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Better together: advancing family-centered care

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Doctoral Project

BETTER TOGETHER:

ADVANCING FAMILY CENTERED CARE

by

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Dedication

I wish to dedicate this doctoral project to all families, and especially to my own. The relationships, occupations, and contexts that we share in the family that I was born into, have chosen, and have birthed, have shaped who I am and whom I aspire to become. Our family has inspired my intrigue in families and the calling to promote health, which resulted in this project. It is my hope that this project will promote health and happiness for many families and for the providers who work with them.

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ABSTRACT

Family-centered care (FCC) is recommended as "best practice" across a variety of pediatric service settings, as it yields better health and wellness outcomes for clients, and greater work satisfaction for practitioners and administrators (American Academy of Pediatrics, 2012). However, providers in multiple health care fields report challenges with translation of FCC concepts into their practice (Bamm & Rosenbaum, 2008; Graham, Rodger, & Ziviani, 2008; Lawlor & Mattingly, 1998; MacKean, Thurston, & Scott, 2005). Therefore, the aim of this doctoral project was to understand the barriers to FCC implementation, and to propose ways for supporting practitioners to enact FCC in their practice. The resulting solution is *Better Together*, an on-line professional development course designed to empower health care providers to become ambassadors of FCC and effectively enact the FCC practices in their daily interactions with clients and their families. The *Better Together* course content and structure are based on findings from a review of the literature specific to identifying core skills and knowledge essential for effective FCC practice, as well as best practices for professional development instruction. Methods for course implementation, funding, and dissemination are described, as well as a research plan for program evaluation.

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Chapter 1: Introduction

Background

Family-centered practice (FCC) is recognized as best practice in child and family health care in a range of professions, including occupational therapy (Graham, Rodger, & Ziviani, 2008). FCC refers to how health care professionals interact, provide services, and involve clients and their families in their care (Dunst & Trivette, 2009). A family-centered approach is characterized by provider practices that convey dignity and respect to families, where information is exchanged so that informed decisions can be made, where there is responsiveness to families' priorities and choices, and where collaborative family-provider partnerships are fundamental to the healthcare encounters and outcomes (American Academy of Pediatrics, 2012). The key elements of family-centered practice include an emphasis on child and family strengths rather than deficits, facilitating family choice and control, and creating a therapeutic environment that optimizes the development of a collaborative family-provider relationship (American Academy of Pediatrics, 2012).

Family-centered approaches have been found to lead to better intervention outcomes for children and their families, providers, and organizations (American Academy of Pediatrics, 2012). Researchers across medical and early intervention service sectors have conducted literature reviews and meta-analyses to examine the extent to which FCC practices are related to child and family outcomes. These reviews and analyses provide solid evidence showing that FCC practices have positive effects in both child and family domains, including efficient use of services, family satisfaction with

services, enhanced family well-being, positive parenting practices, reduced family burden and financial stress, and improved health or developmental outcomes for children (Bailey, Nelson, Hebbeler, & Spiker, 2007; Gooding et al., 2011; Teplicky, King, Rosenbaum, King, 2004; Kuhlthau et al., 2011; Kuo, Mac Bird, & Tilford, 2011; McBroom & Enriquez, 2009; Piotrowski, Talavera, & Mayer, 2009; Raspa et al., 2010).

FCC practices also yield favorable outcomes for providers: providers who engaged and collaborated with families felt that this was valuable to their work (Heller & McKlindon, 1995), created positive change in their perceptions of people with disabilities (Widrick et al., 1991), and overall led to improved job performance, less staff turnover, and a decrease in costs for organizations (Hemmelgarn, Glisson, & Dukes, 2001). Opponents of FCC claim that this approach requires a greater investment of time with each patient. However, there is evidence to suggest that FCC is cost-effective. FCC enhances efficient use of health care resources such as home or community services and effective use of preventive care, which decreased unnecessary costly hospitalizations and emergency department visits (Forsythe, 1997; Kuo et al., 2011; Solberg, 1996; Vander Stoep, Williams, Jones, Green, & Trupin, 1999). Moreover, better communication and relationships associated with FCC have potential to decrease the number and severity of legal claims, and the associated expenses (Beckman, Markakis, Suchman, & Frankel, 1994; Levinson, Roter, Mullooly, Dull, & Frankel, 1997). Finally, FCC practices were found to enhance patient safety, reduce the risk of medical errors, and improve risk management processes (Johnson, Ford, & Abraham, 2010).

Identified Problem

Despite the accumulated evidence regarding the favorable outcomes of FCC, challenges in implementing FCC are described across a multitude of clinical settings and professional disciplines, and hinder providers' ability to translate FCC concepts into practice (Bamm & Rosenbaum, 2008; Hanna & Rodger, 2002; G. King & Chiarello, 2014; Lawlor & Mattingly, 1998). Therefore, the goal of this project is to understand the barriers to FCC implementation and to develop a program to enhance providers' competence in integrating FCC behaviors into their daily practice.

The ability to implement FCC is a result of a collaborative process between a family, the care providers, and the organization in which they operate. In the following sections, to better understand the distinct challenges leading to the identified problem, the characteristics of all members of the family-centered care team will be described.

Family. A family can be described as dynamic system with strong interdependence among its members (Jaffe, Humphry, & Case-Smith, 2010). Examples of internal factors may include parental roles, parent and child priorities and capacities, parenting style, perceptions of a child's disability and his or her level of participation, and the parent's desired involvement in the intervention process (Hanna & Rodger, 2002). Contextual factors impacting a family may include availability of support resources, social networks, health policy, and culture (Jaffe, Humphry, & Case-Smith, 2010; Lawlor & Mattingly, 2013). Providers striving to engage families in a collaborative family-centered relationship must consider the contextual factors above, and the factors that make each family a special, distinctive, and changing entity. Attending to these factors is

a key to the ability to match the care to each family's specific needs.

Researchers in occupational therapy and occupational science describe findings from phenomenological studies of family life and parents' notions about their children's needs (Cohn, Kramer, Schub, & May-Benson, 2014; Lawlor & Mattingly, 2013). These authors highlight the complexities of the parenting occupation and recommend that clinicians strive to understand the subjective experiences of their clients. Cohn et al. (2014) further explain that parents develop explanatory models that include a conceptualization of the cause of their child's challenges and the impact of daily life. The authors demonstrate the importance of understanding parents' explanatory models in order to personalize the assessment and intervention process according to a family's specific concerns, hopes, needs and desired outcomes.

Providers. Lawler and Mattingly (2013) explain that practitioners' understanding of a family's experience and perceptions of an illness or disability shape health care encounters. Each provider has an innate notion of *family* based on his or her own life experience and values. However, practicing from the provider's own perspective of the family will inevitably create barriers in communication limiting the application of effective interventions (Cohn et al., 2009). While occupational therapists are well-versed in client-centered practice models, the shift to family-centered practice cannot simply be added to previous models. To become both client-centered and family-centered, a provider's entire conceptual framework has to be re-organized (Bamm & Rosenbaum, 2008; Lawlor & Mattingly, 1998). Family-centered practice principles are derived from family systems theory, eco-cultural theory, and transactional models of child

development that together lead to the presumptions that children's development is best when the needs of the whole family are addressed (Graham et al., 2008).

Core principles of a family-centered approach include involving families in the care of their child while focusing on family strengths, respecting family diversity and values, encouraging family decision-making and empowerment, communicating with families in an open and collaborative fashion, adopting a flexible approach to service provision, and recognizing the value of informal support systems (Bailey, Raspa, Sam, & Humphreys, 2011). Providers need to be able to expand the evaluation and intervention processes to fully understand a family's life and culture, and then implement practice models that involve family members collaboratively, as opposed to expert-driven models of service (Lawlor & Mattingly, 1998).

Providers from various disciplines report that they do not feel sufficiently confident or competent to become engaged in family-centered care (Johnson, 2000; Litchfield & MacDougall, 2002), and that the knowledge needed to establish an effective collaborative relationship is not part of their formal entry level education (Davidson, 2011; Graham et al., 2008). Gathering information about a family and designing interventions that will address the entire family can be overwhelming in the context of time-limited intervention sessions. Moreover, many providers and families express that they are unclear about what real collaboration is, and therefore how to "make it happen" (Bamm & Rosenbaum, 2008).

Parent-provider collaboration. Both providers and families strive to establish reciprocity and collaboration in the care of a child. Bamm and Rosenbaum (2008)

integrated findings from multiple qualitative and quantities studies and identified that families and providers mutually highlighted the importance of education and counseling, provision of information, advocacy, and coordination of services. Families valued common goal-setting and partnership, availability and accessibility of providers. Interestingly, parents rated human traits such as kindness, concern, compassion, and approachability as more important than technical competence (Briar-Lawson & Lawson, 2010; MacKean, Thurston, & Scott, 2005). An important gap identified between the views of providers and families was that providers tend to view collaborative practice as giving parents more responsibilities in the treatment implementation, and as advocating for clients in interprofessional settings (MacKean et al. 2005).

Another possible barrier to family-centered care is the impact of cultural and demographic differences between families and providers. Coker, Rodriguez, and Flores (2010) presented alarming findings that families of Latino and African-American decent had significantly lower odds of receiving family-centered care as compared to families with white children. Moreover, parents of children in households with a non-English primary language were less likely to receive family-centered care than families in households who spoke English as the primary language. These disparities persisted after adjustment for child health, socioeconomic factors, and access to services.

In her insightful reflective article, Blanche (1996) demonstrated that occupational therapists may truly believe they are open-minded and gauge the cultural impacts on clients' life and actions, yet they may be unaware of presumptions which are grounded in their own cultural background. Thus, demographic and cultural differences between

providers and families seeking care for their children may lead to barriers in communication and trust, and consequently decrease the provision of high quality family-centered care.

Organization and administrative perceptions. Implementation of family-centered models requires change in healthcare policies, programs, facility design, day-to-day practices of individual providers, and professional education. Organizations may be reluctant to change due to inconclusive evidence of the benefits of family-centered care in comparison with a biomedical approach (Johnson, 2000). Contemporary health care service systems value and reward skilled therapeutic interventions that directly address the child's specific physical needs rather than his or her diffuse social and cultural needs or the concerns and the values of the child's primary caregivers (Lawlor & Mattingly, 1998). Organizations often perceive client-centered and family-centered care as requiring more time and resources and thus as more costly compared to traditional models. For example, collaboration requires providers to spend considerable time negotiating decisions with family members, which may lessen the amount of time spent on "hands-on" treatment of the child (Lawlor & Mattingly, 1998). Although FCC requires an initial investment for staff education and development of the new strategies, eventually the benefits outweigh the expenses; suggesting that family-centered practice may be cost-effective when viewed over time (American Academy of Pediatrics, 2012).

In summary, the challenges in implementing FCC are multiple and complex. Therefore, a systems perspective will be used to analyze the barriers to family-centered care. The distinctive features and interactions between families, providers, the

organization in which they interact, prevailing societal perceptions, and influential events and transitions will be analyzed to develop an explanatory model of the factors contributing to barriers to family-centered care.

Domain of Occupational Therapy

The importance of family-centered care and the value of collaborating with families has been consistently documented as an essential component of the OT process in several official American Occupational Therapy Association (AOTA) documents. The *AOTA Standards of Practice* (DeLany et al., 2010) specifically state that "an occupational therapy practitioner respects the client's sociocultural background and provides client-centered and family-centered occupational therapy services" (standard I.10), through collaboration with clients in the evaluation and intervention processes (Standards II.3. and III.3).

Within the AOTA's *Occupational Therapy Services in Early Childhood and School Based Settings* (2011) guidelines, the role of occupational therapists is defined as "working with parents and caregivers to facilitate children's and youth's ability to participate in everyday occupations" (p.S46). The *AOTA Statement on Family Caregiving* (2007) also highlights the roles and skills of occupational therapists in supporting family members in their caregiving occupation. The family caregiving statement reflects a broad conceptualization of the client, with focus on collaborating with the family to promote the health and of all members.

