to participate

Facility: Hospital board room and access to fully equipped ADL/IADL rooms

Problem/ Theory

Nature of the Problem

Lack of written and verbal communication between OTs and parents and decreased understanding of FCC all lead to parents having decreased knowledge of their child's condition and decreased participation in their care

Program Theory

Parent participation in their child's inpatient rehabilitation program improves child outcomes post discharge, increases parents' satisfaction with services, and improves parents' self efficacy for caring for a child with a disability (substantially supported in the health care literature)

Theories: Family Centered Care, Bronfenbrenner's bioecological model, Cognitive Theory of Multimedia Learning

Activities/ Outputs

Interventions and Activities

Two day continuing education course consisting of didactic and role play sections on FCC, effective verbal and written communication strategies, skills training, collaborative goal setting, and matching the intervention to family needs

Program Outputs

- Percentage increase on knowledge assessments pre and post course
- # of OT staff trained
- # of OTs who implement learned strategies in practice
- # of parents participating in their child's inpatient OT
- # of parents who understand their child's therapeutic process

Outcomes

Short-Term Outcomes

Focus on OTs:

Improved communication skills and ability to implement skills training and collaborative goal setting in daily practice

Improved understanding of FCC and how to implement it

Intermediate Outcomes

Increased parent participation in their child's inpatient rehabilitation; increased parental knowledge

Long-Term Outcomes

Improved parent self efficacy in caring for a child with a disability

Improved functional outcomes post discharge for the child with the injury

External/Environmental Factors: Facility offering their space to use for course, time restraints on the OTs placed by facility; rehabilitation laws about reimbursement for parent education; continuing education offerings for participants; expense for the course

APPENDIX B: Executive Summary

Introduction

Occupational therapy seeks to provide evidence based, client centered care throughout the care trajectory. When occupational therapists are working with children who have sustained a recent traumatic injury, they need to not only provide client centered but also family centered care through the incorporation of the child's parents within the rehabilitation process. Parents play a central role in their child's growth and development and are integral parts of a child's environment. Bronfenbrenner's bioecological model emphasizes a need to look at a person's development through the entire ecological system surrounding the individual, which, for children, intimately includes parents (Bronfenbrenner & Morris, 2006).

Family-centered care (FCC), "the innovative approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients and families," has been shown to have a positive impact on child therapeutic outcomes through increasing parent engagement in their child's care (Schrieber et al., 2011, p. 225; Harrison et al., 2007; Bamm & Rosenbaum, 2008; An & Palisano, 2014; Foster et al., 2010). Children with traumatic injuries make better gains during occupational therapy and have better outcomes post discharge from the hospital if their parents play an integral role in the therapeutic process through participation and decision-making (Harrison et al., 2007; Bamm & Rosenbaum, 2008).

Despite the evidence supporting the use of FCC, there still remains a significant disparity between what theory and evidence supports and what is seen in practice (An &

Palisano, 2014; Foster et al, 2010; Arcuri et al., 2015; Harrison et al., 2007; Bamm & Rosenbaum, 2008). *Engaging Families: A Continuing Education Course on Family Centered Care Principles and Practice,* a two day course, was created to address this disparity in order to improve parent participation in their child's inpatient occupational therapy and ultimately improve child outcomes pre- and post-discharge.

Key Findings and Project Overview

In order to explore the discrepancies between theories, principles, and practice a literature review was conducted on the challenges with FCC implementation. Studies report that the main factors that limit the implementation of parent participation and other FCC principles include: decreased provider skills for effective communication; decreased knowledge of FCC principles and implementation; and health care providers' perceptions of parents' role in the decision making health care process (Harrison et al., 2007; Arcuri et al., 2015; Foster et al., 2010; An & Palisano, 2014). These antecedents lead to poor communication and lack of informational exchange between the parents and the providers, which in turn leads to decreased parental understanding of their child's diagnosis, prognosis, and plan of care as well as unclear roles and responsibilities (Power & Franck, 2008; Foster et al., 2010; Arcuri et al., 2015; Roscigno et al., 2013).

A secondary literature review was conducted to determine evidence based solutions to the problems outlined previously in order to develop a continuing education course that would provide therapists the knowledge and skill set to bridge theory and practice. FCC interventions operate on the main principle that parents know their children best, therefore, to promote the optimal functioning of a child with a disability, one must foster family involvement by providing information and skills training; having open communication; allowing parent participation and shared decision making; and meeting the parents' personal needs, such as the need for feedback (Egilson, 2011; Schrieber et al., 2011; An & Palisano, 2014; Bamm & Rosenbaum, 2008).