This doctoral project is congruent with the *Occupational Therapy Practice Framework, 3nd edition* (AOTA, 2014), which states: "the intervention process consists of

the skilled services provided by occupational therapy practitioners in collaboration with clients to facilitate engagement in occupation related to health, well-being, and participation." (p.S14). Providers who are family-centered collaborate with clients, families, and team members as part of their everyday practice. The ultimate goal of FCC is fully consistent with the goal of occupational therapy: "achieving health, well-being, and participation in life through engagement in occupation" (p. S18).

It is important to acknowledge that occupational therapy official documents have been influenced by US legislation. The individuals with Disability Education Improvement Act (IDEA; 2004) federal statute includes occupational therapy as a service for children ages 0-21. IDEA requires that child and family outcomes and services be developed in collaboration with the child's caregivers, and other members of the team. The Patient Protection and Affordable Care Act (2010)which outlines the idea of Patient-Centered Medical Homes, highlights the importance of a patient- and family-centered collaboration as fundamental for quality care for children and their families (U.S. Department of Health and Human Services, Health Resources and Service Administration, n.d. ; HERSA, MCHB, 2007). The collaborative and interprofessional principles of FCC are aligned with this policy.

Although this project has evolved from an occupational therapy perspective, it is widely recognized today that in order to deliver best practices and high quality healthcare, and specifically FCC, it is essential for services to be interprofessional (American Academy of Pediatrics, 2012; King & Chiarello, 2014). The AOTA has been promoting the development of Interprofessional Education and Collaboration (IPEC) as

evident in the *2011 Accreditation Council for Occupational Therapy Education (ACOTE®) Standards* (2012). Specifically. Standard B.5.21, mandates for in all levels of occupational therapy preparation (associate, master or doctoral), graduates will be able to "effectively communicate to work interprofessionally with those who provide services to individuals, organizations, and/or populations in order to clarify each member's responsibility in executing an intervention plan" (p. S48).

Impact of Project

The U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB), defines children with special health care needs (CSHCN) (2007) as: "...those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally" (p.10). The estimate of the prevalence of CSHCN in the population is 13.9% of individuals, and 21.8% of households in the US (HERSA, MCHB, 2007), accounting for 42.1% of total national medical care costs (Newacheck & Kim, 2005). Meeting the needs of these children will require competent interprofessional providers who are skilled in providing FCC.

Project Overview: Better Together

The goal of this project is to develop a professional development course to prepare providers and administrators to implement family-centered care in their daily work and be competent in assuming leadership roles in the promotion of FCC policies and procedures in the workplace. The course, Better Together, was designed according to

best practices in FCC and in professional development for the adult learner. Better Together is an 8-week on-line course that combines self-paced learning, individual reflective inquiry, interactive and dynamic group work, implementation of learning in daily practice, and an ongoing mentorship program to facilitate integration of learned concepts into the learners' practice. Concepts that will be addressed in the course include the essential features of FCC, enhancing listening and cultural sensitivity, collaborative work with families and the interprofessional team, understanding the policies and procedures that influence the provision of FCC, and becoming advocates for the promotion of FCC and quality of care. The course structure is flexible and can be adapted to the needs and personal goals of the learner.

An extensive review of the literature on family-centered care is presented in chapter 2 of this project and provides the foundation for the course content. A detailed description of the course objectives, means to achieve them and sample lesson plans are provided in Chapter 3. The course evaluation plan, including an overall program evaluation and a single-subject design study to establish change in FCC practice, is described in Chapter 4. The funding and dissemination plans are described in Chapters 5 and 6; conclusions are presented in Chapter 7.

Summary

Family-centered care is an important philosophy of health care that is well aligned with current occupational therapy practice frameworks and values and healthcare policies focused on enhancing the quality of care for children and families. Although family-centered care is considered best practice, multiple barriers exist to the implementation of

family-centered practices. Therefore, the goal of this doctoral project is to understand these barriers and to develop a solution to mitigate challenges and facilitate effective integration of family-centered care into every day practice with children and their families.

Chapter 2: Theoretical and Evidence Base to Support the Proposed Project

Problem Overview

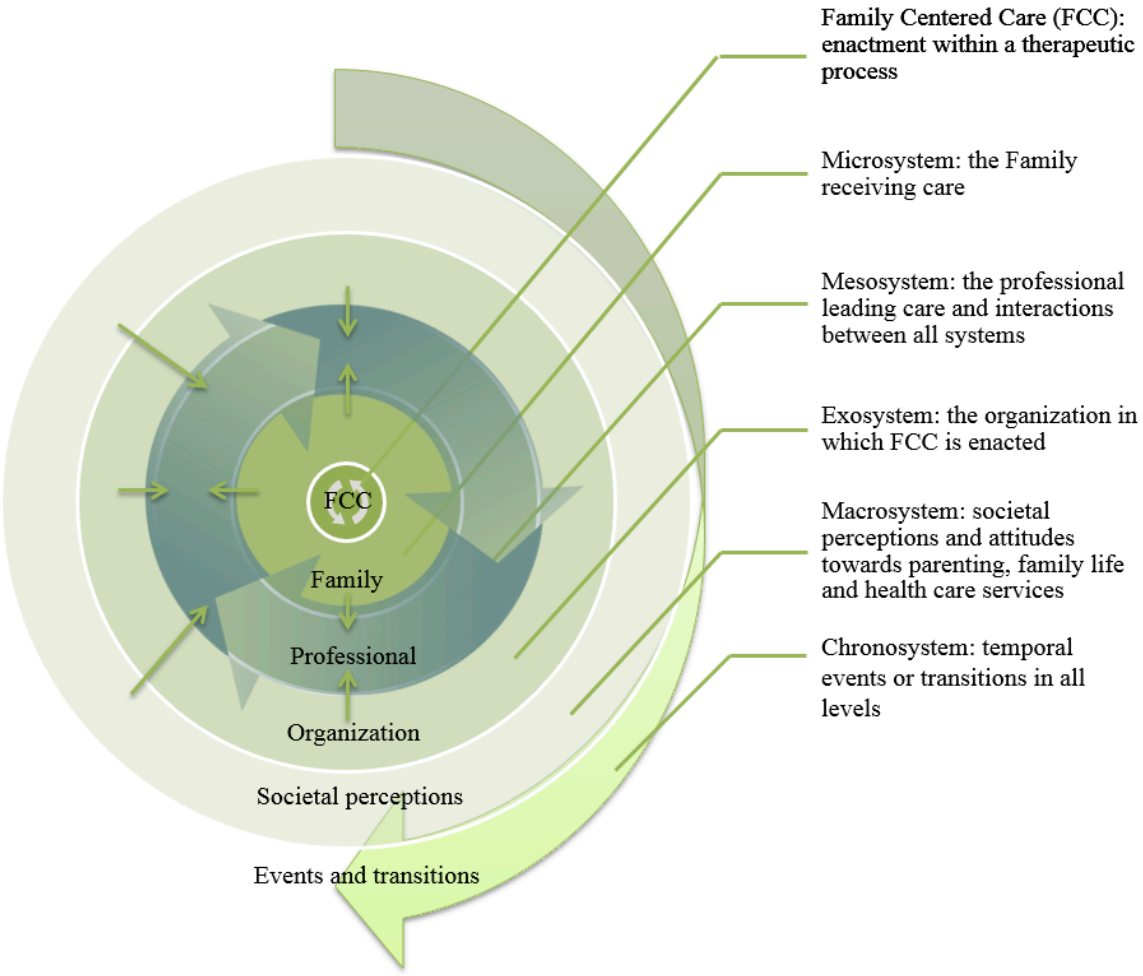
Family-centered care (FCC) is recommended as "best practice" across a variety of pediatric service settings. Yet, professionals in multiple healthcare fields report an ongoing struggle with implementing FCC concepts into their practice (Bamm & Rosenbaum, 2008; Graham, Rodger, & Ziviani, 2008; Lawlor & Mattingly, 1998; MacKean, Thurston, & Scott, 2005). This chapter will present; 1) a proposed theoretical explanatory model that describes the origins of the problem and, 2) a review of previous attempts to address challenges associated with implementing FCC in practice.

A proposed Explanatory Model

The complexity of the causal factors that interact to enable or inhibit family-centered care (FCC) is represented in an explanatory model. Figure 1 depicts a visual representation of the factors that impact family-centered care. The model is informed by Bronfenbrenner's (2004) ecological system theory, which proposes that in order to understand human development, one must consider the entire ecological system in which the person lives and operates. The ecological system is composed of five socially organized subsystems that guide human growth. They range from the microsystem, which refers to the relationships between a developing person and the immediate environment, such as school and family, to the macrosystem, which refers to the institutional patters of culture, such as the economy, customs, and bodies of knowledge (Bronfenbrenner, 2004). In the proposed explanatory model, the different factors hypothesized to influence FCC provision are identified and analyzed according

Bronfenbrenner's ideas of subsystems (or levels) and the interaction between them. These factors, from proximal to distal to FCC, include the family unit and its members, healthcare services, the professionals providing the services, the organization/agency in which services are offered, and the overarching cultural and societal notions and perceptions of families, parenting, and health.

Figure 2.1: *Causal factors that impact family-centered care (FCC)*



According to Bronfenbrenner (2004), the most proximal level, or the *Microsystem,* is the immediate environment and related processes in which a person operates and lives. FCC philosophy views the family as a unit, and attends to the skills and resources needed by all family members to manage the ongoing care of the child within their natural environment (Rosenbaum, King, Law, King, & Evans, 1998). Based on this notion, microsystem factors relevant to FCC include families, each a distinctive dynamic system with unique patterns of activities, social roles, and inter-personal relations experienced in the immediate environment. Each family differs in its culture, routine, and interactions between family members. In the same way, each professional practices its own perceived roles, professional activities, and patterns of interactions with families and colleagues. Every professional is influenced by his or her personal family and cultural background that have shaped personal views, values and behaviors.

Bronfenbrenner's next level, the *Mesosystem,* includes the interactions among the systems. A central component of FCC is a parent–therapist collaboration in evaluation, goal setting, and intervention (American Academy of Pediatrics, 2012; King & Chiarello, 2014). In this model, the professional is viewed as the one who should be guiding and facilitating the interactions between the family and all other levels. Yet, multiple studies indicate that this role is complex and subject to various barriers and challenges (Bamm & Rosenbaum, 2008; Graham, Rodger, & Ziviani, 2008; Lawlor & Mattingly, 1998; MacKean, Thurston, & Scott, 2005). Some examples of barriers are challenges in understanding parent perspectives about their child's functional goals, due to language barriers, cultural differences, or lack of opportunity (Lindsay, King, Klassen, Esses, &

Stachel, 2012).

Interactions that occur in the Mesosystem are also influenced by systems in the *Exosystem,* a more distal level. This distal system is depicted in the fourth nested circle and represents processes and events that indirectly influence the problem. These include policies, procedures and demands that exist in the organizational level. For example, a private practice agency can encourage FCC by scheduling routine parent-professional meetings and allocating a physical space for these meeting to occur (i.e., quiet room with privacy). An insurance policy that does not provide reimbursement for parent meetings (for example, only reimbursing direct treatment when child is present) may be a barrier to FCC practices.

The Individuals with Disability Education Improvement Act (IDEA) is a United States federal law that governs how states and public agencies provide early intervention, special education, and related services to children with disabilities. Part C of the IDEA, focused on services for children aged 0-3, mandates developing an Individualized Family Service Plan, or IFSP (Title 303.340) to address the child and family needs. Therefore, agencies providing the IFSP planning emphasize collaboration with parents and the most common setting is the child's home. In contrast, IDEA guidelines for school systems have a different focus. Part B for children aged 3-21 mandates that Individualized Education Programs (IEP) include parents as an essential part of decision making. Parents must be invited to participate in IPE meetings (Title 300.322), and provide consent for any decision (Title 300.9) (Individuals with Disability Act, 2004). However, the IPE is mainly focused on performance relevant to the academic setting, (Individuals

with Disability Act, 2004) as opposed to the home and family environment. Accordingly, although parents are still part of the decision making process the focus is less centered on the family life and needs.

The most distal level in Bronfenbrenner's ecological systems theory is the *Macrosystem,* or the "societal blueprint" which contains overarching societal characteristics such as culture, belief system, bodies of knowledge, or material recourses. Lack of awareness of these implicit societal characteristics and how they vary between the different systems has the potential to hinder the interacting systems' understanding of each other, and thus limit FCC. For example, parents' belief systems related to what is considered "good" parenting, successful child development, or high quality healthcare services is highly variable among individuals, sometimes individuals within the same family system have different beliefs about parenting. Harkness and Super (2006) explained that parenting is a culturally constructed practice. Cultures tend to have implicit, taken-for-granted ideas that have strong motivational influences for parents. For example, a belief that children's display of behavioral difficulties is the product of "bad" parenting, or the notion that young children must be stimulated in order to develop appropriate cognitive skills may influence how parents interact with their children. If parents and professionals have different or opposing beliefs, their priorities and related goal-oriented actions in intervention may conflict. These belief systems are typically inherent and people are often unaware of them; potentially impeding mutual understanding and collaboration.

Another example of potential barriers in the Macrosystem is notions regarding

health care. One of the main assumptions of FCC is that the client and professional co-construct the intervention, and that the family is the expert regarding their child. However, people who are socialized in a paternalistic view that medical professionals are the authority may believe that professionals have the expertise and should make all clinical decisions (Lindsay, King, Klassen, Esses, & Stachel, 2012). If families expect the professional to guide the intervention and make the intervention decisions then collaboration will not make sense. Moreover, parents who believe the professional ought to have the authority and expertise may view a professional's effort to create a collaborative relationship as an indication of the professional's lack of confidence or knowledge to provide the necessary intervention.

Bronfenbrenner's most distal level is the *Chronosystem*, and includes the influence of temporal aspects such as environmental events and transitions over the life course. The chronosystem is illustrated by a surrounding arrow to demonstrate how the interactive process and the presentation of the problem can change with time. Influential events can occur within each level and system. Examples of transitions and events in the family system may include changes in family structure (e.g. new sibling, divorce, death in the family) or place of living. Events in the professional's life may bring reflection opportunities and related insight into his or her practice. One example is taking care of one's own family member and experiencing health services care from that personal perspective. Another example would be participation in a professional development workshop that facilitates thought and reflection about one's practice and values. Transitions in the organization may be due to change in management, mission statement,

or policies. Finally, temporal aspects in the Macrosystem such as natural disaster events or political instability may have an overarching impact on the life and health of all other systems.

In summary, exploring FCC enactment using an ecological system framework allows to recognize and explain the potential relationships among the multitude of factors that may influence FCC practices. This model serves as an analytical instrument to identify and better understand causal factors, and the interactions among them, that may impact FCC practices.

Evidence to Support the Proposed Explanatory Model

A literature review was conducted to identify evidence to support the underlying assumptions of the proposed explanatory model. Specifically, the search was guided by the following questions:

1. What are the essential components of FCC?
2. What is the evidence to support the relevance of the systems perspective of FCC presented in the explanatory model (family, professional, organizational policies and overall cultural and societal perceptions)?
3. What is the evidence to support positive outcomes and benefits of FCC to identified systems in the model?
4. What is the evidence of barriers to FCC enactment in each system of proposed explanatory model?
5. What is the evidence to indicate the impact of culture on each identified system in the model?

6. How do historic events impact the way that care is provided to families?

A synthesis of the literature is presented below. A detailed description of the findings is presented in Appendix A.

Essential features of Family-Centered Care. Numerous authors and professional association working groups have reviewed the literature to describe the essential features of family-centered care (FCC) (American Academy of Pediatrics, 2012; Dunst & Trivette, 2009c; Teplicky, King, Rosenbaum, King, 2004). Based on findings from over 200 studies conducted in past several decades, The American Academy of Pediatrics (AAP) developed a policy statement to define the core principles of FCC. A foundational belief of FCC is that the family is central to and constant in the child's life, and the child's primary source of strength and support (MacKean et al., 2005). The common features of FCC across studies include mutual respect between professionals and families, establishing collaborative partnerships among parent and professionals, listening and respecting families' choices regarding the treatment, sharing information in a way that supports family decision making, focusing on the family's strengths and providing flexible service delivery and support according to family's unique needs (AAP, 2012; Dunst, Trivette & Humby, 2007; King, Teplicky, King & Rosenbaum 2004; MacKean, et al. 2005).

A systems perspective of Family-Centered Care. The proposed explanatory model is informed by an ecological system theory (Bronfenbrenner, 2004), which espouses a non-hierarchical interaction between multiple systems that lead to FCC enactment. These systems include the family unit and its members, the professionals providing services, the

organization or agency and related policies in which services are offered, and the overarching cultural and societal notions and perceptions regarding families, parenting, and health (see Figure 1). The AAP official policy paper on patient and family-centered care (2012) represents a consensus regarding best FCC practices, and provides support for the systems perspective described in the explanatory model. The AAP policy paper begins with the claim that FCC impacts multiple systems: "When patient- and family-centered care is practiced it shapes health care policies, programs, facility design, evaluation of health care, and day-to-day interactions among patients, families, physicians, and other health care professionals" (AAP, 2012 p. 394). The authors present the core principles and guidelines for implementing FCC. Table 2.1 specifies important underlying propositions related to each system in the explanatory model of FFC and, the corresponding "best practice core principles" for FCC provision recommended in the AAP official policy. Further evidence to support each proposition will be presented below.

Table 2.1: *Systems Proposed in FCC Explanatory Model and Supporting AAP Core Principles*

System	Explanatory model proposition	Core principles to enable FCC (AAP, 2012; p.395)
Family (Microsystem)	Each family is a dynamic system with a unique culture, routines, roles, activities, and interactions between family members	• Recognize and build "on the strengths of individual children and families" • Empower "children and families to discover their own strengths, build confidence, and participate in making choices and decisions about their health care" • Tailor "services to the needs, beliefs, and cultural values of each child and family" • Facilitate "choice for the child and family about approaches to care"
Professionals (Mesosystem)	Professionals' ability to enact FCC is linked to a multitude of behaviors and interpersonal skills	• Listen to and respect "each child and his or her family" • Provide and/or ensure "formal and informal support" • empower families "to discover their own strengths, build confidence, and participate in making choices and decisions about their health care" • Collaborate "with patients and families at all levels of health care" • Share "complete, honest, and unbiased information with patients and their families"
Organization (Exosystem)	Policies, procedures and organizational demands may enable or hinder FCC enactment.	• Ensure "flexibility in organizational policies, procedures, and provider practices so services can be tailored to the needs, beliefs, and cultural values of each child and family and facilitating choice for the child and family about approaches to care"
Societal perceptions (Macrosystem)	Overarching societal characteristics influence how people understand each other and act.	• Honor "racial, ethnic, cultural, and socioeconomic background and patient and family experiences and incorporate them in accordance with patient and family preference into the planning and delivery of health care."

Benefits of FCC: children, families, professionals, and organizations. Family-centered approaches have been found to lead to better intervention outcomes for children and their families, professionals, and organizations and are summarized below (American Academy of Pediatrics, 2012). Recent literature reviews and meta-analyses of research across medical and early intervention service sectors have examined the extent to which FCC practices are related to wide variety of child and family outcomes. Research evidence suggest that FCC practices have positive effects in a diverse array of child and family domains, such as more efficient use of services, family satisfaction with services, family well-being, parenting practices and psychosocial components, reduced family burden and financial stress, and improved health or developmental outcomes for children (Bailey, Nelson, Hebbeler, & Spiker, 2007; Gooding et al., 2011; Teplicky, King, Rosenbaum, King, 2004; Kuhlthau et al., 2011; Kuo, Mac Bird, & Tilford, 2011; McBroom & Enriquez, 2009; Piotrowski, Talavera, & Mayer, 2009; Raspa et al., 2010).

Studies that described the impact of FCC practices on professionals identified that staff members who engaged and collaborated with families felt it was valuable to their work (Heller & McKlindon, 1995), created positive change in their perceptions of people with disabilities (Widrick et al., 1991), and overall led to improved job performance, less staff turnover, and a decrease in costs for the organization (Hemmelgarn, Glisson, & Dukes, 2001). Opponents of FCC claim that this approach requires a greater investment of time in each patient. However, there is evidence to suggest that FCC is cost-effective. FCC enhances efficient use of health care resources such as home or community service and effective use of preventive care, which decreased unnecessary costly hospitalizations

and emergency department visits (Forsythe, 1997; Kuo et al., 2011; Solberg, 1996; Vander Stoep, Williams, Jones, Green, & Trupin, 1999). Moreover, better communication and relationships associated with FCC have a potential to decrease the number of legal claims and their severity, and associated expenses (Beckman, Markakis, Suchman, & Frankel, 1994; Levinson, Roter, Mullooly, Dull, & Frankel, 1997). Finally, FCC practices were found to enhance patient safety, reduce the risk of medical errors, and improve risk management processes (Johnson, Ford, & Abraham, 2010).

In addition, involving families in key decision-making roles in an organization's management was also found to yield positive results. Hospitals and community-based services that included family members in key decision-making roles (for example, in institutional quality or safety committees, staff education, program planning, and resource allocating) received high patient, family, and staff satisfaction scores, which translated into a more competitive position in the healthcare marketplace (Britto et al., 2006; Jones, Fournier, & Moore, 2002; Sodomka, Scott, Lambert, & Meeks, 2006).

Barriers to FCC enactment. Although the importance and value of FCC has been documented in hundreds of studies in the past decades (AAP, 2012), professionals in multiple healthcare fields are reporting an ongoing struggle with the implementation of the core principles of family-centered care in their practice due to factors related to the families, to the organization, and to themselves (Bamm & Rosenbaum, 2008; Graham, Rodger, & Ziviani, 2008; Lawlor & Mattingly, 1998; MacKean et al., 2005).

Factors associated with families include barriers to communication and trust building related to diversity in culture, language, socioeconomic status, and personal

stressors (Fingerhut et al., 2013; Lindsay et al., 2012). Fingerhut et al. (2013) found that characteristics of the organization create expectations regarding the roles of families and professionals. For example, professionals in home-based practices tend to view the parents' contributions as integral in the intervention while in school settings parent involvement was encouraged but not a central part of a child's intervention plan. Other barriers related to organizational policies include evaluation processes (including the types of assessments and extent to which information is gathered with and from families), and availability for face-to-face meeting times to share and discuss information with parents. Challenges related to the professionals include attitudinal factors such as how professionals view FCC and evaluate their confidence in implementing it (Bamm & Rosenbaum, 2008), lack of quality training (Campbell, Chiarello, Wilcox, & Milbourne, 2009) and barriers to developing cultural sensitivity (Lindsay et al., 2012). This evidence supports the assumption of the proposed explanatory model that barriers to FCC enactment may originate from numerous systems. This evidence highlights the need for development and implementation of innovative approaches to better prepare providers to practice FCC in diverse settings and organizations.