Keeping in mind the evidence, *Engaging Families* focuses on educating pediatric occupational therapists on FCC and strategies to use during every day practice in order to increase parent participation and self-efficacy in caring for a child with a recent change in functional status secondary to a traumatic injury. Topics included in the two-day course include the following evidenced based intervention skills and strategies: effective communication, evaluation of parental characteristics and needs for individualized education, parental skills training through occupational performance coaching, and collaborative goal setting. *Engaging Families* consists of didactic, lectured based sessions as well as role playing/practice sessions in order to provide a safe environment for the program participants to bridge theory with practice and allow the practitioner to explore their own actions, construct meaning through discussions with other participants, and trial new ways to problem solve common communication barriers (Zubairi et al., 2016).

In order to create and implement *Engaging Families* a total expense of $5,243.80 will be required. This cost includes salary, supplies and materials for creating, implementing and disseminating the program. Dissemination to the primary target audience, the heads of rehabilitation and the clinical education coordinators at pediatric rehabilitation hospitals in NYC, will include mail correspondences with a cover page, the course brochure, and the executive summary. This therapist will follow up with a phone call in order advocate for the program being implemented at their hospital and to their staff. Dissemination activities for the secondary target audience, pediatric occupational therapists, will include course brochures with a description, objectives, and goals of the program. After the initial course in year one, participant testimonials will be added. Brochures will be mailed to NYC/tri-state area pediatric hospitals. Additionally, this therapist will present her doctoral project's research supporting *Engaging Families* and a description of the course at the American Occupational Therapy Association (AOTA) conference and the New York State Occupational Therapy Association (NYSOTA) conference.

Recommendations

There is ample evidence to support that FCC and its principles have a positive impact on parental satisfaction with their child's care, improve parent participation and self efficacy, and improve child outcomes pre and post discharge (Harrison et al., 2007; Bamm & Rosenbaum, 2008). Based on this evidence about the nature of the problem and the solutions to the problem, it is recommended that hospitals formally adopt a FCC approach to service through training their staff in FCC principles and practice. *Engaging Families* provides hospitals this ability to train their staff through an evidence and theoretical based two-day training course.

General Conclusions

Engaging Families is a two-day continuing education course that provides practitioners with education on FCC, the best practice for pediatric rehabilitation. The course focuses on topics that have a sound evidence basis to support their use; they are as follows: effective verbal and written communication skills, evaluation of parental characteristics and needs for individualized education, skills training through occupational performance coaching, and collaborative goal setting. While the evidence and theories support that FCC principles and practice improve parent participation, parent and child psychosocial wellbeing, and child outcomes pre and post discharge, there is a gap between what this evidence supports and what is then seen in practice. *Engaging Families* seeks to address this gap and eliminate it in order for evidence based, best practice care to be provided in the pediatric occupational therapy rehabilitation setting.

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APPENDIX C: Supporting Documents

Collaborative Goal Setting- Practice Scenarios

The following will be used during the practice section of collaborative goal setting, on Day 2 of *Engaging Families,* if it has been determined that participants are familiar with the Canadian Occupational Performance Measure (COPM).

Participants will break up into groups of three for this practice portion. Participants will practice asking open-ended questions to families, exploring parents' and children's responses through asking follow up probing questions, and taking this information and creating goals that have meaning for the parents and the child. There will be three cases so that each practitioner has the opportunity to be the therapist. The practitioners playing the parent and the child will be given a sheet of paper that states their main goal as well as the case study, while the therapist will be given the case study only. The goal is that the therapist, through asking probing questions, is able to determine the parent and child goals using the skills and strategies they have learned thus far in the course.

Case 1: Sammy is a 10-year-old female who presents with an anoxic brain injury secondary to an asthma attack. Her rescue inhaler was not near by, and therefore Sammy was unable to be treated in enough time to prevent anoxia. Sammy presents with cognitive and physical deficits including: decreased attention and focus towards tasks, poor judgment and memory, mild dysmetria (overshooting/undershooting a target), decreased visual perceptual skills, decreased balance, and poor postural control. As a result, Sammy requires minimum assistance for all transfers and moderate assistance and cues for all ADLs. She currently is using a wheelchair as a mode to get around the hospital. Sammy is the oldest of three children and is very close to her younger brother and sister. Both of Sammy's parents work full time to support the family. Sammy is finishing up her 5th grade year and will be graduating from elementary school.