Cultural impact on FCC. Culture is considered to be a core factor of the human experience, yet it has been notoriously difficult to define (Fitzgerald, 2004). Fitzgerald (2004) offers this working definition of culture: "*culture is the learned, shared, patterned ways of perceiving and adapting to the world around us (our environment) that is characteristic of a population or society"* (p. 949). Multiple studies have demonstrated that family members' roles, beliefs, and behaviors are influenced by culture (Harkness et

al., 2007). Culture also impacts people's perceptions of health, illness, disability, normality, expectations about the role, and the rights and responsibilities of the people involved (Cohn et al., 2009; Fitzgerald, 2004; Sara Harkness et al., 2007; Lawlor & Mattingly, 2013; Lindsay et al., 2012). Professionals, which act as the instrument of intervention, are also the product of their own culture. They bring their own views of families, which are shaped by their past experiences and culture, into clinical interactions (Lawlor & Mattingly, 2013). A professional's assumptions related to his or her concept of "family" tend to rely on his or her personal experience and to be tacit and unconscious. Yet, these assumptions have a potential to create a gap in expectations between the client's family and the professional, which can hinder communication, trust, and interfere with collaborative goals in a therapeutic encounter.

Another important concept to consider is ethnicity. Ethnicity is another debatable term. It refers to a sense of shared identity that can be based on many things (such as geographical, national, or racial origin, for some examples), only one of which is shared culture (Fitzgerald, 2004). It is important to differentiate between these concepts because we cannot assume that people who share an ethnic background share the same cultural beliefs or vice versa. This confounding notion can lead to incorrect assumptions about a family's beliefs and values (Imperatore Blanche, 1996). Corporate culture is another factor that is acknowledged in multiple studies as having a powerful influence over an entire organization, which impacts an organization's ability to deliver quality care, including FCC or patient-centered practices (Glickman, Baggett, Krubert, Peterson, & Schulman, 2007; Luxford, Safran, & Delbanco, 2011; Shortell et al., 2000).

The first core principle in the AAP official policy for patient- and family-centered care guides professionals to respect the family's background. The statement suggests that professionals: "Honor racial, ethnic, cultural, and socioeconomic background and patient and family experiences and incorporate them in accordance with patient and family preference into the planning and delivery of health care" (AAP, 2012, p. 395). While this statement represents an awareness of the importance of attending to cultural and ethnical background, studies have demonstrated that diversity may actually lead to disparities in FCC provision. Coker, Rodriguez, and Flores (2010) surveyed 30,902 households with a child with special needs in 50 states and reported alarming evidence of injustice. Survey results indicate significantly lower odds of FCC provision for people of Latino and African-American origins, and other ethnic backgrounds, as compared with White children. Higher incidences of disparities were also noted for children in households with a non-English primary language, compared with children in households with English as the primary language. These disparities persisted after adjustment for child health, socioeconomic factors, and access to services.

Lindsay, King, Klassen, Esses, and Stachel (2012) sought to understand reasons for such disparities. In-depth interviews were conducted with 13 health care providers to explore their perceptions of challenges related to delivering FCC to immigrant families raising a child with a disability. Main findings indicated that barriers were mainly due to lack of staff training in providing culturally sensitive care, challenges overcoming language and communication barriers, and discrepancies in conceptualizations of disability between healthcare providers and immigrant parents.

Temporal influences on FCC. Temporal contexts are defined as the experience of time as shaped by engagement in occupations. Temporal aspects include stages of life, time of day or year, duration, rhythm of activity, or history (American Occupational Therapy Association; AOTA, 2008). AOTA recognized that these contexts are broad and relevant to individuals, families, organizations, and populations. Changes in any temporal aspect may lead to changes in related activities. Examples for individuals would be the roles and activities that are linked to different stages of life. Each stage of life includes specifics family roles linked to cultural expectations. For example, in some cultures, children are not expected to take care of their parents in childhood or adolescence, but are expected to do so when they are middle aged and their parents are elderly. Family life examples would include rituals for celebrating birthdays or holidays, or everyday behaviors such as morning or evening routines (Lawlor & Mattingly, 2013).

Elder's groundbreaking work on the "Children of the Great Depression" demonstrated how "the life course of individuals is embedded in and shaped by the historical times and places they experience over their lifetime" (Elder, 1998, p. 3). Findings from longitudinal interviews with children whose parents lived through the Great Depression demonstrated how their developmental trajectories and outcomes changed according to the life stage in which they experienced the Great Depression (infancy, childhood, adolescence). Elder described two cohorts of children. One cohort encountered depression hardships during middle school years. They reported a fairly financially secure early childhood in the 1920s, but then had to leave the home after the worst years of the 1930s to engage in education, work, and establish their own family.

Life patterns were very different for the younger cohort of children who were born at the end of the 1920s or during the Great Depression. These children experienced the extreme stress and instability during their most vulnerable years of childhood. They were adolescents during World War II, which was characterized by "empty homes" due to parents working long hours in essential industries. Elder and his colleagues found that the later born group of children was more adversely influenced by the economic collapse. They indicated that the most severe impacts were found for boys, possibly due to the unavailability of the male figures in the family (Elder, 1998).

Healthcare encounters are also significant experiences in an individual's and family's life. Lawlor and Mattingly (2013) argued that such encounters are often "episodes in the histories of client and family life, and conceivably, also episodes that are embedded in the practitioners life and institutional cultures" (p.150). Findings from their qualitative studies demonstrated that although healthcare encounters may seem casual and brief, these encounters can deeply affect the experience of family members and providers, and possibly even the outcomes of therapy. Excerpts from in-depth interviews with providers and parents illustrated that encounters that involved finely-tuned engagement yielded deeper understandings of the health and behavior of a child. Such encounters were pivotal and the insights were then transferred to other contexts such as school, work, and home. Based on these finding, one can assume an opposite result: encounters that do not afford understanding or solutions may lead to neglect or even an exacerbation of health conditions.

FCC development has also been impacted by a variety of macro-level temporal

influences. FCC history can be traced back to the middle of the 20th century, when the psychiatrist Carl Rogers promoted client-centered therapy. Rogers (1951) defined client-centered therapy as a process in which the therapist treats the individual as a person of worth and significance, and respects the client's capacity and right to self-direction. Client-centered practice built the foundation for family-centered practice, as the importance of a family to a child's well-being is now widely acknowledged (AAP, 2012). FCC ideas became increasingly accepted by families, professionals and different organizations, but it wasn't until the Education of the Handicapped Act Amendments of 1986 (Public Law 99-457), that the United States granted families of children with special needs legal power to become an equal partner in the health care team (Bamm & Rosenbaum, 2008). Additional federal legislation of the late 1980s and 1990s addressed children with special needs and provided further validation of the importance of family-centered principles. Examples include Individuals with Disabilities Education Act of 1990 (Public Law 101-476); the Developmental Disabilities Assistance and Bill of Rights Act of 1990 (Public Law 101-496); Mental Health Amendments of 1990 (Public Law 101- 639); and Families of Children with Disabilities Support Act of 1994 (Public Law 103-382) (AAP, 2013). These statutes paved the way for further implementation and research in family-centered care. Gradually, more and more organizations have acknowledged the importance of FCC, and began to practice it and study the outcomes.

Today, approximately 60 years after the initial conception of FCC ideas, the enactment of this approach is still evolving. Current global temporal trends in health care emphasize outcome based interventions; evidence based practice; client-centeredness;

and participation as the source and outcome of health. FCC is aligned with all of these trends and can be most beneficial for clients, professionals, and organizations.

Conclusion.

The theoretical model guiding this doctoral project is supported by extensive evidence. This model espouses that FCC is a result of multiple interactions: between professionals and families, among professionals in interprofessional teams, and among professionals and families and the environment in which they work together. The environment includes the healthcare facility or organization in which healthcare encounter takes place, as well as the surrounding society, its dominant culture, and impact of temporal factors. Explicating the complexity of FCC helps to understand why, although it is considered best practice, it is difficult to implement this approach in daily practice. The next section will describe evidence on previous attempts to address this problem in order to identify effective mechanisms to promote FCC.

Evaluative Summary of Effective Mechanisms to Promote FCC

An exploration of evidence on effective mechanisms to promote FCC was conducted to evaluate:

1) the required content (i.e., knowledge and skills) and, 2) the recommended process (i.e., methods of teaching and learning) most effective for professionals to gain expertise in FCC. The essential knowledge and skills that providers need to develop to successfully enact FCC practices include: effective communication, behaviors to support parents, cultural sensitivity and understandings of how to integrate collaborative goal setting and coaching models. Furthermore, providers must learn how to be coordinators of

interprofessional teamwork, implement specific FCC processes, and develop supportive workplace policies. To identify effective approaches to promote general professional development a review of best practices for adult learning, reflective inquiry, mentoring, and on-line learning was conducted. A detailed description of the evidence reviewed can be found in appendix B. A summary of the evidence is presented below.

Approaches for preparing providers to implement FCC. In order to effectively enact the essential features of FCC, providers should acquire knowledge to prepare them to be collaborators, consultants, facilitators, educators, and coaches (King & Chiarello, 2014). This section will highlight recommendations for preparing providers to implement FCC.

Effective communication. Effective communication is a two-way exchange of information needed to for clients and providers to understand each other's worldviews (King & Chiarello, 2014). This understanding enables providers to tailor information, advice, and recommendations to the unique circumstances, resources, day-to-day concerns, and routines of families (Bedell, Khetani, Cousins, Coster, & Law, 2011; King, Baxter, Rosenbaum, Zwaigenbaum, & Bates, 2009). It is also fundamental for establishing strong, ongoing client-practitioner relationships. Thus, effective communication is strongly linked to client satisfaction and is an essential aspect of high-quality care (King & Chiarello, 2014).

Supporting parents. Dunst, Trivette, and Hamby (2007) published a meta-analysis of 47 studies (including 11,000 participants from seven different countries), indicating that FCC practices enhance parent empowerment, self-efficacy, control,

capacity, and client engagement (Dunst & Dempsey, 2007; Dunst et al., 2007). Dempsey and Keen (2008) present a FCC model that proposes that these parent characteristics act as central mediating variables that influence parents' own judgments and capabilities in providing learning and development opportunities to their children. Interpersonal and goal-oriented practices were particularly helpful in strengthening parenting skills. Interpersonal practices include active listening, compassion, empathy, respect, and focus on family strengths. Goal-oriented practices include informed family choices and family involvement in achieving desired goals (Dunst & Trivette, 2009a; Forry, Moodie, Simkin, & Rothenberg, 2011). In addition to interpersonal and goal-oriented practices, Woods et al (Woods, Wilcox, Friedman, & Murch, 2011) demonstrated the importance of considering the principles of adult learning theory in family-centered interventions. Professionals can better support parents in acquiring the skills they need to support their child's development by using modeling, reflective listening, questioning, performance feedback, prompting, and problem-solving strategies (Woods et al., 2011).

Cultural sensitivity. Cultural differences between families and providers are inevitable. Lack of awareness of these differences may hinder the communication and a collaborative parent-practitioner relationship. Beach and her colleagues (2005) systematically reviewed 34 studies describing cultural competency education programs for health professionals. They concluded that cultural competence training is an effective strategy for improving professionals' knowledge of, attitudes towards, and communications skills for interacting with culturally diverse patients. Although professional training improved patient satisfaction, no evidence was found to indicate

improved patient adherence to recommended intervention regimes, health outcomes, or equity of services across racial and ethnic groups. Based on in-depth interviews with providers working with immigrant families, Lindsay and colleagues (2012) formulated several recommendations to enhance culturally sensitive FFC. First, providers must seek education on culturally sensitive care to better meet the needs of clients from diverse backgrounds. Second, spending time with families is important to build trust and rapport. Third, providers should be sensitive to gender issues and try to involve both parents in decision making regarding their child's care. Finally, healthcare providers should explore and share information on resources available in the healthcare center and in the community that are culturally appropriate and financially feasible for each family.

Collaborative goal setting and coaching models. Goal setting and coaching are corresponding processes. Collaborative goal setting is often recognized as a key component of the foundational family-professional partnership (American Academy of Pediatrics, 2012; AOTA, 2014; King & Chiarello, 2014; Woods, Wilcox, Friedman, & Murch, 2011). Evidence points to that fact that clear and functional goals enhance motivation and lead to improved outcomes (Eccles & Wigfield, 2002; Locke & Latham, 2002), and that joint goal setting can build a sense of partnership, enhance feelings of competency, and encourage client engagement in therapy (Øien, Fallang, & Østensjø, 2010). King and Chairello (2014) recommend two models to enhance collaborative work. Both models provide strategies to optimize outcomes by enhancing family-practitioner collaboration throughout the intervention process through sharing knowledge and skill in joint decisions on goals and intervention. The Collaborative Practice Model (An &

Palisano, 2013) provides a detailed framework with specific strategies and procedures for professionals to negotiate collaborative processes with families. The Relational Goal-Oriented Model of Optimal Service Delivery (King, 2009b) emphasizes the role of both client–practitioner and practitioner–organization relationships in the goal-related aspects of practice. This model is designed to help providers identify and establish 6 essential elements of quality practice: overarching goals; desired outcomes; fundamental needs; relational processes; approaches, worldviews, and priorities. While both models are recent and have little accumulated supportive evidence of implementation, they appear to be useful for supporting providers in enhancing their collaborative practice with clients and the organizations.

Emerging evidence points to effectiveness of coaching models to assist families in meaningful goal setting and attainments (King & Chiarello, 2014). King and Chiarello (2014) reviewed three coaching models that could be useful frameworks to guide providers in collaborative goal setting. All three models were developed by providers, are strength-based, relational, and foster change through collaborative goal-setting and client empowerment. These models share similar theoretical foundations with the collaborative models presented above, and elaborate on the models by providing specific guidelines to assist families in meeting the goals in real-life environments. The Occupational Performance Coaching Model (Graham et al., 2008) focuses specifically on the enablement of children's and parents' participation in occupations in home and community contexts through parent-identified solutions to performance barriers. The therapist employs specific language, questioning and reflection cues to guide parents'

self-discovery of solutions, and their implementation and evaluation within a problem-solving framework. The Transdisciplinary Model of Solution Focused Coaching for Pediatric Rehabilitation (SFCPeds) (Baldwin et al., 2013) emphasizes an exploration of a family's preferred future and utilizes solution-focused strategies rather than collaborative problem solving. The main methods include working with resources and asking strategic questions to construct customized interventions with families. Foster, Dunn and Lawson (2013) describe a coaching model which highlight the elements of change and importance of reflection on the parent-coach relationship and the child's engagement.

Although evaluation of these models in still in its early stages, it appears that coaching models can provide providers with mechanisms needed to enhance the partnership and work collaboratively towards personalized family goals.

Interprofessional teamwork or team coordination. The growing emphasis on interprofessional education and collaborative practice brings additional interactions and complexities to FCC (King & Chiarello, 2014), as families need to work with larger teams of professionals, with different styles of communication and different professional foci. To mitigate these challenges studies are now recognizing the importance of collaboration among the intervention team members as an essential component for the successful implementation of FCC (Wright, Hiebert-Murphy, & Trute, 2010).

Family as faculty. One of the essential training elements required to transform professionals from understanding FCC to being family-centered is a variety of experiences with families of children with special needs (Beatson, 2006). The idea of family as faculty suggests that family members should be embedded in all aspects of the

curriculum for preparing FCC health professionals. This includes parents and siblings as teachers during didactic seminars, as mentors in practicum experiences, and as members of professional development planning and evaluation advisory boards (Beatson, 2006; Sewell, 2012; Whitehead, Jesien, & Ulanski, 1998). Opportunities for service providers to spend time with the families without intervening (for example, joining dinner, birthday party, doctor visit, therapy session or other family activities) can sensitize providers to the reality of everyday life and cultural differences, and enhance empathy and understanding (Whitehead et al., 1998). Moreover, collaborating with families on professional preparation is an important way to role model family-practitioner partnership, and an opportunity to empower families to impact health care, and provide an opportunity for professionals to gain real world examples and insights.

Assessing FCC processes. Effective FCC optimally involves continuity across all aspects of care, from initial contact with a family, through examination, diagnosis, intervention planning, intervention, and discharge from services (King & Chiarello, 2014). Providers should have sufficient opportunities to hold conversations with families to clearly establish the extent and focus of service. Evaluation and intervention should then be provided according to the agreed upon-goals and expectations. One assessment tool that can be used to evaluate the level of FCC provided is the Measure of Processes of Caregiving (MPOC) (King, Rosenbaum, & King, 1995).The MPOC is a standard assessment including a parent self-report version and a provider self-report version, with a full length (56 item) and short (20 item) versions. Providers can use this questionnaire to assess their FCC behaviors according to five constructs 1) Enabling & Partnerships; 2)

Providing General Information; 3) Providing Specific Information about Child; 4) Coordinated and Comprehensive Care for the child and family; and 5) Respectful and Supportive Care. Feedback from the MPOC can be valuable for directing reflection and professional growth.

Work culture and organizational policies. While many families and professionals are interested in FCC, it cannot be effectively implemented without supportive organizational policies. A growing number of studies indicate the importance of organizational culture and administrative factors on service providers' ability to deliver family-centered care (Kuo et al., 2012; Law et al., 2003; Wright et al., 2010). Barriers to FCC in the workplace included heavy caseloads, supervisors who do not support family-centered care as a priority, limited professional development education, lack of collaborative policies, and lack of resources, mainly time. FCC supportive factors include service coordination and interagency collaboration (Kuo et al., 2012; Nolan, Orlando, & Liptak, 2007; Wright et al., 2010). King and Chiarello (2014) concluded that the extent to which family-centered care is valued, supported through policies and resources, and expected by administrative leadership appears to be a key determinant of its actualization. Effective approaches to professional development.

Best practices for adult learning. Malcolm Knowles, an American practitioner and theorist of adult education, defined the term *"andragogy"* as the art and science of helping adults learn (Knowles, Holton III, & Swanson, 2011). Knowles identified six principles of adult learning:

1. Adults are internally motivated and self-directed

2. Adults bring life experiences and knowledge to learning experiences
3. Adults are goal-oriented
4. Adults are relevancy-oriented
5. Adults are practical
6. Adult learners like to be respected

Dunst, Trivette, and their colleagues have been leaders in scholarship of both FCC and the application of adult learning principles to professional development programs. Findings from their extensive survey (Dunst, Trivette, & Deal, 2011), meta-analysis (Trivette, Dunst, Hamby, & O'Herin, 2009), and evidence based program (Dunst & Trivette, 2009b) have indicated several key aspects required for optimal learning benefits for providers. These key elements were used to design the Participatory Adult Learning Strategy (PALS)(Dunst & Trivette, 2009b), a four-phase learning and capacity building process:

1. *Introduction and illustration.* In this phase the instructor engages the learner in a preview of the content and demonstrates or illustrates the use or applicability of the material, knowledge, or practice for the learner. The learner's main roles in this phase are to prepare according to assigned preview content, provide input on the learning topic and its relevance to the learner's area of practice.
2. *Application.* In this phase the instructor engages the learner in application of the material, knowledge, or practice and in an evaluation of the consequence or outcome of the application of the learned content. The learner implements or practices the learned content and self-evaluates the learning progress.

3. *Informed understanding*. The instructor guides the learner to acquire an informed understanding by reflection on the application experience and use of formal assessments of mastery of the content or skill.
4. *Repetition and identification of next steps in the learning process*. The instructor and learner engage in joint planning of continued steps in the learning process to further develop learner understanding, use, and mastery as needed. This phase may include guidance for additional learning experiences and instructor-learner mentoring.

Data collected 1 and 6 months after implementing the PALS process identified high levels of learner satisfaction, with optimal learning benefits. The learners were actively involved in the four phases of learning, and implemented the content on multiple occasions over time (Dunst et al., 2011).

Other professional development programs designed to prepare providers to implement FCC ranged from a few hours (such as a conference or one-day workshop) up to an entire year (an ongoing mentorship program). Findings indicate that more training time is perceived by providers as more beneficial and more influential on their practice (Dunst et al, 2011; King et al., 2011; MacPherson-Court, McDonald, Drummond, Kysela, & Watson, 2005; Sewell, 2012; Whitehead et al., 1998).

Reflective inquiry. A systematic review of 29 studies on reflection in health professionals concluded that reflection in and on practice leads to deeper learning, stronger social connections, and better linkage of theory and practice (Mann, Gordon, & MacLeod, 2009). Literature on professional development highlights the importance of

reflective inquiry as a means of learning and advancing skills needed to develop expertise (Cohn, Schell, & Crepaeu, 2010; King et al., 2011; Schell, 2013). Reflective practice is particularly important in FCC as practitioners' lived experiences as family members shapes their perceptions and beliefs on what a family ought to be. These assumptions are usually tacit, and unless we reflect on them and bring them to our awareness they can influence our actions in unintended ways (Hanna & Rodger, 2002; Lawlor & Mattingly, 2013). Lawlor and Mattingly (2013) suggest that incorporating guided reflection through mentorship and supervision, as well as discussions with other team members concerning beliefs about specific families, is an essential component of intervention planning and implementation with clients and their families.

Formal and informal feedback and practitioner self-assessments are also helpful in developing awareness and eliciting reflection (King et al., 2011). Madsen (2014) described the Collaborative Helping Map, which can be useful to enhance reflection, collaboration, and goal-setting. This map incorporates ideas from cognitive behavioral theories, goal-setting theories, and business models (similar to SWOT analysis), and can be administered as a self-assessment or an interview. The Collaborative Helping Map requires that the professional or family identify their Vision ("Where do you want to be headed in your life or work?"), Obstacles (What gets in the way of your Vision?), Supports ("who and what support you in moving towards your vision?") and Formulating an action plan ("How can we draw on supports to address obstacles to help you move towards your Vision?"). In order to practice this assessment it will be used as part of the

mentoring process to enhance collaborative work towards professional development goals.

Mentoring. Multiple researchers have identified mentoring as a mechanism to promote practitioner expertise (Brockbank & McGill, 2012; Campbell, Chiarello, Wilcox, & Milbourne, 2009; King, 2009a; Myall, Levett-Jones, & Lathlean, 2008). Mentorship is the process in which a more experienced person helps someone less experienced to develop skills and abilities (King, 2009a). The role of a mentor can include providing feedback on observed performance, serving as a role model, providing one-on-one instruction, encouraging reflection through guided discussion, and giving emotional support (Rees & Hays, 1996). Mentorship can be provided in individual or group settings, face-to-face or remotely, on a routine basis or according to needs. Effective professional mentoring utilizes many of the skills needed for effective FCC, and thus can offer participants, both mentors and mentees, an opportunity to practice listening, communication, coaching, collaboration, and cultural sensitivity skills in an additional setting, reflect on their work, and identify ways to enhance learning and effectiveness.

A mentorship program developed by King, Tam, Fay, Pilkington, Servais, and Petrosian (2011) was designed to foster occupational therapists' development of expertise in family-centered behaviors. This 11-month long intervention involved one-on-one and group mentoring, and voluntary participation in a variety of educational activities. The program was designed according to a theoretical framework developed by King (2009b) which described learning strategies aimed to foster therapist expertise. Based on this

model, therapists' engagement in deliberate practice generates feedback, which in turn is instrumental for processing and reflecting on the experience. King suggested that effective reflection will lead to further engagement in deliberate learning opportunities. The cycle is presumed to enhance therapists' knowledge and behaviors, which will ultimately lead to enhanced expertise. Mentoring is an instrumental aspect to guide and enhance individual learning in all stages of the process. King and colleagues' 2011 study results validated these propositions by demonstrating significant changes in mentorship program participants' expertise as assessed by multiple self- and peer-report measures, including standard assessments and a focus group. This study was the first of its kind to describe psychometrically sound evidence from a mentorship program, specifically in occupational therapy.