Caregiver's goal: I would like Sammy to be able to dress herself in the morning. I need to help my two youngest children get ready in the morning. I am worried if I need to help all three children that I will not be able to get my children off to school on time so that I am able to get to work on time myself. My husband is unable to help in the mornings as he commutes to work, on the train, very early.

Child's goal: I want to get better so that I can join my classmates in the 6th grade. In 6th grade we transition between classrooms for each subject and I want to be able to remember where all my classes are and get from one classroom to another without someone pushing me in a wheelchair.

Case 2: Johnny is a 17-year-old male who sustained a complete C7 spinal cord injury from diving into a shallow pool. Johnny was able to be treated right away and fortunately sustained no trauma to his brain, resulting in no cognitive deficits. However, due to the level of Johnny's injury he presents with quadriplegia. He has total paralysis from chest down as well as no sensation. Johnny is able to move his shoulder and elbow joints and has wrist extension bilaterally, however he is unable to move his fingers.

Johnny currently requires maximum assistance for all ADLs and transfers. Johnny has had multiple urinary tract infections over the course of his acute hospital stay secondary to catheterizations. Johnny and his family are having difficulty coping with Johnny's injury; Johnny is showing signs of depression. Johnny is the only child. His father died when he was young and therefore his mother is his primary caregiver. She is 50 years old and she and Johnny live in a small 2-bedroom apartment in the city.

Caregiver's goal: My main goal for Johnny is that he is able to transfer himself from his wheelchair to the bed, toilet/ commode and shower chair. I want to change the layout of Johnny's room and bathroom so that it is accessible for him, however I have a bad back and do not feel safe helping Johnny transfer. I am scared that I will hurt him and myself.

Johnny's goal: I do not want to rely on people to help me do everything. I am tired of having someone need to feed me at every meal. I just want to be able to do it myself. I want more freedom and independence like I use to have before the injury.

Case 3: Mary is a 13-year-old girl who was a passenger in a car during a severe car accident in which she sustained a closed brain injury with loss of consciousness. Mary presents with global delays due to the diffuse brain injury. Cognitively Mary presents with decreased safety awareness and poor short-term memory. Motorically she presents with poor balance and delayed initiation. Mary is having difficulty with body awareness, which is impacting her mobility and ability to perform everyday occupations.

She is also presenting with personality changes; she is easily irritable and frustrated during ADLs. Mary currently requires minimum assistance for ambulation due to weakness, poor body awareness and poor balance and is able to ambulate only short distances (less than 100 ft.). Bed mobility is completed with CTG however she requires maximum cues to initiate and motor plan the movement. Mary requires moderate assistance to bathe, dress, and groom due to poor safety awareness, body awareness, decreased memory, and decreased balance. Mary is the youngest of 2 siblings and lives with her mother and father in a two story home. The family is very active and engages in a lot of extracurricular school and family activities. Mary is in the 8th grade.

Caregiver's goal: It is hard for me to see Mary get so frustrated and angry doing activities that she has always been able to do, but now cannot because of her injury. I want Mary to be able to complete her morning and nighttime routines without getting so frustrated and needing me to assist her and help remind her what she needs to do. She used to love picking out what clothes she was going to wear to school each day!

Mary's goal: I want to be able to go back to playing my favorite sports with my friends. I love playing tennis and am excited about trying out for the team when I go on to high school. I don't want to have to stop playing because of my injury.

Collaborative Goal Setting Group Discussion Questions

1. Were you able to correctly determine the meaningful goal for the child and the parent?
2. What aspects of the practitioners questioning/ interviewing were most effective or least effective? (i.e. communication strategy, effectiveness of probing questions, appropriateness of questions, ability to engage the child and the parent in a collaborative discussion, etc.)?
3. What was the most challenging aspect of this role-play? Why?
4. As the therapist, were you able to implement learned knowledge from the course so far in your interview process? If so, what of your learning thus far was most helpful during this role-play process?