Another method of mentoring for professionals is an electronic mentoring, or: E-mentoring. E-mentoring refers to the use of technology such as electronic communication platforms (Skype, google hangout, or Adobe connect) and Web cameras as well as telephone and e-mail communications. E-mentoring has been shown to be a promising alternative to in-person mentoring (DiRenzo, Linnehan, Shao, & Rosenberg, 2010; Schichtel, 2009). DiRenzo et al. (2010) have found that e-mentoring is particularly successful when participants are comfortable navigating the Internet and are motivated to be involved in the mentoring dyad. Additionally, the frequency of e-mentoring interactions mediates outcomes of general self-efficacy and task efficacy among the peer mentors.

Finding from both programs set the foundations for future implementation and

investigation of mentorship programs to better prepare providers to provide FCC.

On-line learning. Participation in professional development courses and workshops is often restricted due to obstacles such as timing and scheduling, location and commute, and costs associated with time off and travel to courses. On-line learning presents an ideal solution for these problems while providing high quality learning opportunities (Brown & Woods, 2012; Chen, Klein, & Minor, 2009; MacPherson-Court et al., 2005). MacPhearson-Court and colleagues (2005) described an on-line course for FCC in early-intervention that yielded positive learning outcomes and student satisfaction. Students and instructor encountered some challenges associated with on-line course design such as difficulties navigating sites and submitting assignments, or organizing schedules to complete course assignments in a timely manner. Effective course design and organizational aids can minimize these challenges. Course materials included self-study modules focused on family-centered practice and the assessment of family strengths and needs; teaching strategies; and family problem solving. Assignments engaged students in real-life situations through required case study reports on experiences with families. Deeper thought and reflection was elicited through participation in discussions.

Brown and Woods (2012) described the promising impact of an on-line multi-component professional development program for providers working in Early Intervention settings. The authors presented the Read, Observe, Practice, Exhibit (ROPE) model which is based on principles of adult learning (Bransford, Brown, & Cocking, 2000), on-line instruction (Johnson & Aragon, 2003), and on the effective professional

learning components described above by Dunst & Trivette (2009b). According to Johnson and Aragon (2003) recommended principles for effective on-line learning include addressing individual differences by using multiple learning styles, creating a real-life context, motivating the learner, providing hands-on activities, avoiding information overload, encouraging social interaction, and encouraging student reflection. By incorporating these principles one can assume that learning will be an active, engaged, and relevant process for the learner. Brown and Woods' (2012) ROPE program guides students to read assigned content, engage in diverse opportunities to observe, practice skills, apply them in real life settings, and reflect on skills in the actual context in which the students will be using them. Students' learning is evaluated according to how they exhibit their skills and knowledge in real life settings. Situated learning was supported by annotated video examples, narrated presentations, video camera access, and practice video examples. Pre-post evaluation of participants' learning indicated significant changes in knowledge as observed during application and self-report measures, along with participant's satisfaction and perceived benefit from on-line professional development. These positive findings suggest that on-line instruction can make FCC skills and knowledge more accessible for many providers who otherwise would not be able to receive training. On-line instruction can be tailored to the learner's needs and practice settings to enhance relevance, engagements, and implementation of acquired knowledge and skills.

Conclusion.

A review of literature concerning preparation of practitioners for FCC enactments identified the core skills and knowledge practitioners must have, as well as best practices for professional development instruction. Agreed-upon capacities for FCC enactment include the skills essential for guiding a collaborative intervention process. These are: effective communication; cultural sensitivity; collaborative goal setting and coaching; and specific knowledge on ways to support families and implement FCC assessments and processes. Promoting interprofessional teamwork and supportive workplace policies are also imperative for delivery of FCC.

Best practices in professional development instruction include adult learning principles, enhancing reflective inquiry, and incorporating ongoing mentoring, all of which can be delivered via face-to-face or on-line instruction. Most importantly, learning must be meaningful and relevant to the learners. Making learning meaningful can be achieved by engagement of the learner in all stages of learning from self-identified learning goals and their relevance to daily practice, through implementation and self-appraisal of skills, to planning of future learning goals. Instruction must include multiple options for practice and implementation of FCC behaviors in different settings. Longer programs (over 10 hours) with ongoing mentoring to support continued learning and expertise are recommended.

Chapter 3: The Proposed Program

"Better Together"

Introduction

The proposed program is a professional development course for preparing providers to enact best practice family-centered care (FCC). The course will be offered in an on-line format to interprofessional providers and administrators working with families. The course content and structure were developed according to findings from an extensive literature review, which examined causal factors leading to challenges with FCC enactment and effective means for remediating and preparing providers for successful implementation of FCC, as well as best practices for fostering professional development. An overview of the course logic model is presented in appendix C.

A systems perspective was used to develop an explanatory model of challenges to implementing FCC. This explanatory model may be useful to providers as they strive to provide FCC. Proficient providers recognize the different systems that impact families and the care they receive. These providers effectively negotiate among family members, the care team, and the organization, and use reflective inquiry throughout the process. The proposed course will address FCC from this systems perspective and provide providers with evidence-based mechanisms to collaborate and facilitate effective interactions among all systems.

Program Description

Program goal. Providers will be confident and proficient in enacting best practice FCC in their practice area to promote quality care.

Objectives. By the end of the program, participants will be able to:

- Identify the essential features of FCC
- Discuss FCC mechanisms that can be applied to participant's practice area
- Apply FCC in participant's practice area
- Evaluate and analyze their performance and understanding of FCC
- Devise a personal plan for continued learning and improvement

Outcomes. Proximal outcomes include improving knowledge of FCC principles and implementation of these principles into practice as measured by pre-post self-report on the Measure of Processes of Care – Service Provider version (MPOC-SP; Woodside, Rosenbaum, King, & King, 1998) and client report on the Measure of Processes of Care (MPOC; King, Rosenbaum, & King, 1995). A distal outcome is child performance relevant to individual treatment goals.

Recipients. Program participants will include providers and administrators from various health-care fields who work with children and their families who registered for and completed the professional development on-line course.

Course format and delivery method. The course will be offered in an on-line format including on-line modules, video-conference for virtual chat (VC) meetings, and a peer-mentoring program. On-line modules will be structured according to Brown and Woods (2012) recommendations to enhance participants' knowledge and skill by providing readings, observations, assignments to apply knowledge to participants' real-life environments, and individual reflection and self-evaluation. These modules will each be available for two weeks duration to be completed, with an expected time investment of

6-8 hours for each module. VC meetings will be offered within each module and include four one-hour sessions dedicated to live discussions on module content and to group work on identifying goals for change and service enhancement. The time of these meeting will be determined according to participants' availability and convenience. The mentoring component will be integrated to support continued skill enhancement and application into practice (Andersen, 2001; King et al., 2011; King, 2009a). Peer-mentors will be assigned at the program start and will be guided to collaboratively set goals for professional enhancement. Peer-mentoring sessions can be conducted in person or on-line, according to participants' preferences. Group mentoring sessions with the course facilitator will be offered to participants after course completion on a monthly basis to discuss challenges and success stories of FCC practice.

Key components of course. Five key components were used as foundations for course development. These include (a) reflective inquiry (b) learning from family as faculty, (c) evidence based educational materials (d) content delivery according to the adult learning theory and the Participatory Adult Learning Strategy (PALS) model, and (e) ongoing mentoring.

Reflective practice. Reflective inquiry is essential to professional reasoning , clinical expertise (Cohn, Schell, & Crepaeu, 2010; King, 2009a; Mann, Gordon, & MacLeod, 2009; Schell, 2013) and family-centered skills and behaviors (King et al., 2011; Lawlor & Mattingly, 2013). Reflection refers to focused inquiry aimed at attaining a comprehensive, nuanced understanding of the way one thinks and operates professionally (Higgs, 2008). According to Schön (1983, 1987), the reflective process is

triggered by a professional experience that presents a provider with a surprise or puzzlement which makes a provider "stop and think". This thinking prompts two associated processes, reflection-in-action (during the experience) and reflection-on-action (after the experience or in preparation for another experience), which mediates a change in perception and understanding. The outcome is learning resulting in an expanded repertoire of knowledge, conceptual perspectives and alternative approaches to practice which advance professional expertise. Schön's reflective practice ideas are commonly used in healthcare education (Mann et al., 2009), and will therefore guide this program.

The proposed course will incorporate multiple opportunities for course participants to reflect on their practice in order to gain a deeper understanding of their views and behaviors, and to expand their "tool kit" of possible actions for future situations. Learning activities were developed with inspiration from reflective assignments collected and described by Cohn and colleagues (2010) for pre-professional training. Example of activities include:

- Group discussions of participants' past challenges and success stories with families: facilitator will guide participants to list all possible reasons (not just the one that immediately came to mind) of why a particular event occurred. This group discussion will encourage participants to expand their thinking and reflection, and thus consider other alternatives.
- Analysis of therapeutic encounters (videos and role-playing). Group discussions will expand and enrich participants' repertoire by offering multiple viewpoints and suggested actions for different situations.

- Reflective journaling: each participant will record reflections on his or her FCC enactment during the course and mentoring.
- Developing a FCC "tool kit": each participant will articulate "take away" messages from different experiences in the course, and describe how new learning may be implemented in their practice.
- Goal setting and commitment strategies: to help ensure that participants apply the new learning, as a group and individually, participants will develop a list of goals for FCC implementation and continued learning with actionable steps and possible obstacles to overcome. The plan will be used in continued professional development and monitoring during peer-mentoring.

Learning from families. Previous reports of professional preparation programs for FCC highlight the importance of providing students with a variety of experiences with families to understand the context in which families live and how the families support their children with special needs (Beatson, 2006; Sewell, 2012; Whitehead, Jesien, & Ulanski, 1998) . Learning firsthand about families' lived experiences can enhance learners' interest, empathy, understanding, and cultural sensitivity. Learning experiences may include having family members function as faculty in the formal teaching environment, having students visit and observe families who have children with special needs in their home environment, and working together with families as part of collaborative assessment teams (Beatson, 2006; Whitehead et al., 1998). Embedding families in professional preparation is also an important way to model family-provider

partnerships (Whitehead et al., 1998).

Based on these suggestions, a course development advisory board will include family members (parents and siblings) to suggest and provide feedback about course content and ways to evaluate FCC practice. One of the course assignments, as suggested by Whitehead et al. (1998), will include spending time with a family that has a child with special needs. Course participants can join a dinner, birthday party, doctor visit, therapy session, or other events in a family's life. Participants will later reflect on their experience to analyze their learning about the family's strengths, challenges, and cultural values, and their own reactions and judgment of the situation.

Evidence-Based Educational Materials. Law, Rosenbaum, King, King, Burke-Gaffney, Moning-Szkut, Kertoy, Pollock, Viscardis, and Teplicky (2003) of the CanChild Centre for Childhood Disability Research in Ontario, Canada, have developed and evaluated 18 Family-Centered Service - Facts, Concepts, Strategies (FCS) educational sheets. These 3-4 page sheets address different FCC concepts and challenges, and provide rational and practical guidelines to address them. Examples of FCS educational topics are: What is family-centered service; Becoming more family-centered; Identifying and building on parent and family strengths and resources; Effective communication in family-centered service; Making decisions together: how to decide what is best; and Fostering family-centered service in the school ("FCS Sheets - CanChild," n.d.). All FCS sheets were written for a diverse audience including families and providers.

The CanChild FSC educational sheets were evaluated by 36 readers, which included 12 parents, 12 children's rehabilitation service providers and 12 health science

students (Law, Teplicky, King, King, Kertoy, Moning, & Burke-Gaffney 2005). Findings from this study indicate that the FCS educational materials, even those less familiar to participants, were rated highly on format and content, and the readers found them beneficial. Analyses found that there were no significant differences between participant groups for ratings of format and content, and impact on the service. All FSC sheets are available free of charge at CanChild's website (http://www.canchild.ca/en/childrenfamilies/fcs_sheet.asp), and can be accessible to course participants, and will be used as part of the course materials. Additional course materials will be based on published books and scholarly articles.

Participatory Adult Learning Strategy (PALS). The PALS model is an evidence-based approach to professional development, developed by Dunst and Trivette (2009), and based on an extensive research syntheses and meta-analyses of adult learning methods and strategies. The PALS approach emphasizes active learner involvement in all aspects of the learning, and utilizes principles for designing effective instructor-guided learner experiences. Guidelines for content delivery include (1) introduction and illustration of the topic to examine its relevance to the learner's daily practice; (2) application in simulated or real life situations, (3) self-evaluation and appraisal of understanding, and (4) planning next steps for learning and repetition. A program evaluation of the PALS model for educating practicing professionals documented improved learner knowledge, use and mastery of different types of intervention practices, and learner satisfaction (Dunst & Trivette, 2009; Dunst, Trivette, & Deal, 2011).

Dunst and his colleagues' (2011) surveyed 473 providers who participated in

various professional development opportunities, including conference presentations, workshops (half/full day or multi-day), or on-site, field-based training. Optimal participant benefits were reported for field-based training compared with the other types of training. Field-based training included an opportunity to participate in family assessments, work with experienced staff while they implemented family interventions, and interacting with families who described and illustrated how they experienced family intervention practices and how the practices affected themselves and their children. The on-line format for this course proposed in this OTD project is ideal for integrating the principles of PALS and field-based training format, while maintaining convenience and low costs. Field-based training will be provided during VC meetings as well as via course assignments focused on applications of learning into practice settings.

Mentoring. Mentorship programs recognize and utilize the skills of professionals to guide each other's professional development. Mentoring can occur when a more experienced professional guides a less-experienced professional, or as peer-mentoring when colleagues work to support each other's learning regardless of their professional background. Peer-mentor pairs will be assigned on the first day of the course and will be guided to collaboratively set goals and initiate contact once every module (2 weeks) to discuss their progress. Mentoring with a peer is a good opportunity to practice FCC skills such as listening, respecting, collaborating, sharing information, and being sensitive to cultural differences. King (2009) suggests providing clear structure and guidelines for effective mentorship. The Collaborative Helping Map (Madsen, 2014), was chosen as a semi-structured assignment to guide and structure the peer-mentoring process. The

Collaborative Helping Map was developed to help providers think their way through complex situations and to provide a guideline for constructive conversations between families and helpers about challenging issues. The mentorship structure should also be flexible to meet the needs of busy providers: although the peers will be expected to complete the helping map, the format of mentorship relationship should be negotiated among participants to best meet their needs. Due to the program length and lack of familiarity of the registered participants, peer-mentoring pairs will be pre-assigned in this course. However, evidence documents that informal mentoring relationships that develop spontaneously are often more effective than assigned pairs (Ragins & Cotton, 1999). Therefore, individuals should be offered the opportunity to reach out to an additional mentor; someone they respect who has skills they want to learn, either from the same or a different discipline.

Once the program is completed, participants will be encouraged to maintain contact with his or her mentor on a routine or as-needed basis. As mentioned previously, participants will also be invited to join a monthly group mentoring program facilitated by the course instructor. A combination of individual mentor-mentee meetings along with group mentorship meetings could potentially provide the most benefits of learning and support for all participants.

Course content outline. Course content was chosen and designed to address the essential FCC features (as presented in chapter 2). The content will be presented in 4 modules:

1. Family centered care: essential elements

2. Implementing FCC: processes and mechanisms for the work-place
3. Partnership: collaboration and goal-setting
4. The bigger picture: Promoting FCC in the workplace.

Each module will be available for two weeks and will include three components: (1) a guided independent study section with readings and assignments; (2) a scheduled virtual meeting of all course participants and the instructor via videoconferencing, and (3) a peer mentoring component. Figure 3.1. offers a visual representation of the components of each module. Module topics, learning objectives, and main learning activities are presented in Table 3.1. For examples of completed modules see appendix B.

Figure 3.1: *Module Instructional Components*

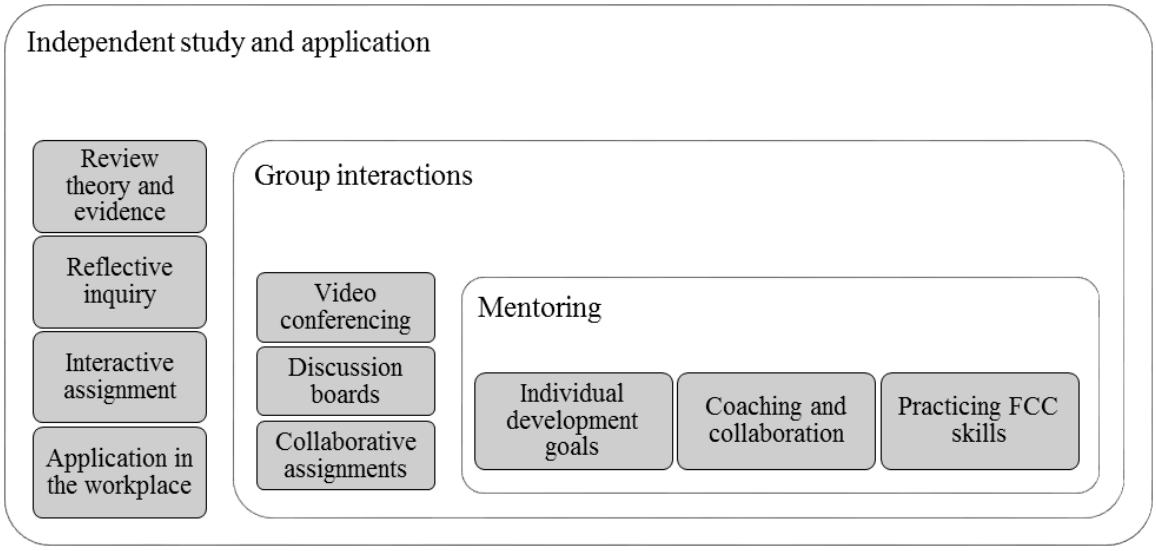


Table 3.1: *Outline of FCC On-line Course Content and Objectives*

Module 1: FCC: Essential elements		
Delivery	**Learning objectives** by the end of this lesson, learners will be able to:	**Learning activities**
Independent learning ***see appendix I for lesson outline***	• Identify strengths and areas of opportunity in learner's FCC practice • Identify the essential features of FCC • Describe ways to identify cultural diversity and modify care to meet family's values • Apply strategies to promote parents' self-efficacy, empowerment, and engagement • Practice active listening skills and strategies for effective information exchange according to family's needs and capacities	• Read the module and answer reflective questions • Complete and analyze MPOC-SP self-assessment • Devise a personal plan for developing expertise in FCC behaviors relevant to the workplace • Interview and observe a family • Reflect and post a journal entry on lessons learned from interview and observation, and respond to on-line posts of two peers
Virtual chat ***see appendix II for lesson outline***	• Introduction of course participants • Define the terms "Family" and FCC • Identify and analyze FCC key aspects in participants' workplace	• Reflective assignments to identify implicit views on "family" and parenting through reflective assignments • Identify values of FCC • Share narratives on experiences with client families
Peer-mentoring ***see appendix III for lesson outline***	• Identify personal goals and collaboration process	• Self-introduction • Complete collaborative helping maps for each mentor • Develop mentorship agreement
Module 2: Implementing FCC: processes and mechanisms for the workplace		
Delivery	**Learning objectives**	**Learning activities**
Independent learning	• Apply three techniques for collaborative goal setting and coaching • Name four FCC assessments • Administer one FCC on a family	• Review evidence based educational materials: CanChild Centre FCS sheets (Law, et al , 2003) • Describe and compare family

	• Describe an effective FCC process	assessment tools: • Family Quality of Life Questionnaire and Interview (FQOL) (Beach center: Hoffman, Marquis, Poston, Summers, & Turnbull, 2006) • Family support and resource questionnaires (Dunst, Trivette, & Deal, 1988) • Explanatory Model eight questions (Kleinman, 1987) • Questions about parents' concerns and hopes (Cohn, Kramer, Schub, & May-Benson, 2014) • Measure of Processes of Care 56/20 (King et al., 1995) • Select, administer, and interpret an assessment for a family of your choice • Reflect and post a journal entry on lessons learned from this experience; respond to two peers
Virtual chat	• Apply FCC behaviors in simulated scenarios. • Evaluate FCC behaviors of self and others. • Analyze FCC from a systems perspective.	• Reflect on interview and observation experiences with course participants • Role play to simulate FCC • Analyze case studies • Review and discuss a systems model to understand FCC enactment enablers and inhibitors.
Mentoring	• Monitor progress and identify next steps.	• Review collaborative helping maps and progress towards personal goals
Module 3: the partnership: collaboration and goal setting		
Delivery	**Learning objectives**	**Learning activities**
Independent learning ***see appendix IV for lesson outline***	• Identify strategies for collaboration with families • Apply collaborative strategies in the workplace • Establish Goal Attainment Scaling follow-up chart	• Review collaborative service delivery model • Collaboratively set goals with one family in practice • Post a journal entry on the experience and respond to two peer posts

Virtual chat	• Demonstrate two strategies for effective collaboration and information exchange between interprofessional team and a family	• Group activity to collaboratively solve a problem; debrief on enabling and hindering components • Role-play and discuss scenarios of teamwork and family
Peer-mentoring	• Monitor progress and identify next steps	• Review collaborative helping maps and progress towards personal goals
Module 4: The bigger picture: promoting FCC in the workplace		
Delivery	**Learning objectives**	**Learning activities**
Independent learning	• Appraise existing FCC process and collaborative work with families and teams • Identify strengths and areas of opportunity in own FCC performance • Identify two challenges and two potential solutions to enhance adherence to FCC essential features	• Develop a flow chart of the FCC processes in the workplace • Analyze a video recording of learner interacting with a client and family to evaluate FCC behaviors • Reflect and post on discussion board lessons learned from video analysis; respond to two peer posts • Complete a post assessment of MPOC 56/20 and assess personal development
Virtual chat	• Describe two strategies to enhance FCC delivery by interprofessional teamwork in workplace	• Discuss workplace challenges. • Develop together a "toolkit" for the FCC provider, including key "take away messages" learned in the course and ways to support the implementation
Peer-mentoring	• Identifying three strategies to enhance self-competence and leadership • Identify three individual learning and professional development goals to monitor and achieve with mentoring	• Reflect and discuss progress towards identified goals • Develop new helpgiving maps for future professional development • Plan how the mentoring relationship will be utilized in the future

Barriers and challenges for implementation.

The main barrier for implementing this course is a lack of an identified need for or interest in learning about FCC. Marketing efforts that highlight the contribution of FCC to quality of care and provider satisfaction, as well as measurement of current FCC behaviors (i.e. MPOC-20) can assist to raise interest and recognition of a need. Even with interest, providers and workplaces may encounter challenges to find convenient times for meetings, and for offsetting costs. With respect to practice realities, the course was designed to maximize accessibility and minimize inconvenience to providers and their clients. The on-line format allows for flexibility as participants can complete on-line learning at their convenience; during or after work hours, and the content can be divided into shorter lessons that require less time. This format also helps to reduce costs of travel and loss of treatment hours for participants or their organization.

Workplace culture is another factor highly influencing motivation and learning (King, 2009a). Workplace culture, as well as personal factors, can impact the participants' emotional and cognitive energy devoted to learning. Supportive and positive workplace cultures will enable more motivation to participate and implement lessons learned. Finally, fear of change may cause frustration and anxiety and limit learning and implementation of new learning in the situation of practice (Kolehmainen & Francis, 2012). A thoughtfully designed program that is adapted to participants' interests, relevant challenges, and personal goals of professional development will help to enhance motivation for learning and application to practice (Dunst et al., 2011).