Skills Training Using Occupational Performance Coaching Practice Scenarios

The following will be used during the skills training using occupational performance coaching practice section on Day 2 of *Engaging Families.*

During this practice portion participants will break up into groups of 3 to engage in small group role-plays. Each member will have the opportunity to be the child, the parent, and the therapist. The "therapist" will pick out of a hat a type of transfer or dressing ADL listed on the following page under the therapist heading. The "child" will pick out of a hat the level of assistance to act out, listed on the following page under the child heading. The "child" and "therapist" participants will show each other their selected cards. The therapist will practice using the problem solving skills training approach and occupational performance coaching to help guide the participant playing the parent through the ADL or transfer chosen. Feedback will then be provided by group members after each role play to help each therapist critical appraise their own role play in terms of their use of strategies and effectiveness of these strategies on educating the "parent."

Note the amount of assistance cards will be placed back into the hat after the role play and can be reused, however the type of transfers or ADL will not be repeated. Additionally scrub pants and shirts will be provided for the ADL cards.

Therapist

Transfers:

1. *Stand-step transfer- sitting at edge of bed to wheelchair.* Note: child has orthostatic hypotension and has had 2 episodes of fainting during transfers with the nursing staff.
2. *Slide board transfer - Wheelchair to shower chair.* Note: the child has a left side neglect secondary to trauma to the right side of her brain.
3. *Squat-pivot transfer - Wheelchair to toilet.* Note: the child presents with hemi-paresis and decreased sensation on the right side of the body secondary to a cerebral vascular accident (CVA) caused by trauma to the head.

ADLs:

1. *Donning/doffing pull over shirt seated at edge of bed.* Note: the child presents with hemi-paresis and decreased sensation on the left side of the body secondary to head trauma.
2. *Donning/doffing pants.* Note: the child presents with poor balance and decreased balance reactions secondary to a cerebellar tumor.

Child

- Contact Guard Assistance (CTG)
- Minimum Assistance (Min A)
- Moderate Assistance (Mod A)
- Maximum Assistance (Max A)

Skills Training using Occupational Performance Coaching Group Discussion Questions

1. What occupational performance coaching and skills training strategies did the therapists use? Which were most effective? Which were less effective?
2. How did the overall role-play go? Was the transfer able to be completed “safely” and correctly based on the therapist’s verbal and physical guidance?
3. What was challenging about training the parent on the particular type of transfer/ADL?
4. What other strategies could have been used to help the parent learn the transfer/ADL?

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EDUCATION:

Post-professional Doctorate in Occupational Therapy anticipated graduation, May 2017
Boston University-Sargent College
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Master of Science in Occupational Therapy, January 2016
Boston University- Sargent College
Boston, MA
GPA: 3.92/4.00

Bachelor of Science **Major: Human Science** **Minor: Psychology**
May 2013
Georgetown University
Washington, DC
Magna Cum Laude GPA: 3.7/4.0
Undergraduate Research:

- The efficacy of deep touch pressure techniques as a therapy modality for children with autism spectrum disorder
- Physiological adaptations to blindness: Cross-modal plasticity

HONORS:

Omicron Chapter of Pi Theta Epsilon: Occupational Therapy Honor Society
Merit Scholarship, Boston University

RELEVANT EXPERIENCES:

Staff Occupational Therapist July 2016 – present
Children's Rehabilitation Center
White Plains, NY

- Conduct evaluations, treatment sessions and discharge planning for children ages birth to 21 years with various diagnoses including prematurity, cerebral palsy, autism spectrum disorder, down syndrome, brain injury and developmental delay
- Responsible for a caseload of 60 patients, providing 10 to 14 treatment sessions per day
- Provide treatment in aquatic as well as land settings

- Attend weekly in-services as well as presented an in-service on a course attended called Combining NDT and SI for Optimal Function in Children with Neuro-muscular Challenges by Leslie Adler

Graduate Assistant for Professors Escher & Kaldenberg September 2013– May 2015
Boston University

- Liaison for MSOT students and Professor Escher and Kaldenberg
- Transcribed AOTA Level II fieldwork forms and evaluations to online format

Occupational Therapy Department Intern- Senior Internship September 2012– April 2013
The HSC Pediatric Center
Washington, DC

- Worked with OT preceptors in both inpatient and outpatient pediatric rehabilitation settings
- Created a research proposal with data presentation and analysis

PROFESSIONAL AFFILIATIONS:

- Member, American Occupational Therapy Association
- Member, American Telemedicine Association
- Member, Omicron Chapter of Pi Theta Epsilon

SKILLS:

- Certified in Cardiopulmonary Resuscitation and Automated External Defibrillator Device
- HIPPA Certified and “Protecting Human Research Participants” NIH Certified