Chapter 4: Evaluation Plan

Introduction

Family-centered care (FCC) is recommended as "best practice" across a variety of pediatric service settings. Yet, professionals in multiple healthcare fields report an ongoing struggle with implementing FCC concepts into practice (Bamm & Rosenbaum, 2008; Graham, Rodger, & Ziviani, 2008; Lawlor & Mattingly, 1998; MacKean, Thurston, & Scott, 2005). Therefore, the proposed program, *Better Together* (BT), is an on-line professional development course to prepare practitioners to effectively deliver best practice FCC in their daily interactions with clients.

The course will be offered to interprofessional practitioners and administrators working with families. Program content was based on findings from an extensive literature review examining factors leading to challenges with FCC enactment and effective means for remediating and for preparing practitioners for successful implementation of FCC (American Academy of Pediatrics, 2012; King & Chiarello, 2014). A program manual has been developed according to current best practices for adult learning and recent evidence on essential elements of FCC (Brown & Woods, 2012; Dunst & Trivette, 2009; Dunst, Trivette, & Deal, 2011). The on-line course will include reading materials and videos of case studies, virtual conversations via videoconferencing, written ongoing on-line discussion, and individual assignments to apply the theoretical learning into participants' daily practice. The majority of instruction will be done by the program developer and supplemented with guest lectures / stories told by family members (parents and siblings) and readings. A **logic model** presenting BT resources,

supportive theory, activities, and desired outcomes is presented in Appendix C.

While there is abundant evidence on the benefits of FCC, published studies evaluating the effectiveness of programs that prepare practitioners to skillfully provide FCC are sparse. This lack of information makes it difficult to determine the best ways to design and implement a course or to anticipate the outcomes. Therefore, the evaluation plan for BT is developed to address this problem and provide guiding information for future program development. The evaluation plan includes a program evaluation proposal and a single-subject research proposal, both described in the following sections.

Program Evaluation Proposal

This program evaluation is designed to appraise the course *Better Together (BT),* an on-line professional development course to prepare professionals to practice from a family- centered approach. The main outcomes to be assessed are: (1) Change in course participants' FCC performance (summative) measured by actual change in FCC skills and behaviors using a questionnaire; and, (2) Satisfaction with learning experience (formative) assessed by feedback surveys during and following the course. Focus groups with potential course participants will be conducted to provide preliminary data to identify participants' perspective of the skills they would need to develop to enhance their ability to provide FCC.

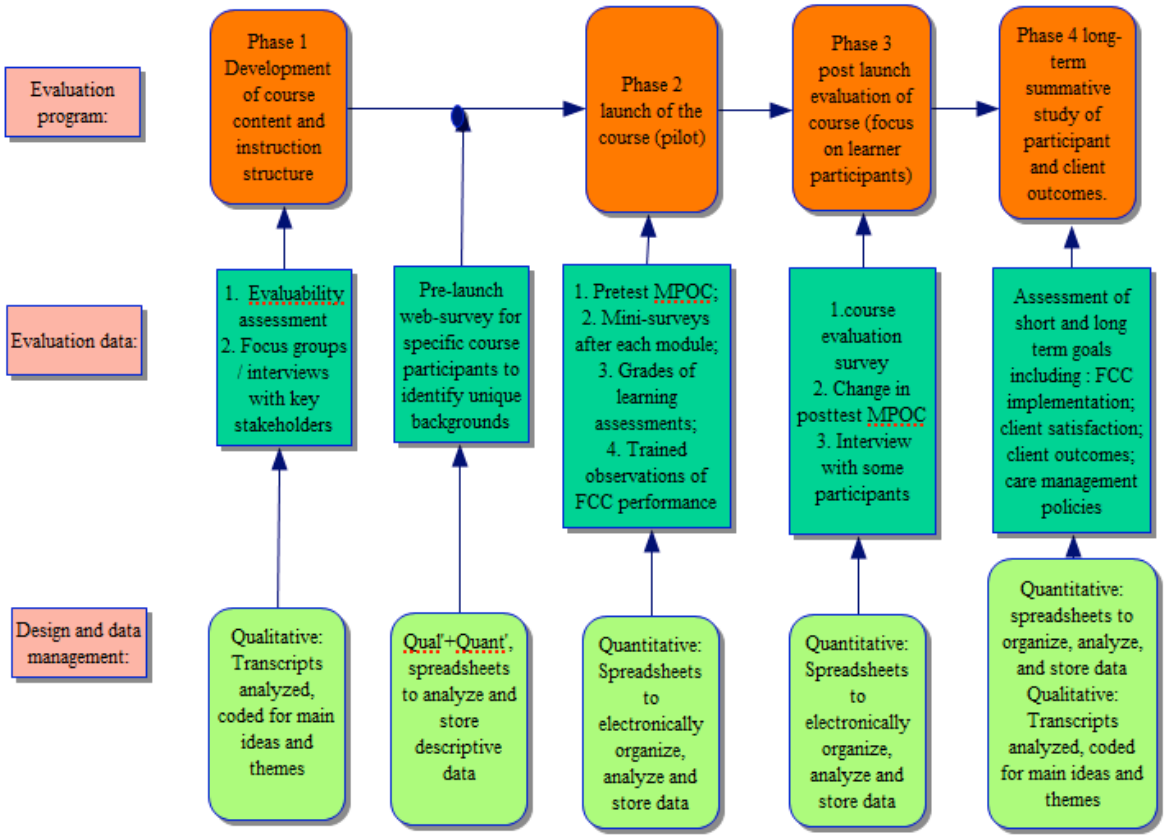
Data gathered from this evaluation is needed to demonstrate the value and impact of the program. If the value of the on-line course is established, it will serve as a central "selling point" to convince practitioners, employers, and organizations to invest the necessary time and money in this course. This data will also be important to improve the

course content and structure to enhance learning quality.

Evaluation findings will be shared with a wide range of stakeholders (and/or intended users), which include those who pay for the course, including practitioners, organizations, health insurance companies, potential continuing education companies (as distributers) and the people who will benefit from the enhanced clinical expertise of course participants, which are healthcare consumers and their families. Another stakeholder is the course developer (myself). More information about information users, their interest in the course and in the program evaluation is presented in Table 4.1.

Figure 4.1 below presents an overall graphic illustration of a four-phase program evaluation process. The rationale and components of each phase will be described in the following sections.

Figure 4.1: *Evaluation Program Design*



Evaluability assessment.

The BT on-line course is developed with the hope that it will address the needs of practitioners from different professions and diverse settings. Therefore, an evaluability assessment team should be recruited from a variety of backgrounds and different cultures and environments. Potential participants include the OTD project advisors (content experts in family-centered care, adult learning, and research), interprofessional practitioners (OT, PT, Social worker, nurse, and physician) who work with families in different settings (inpatient and outpatient, school based and more), administrators, and family members.

Ideally, conversations with the evaluability team will be conducted in the form of a focus group or, if that is impossible, in an individual format (face to face, by phone or via videoconference). At the first stage, information regarding the goals and main features of the course will be shared with the team members. Additional information that will be shared briefly includes-

- Supportive evidence on the importance and benefits of family-centered care services, as they pertain to children, families, providers, organizations, and payers.
- Current healthcare policies including the Medical Home model and the Affordable Care Act, to link family-centered care with coordinated, quality, patient-centered care.
- Program logic model with evidence on best practices in professional development programming, and essential features for preparing professionals to deliver family-centered care as identified in literature will be beneficial to demonstrate the rational for program structure.

The assessment will include a discussion on the extent to which the program's structure and content can meet the needs of the members and the groups that they represent. I hope to learn more about each member's individual goals and what type of evaluation information is important for him or her. I will then be able to refine the evaluation program and course accordingly. In a case of opposing interests or lack of agreement, I will initiate more in depth conversations to see if it is possible to negotiate a "win-win" situation where all needs are satisfactorily met.

Core purpose of the evaluation

The primary core purposes of the evaluation program are descriptive and causative, by use of a combined formative and summative assessment. Since this is a new program, descriptive data will be used to inform course development and to assess program goal attainment (i.e. enhance FCC skills of participants and their satisfaction).

Once the model of delivery and assessment are established, a preliminary, pilot-level causative core purpose study will be needed to answer the question: "Does the program produce change that is consistent with anticipated program benefits?" A one-group before-and-after, pre-test post-test, summative outcome study will be conducted in phases 2 and 3. The dependent variable will be continuous to measure change in mastery of FFC according to a standard FCC measure, Measures of Processes of Care (MPOC; King, Rosenbaum, & King, 1995). This questionnaire has two versions: a parent report and self-report. Both versions will be used at pretest and posttest.

A predictive model will also be employed that will involve regression analysis. The object will be to predict the dependent variable based upon the values of one or more independent variables and to answer the question, "What factors predict participant success in learning family centered care?". Potential independent variables that predict the dependent variable include professional background, participants' identified needs and wants, learning style, performance on course assignments, and other information. Each independent variable will be coded as a numeric value. With use of a regression statistic, the strength of relationship between any combination of independent/ predictor variables and the dependent variable can be explored.

Evaluation questions

Evaluation questions were developed with considerations of the various intended evaluation users, also known as the stakeholders. Bryson and Patton (2010) stress the importance of identifying key stakeholders groups and the questions that are relevant to each group. Table 1 presents the evaluation questions according to the interests of each stakeholder group:

Table 4.1: *Key stakeholder groups' interest in program evaluation*

Key stakeholder groups	Interest in the course	Questions to be asked in the program evaluation
Children	Enhance skill and participation in meaningful occupations	Is the practitioner helping me do the things that I want and need to do in my home and with my family better?
Family members	Receive best practice in care, addressing family needs	Are the practitioner, care team, and agency listening to me, respecting the family values and priorities and tailoring the care according to my family's needs and wants?
Practitioners	Provide best practice, i.e., family centered care (FCC), to increase work satisfaction and reduces burnout	How do practitioner's efforts to enact FCC impact client outcomes, family satisfaction and practitioner satisfaction?
Administrators / policy makers	Enhance client and employee satisfaction and effectiveness, reduce costs related to care and turnover	Does FCC indeed occur in the workplace? What policies and procedures can support implementation of FCC?
Payers for services (i.e. insurance companies)	Referrals to agencies trained in FCC may result in lower costs for services	Are costs of services reduced following FCC training? Is effectiveness of interventions enhanced? Member satisfaction?
Continuing-education (distributers)	Interested practitioners will pay for course	Are practitioners demonstrating interest and willingness to pay? Practitioner feedback following the course?
Course developer	Success and usefulness of the course	**Outcomes:** Does the program work? Does it do what it is intended to do? Are practitioners implementing more family-centered care behaviors in their daily

		practice? Are clients benefiting from this change? **Cost effectiveness:** How much time and money is going to be spent on the program? Will this cost be returned as a result of the new skills (income, client outcome, more efficiency to agency) **Outputs:** How many participants are registered for the course? How should the services involved in the course be offered (course structure, instruction)? **Efficiency:** Is the use of resources optimal for the most efficient learning? **Service quality:** What improvements are needed to enhance quality of the course and better meet the needs of the learners? **Customer satisfaction:** What are the course elements that yield highest satisfaction? What changes are needed to increase learner and stakeholder satisfaction?

Scope of the evaluation and data gathering approach

The evaluation will take place prior to course launch, during the course, and following completion of the course. The evaluation will assess all course participants (approximately 10-15), who will be professionals and administrators from different professions. Additional information from participants' clients (parents of children receiving healthcare services) will be collected during pretesting and posttesting. In the case of attrition, data will also be explored to identify causes for dropping out. All data will be collected using web assisted technology including videoconferencing for focus groups and interviews, web based satisfaction survey and MPOC questionnaires, and course assignments submitted and graded virtually. As seen in Table 2 (p.10), the

evaluation project includes 4 phases, which include different data collection measures and approaches.

Table 4.2: *Evaluation Phases and Approach to Data Collection*

	Time	**Data collected**
Phase 1	Prior to course start (to inform the development of course content and instructional methods)	-Evaluability assessment – focus groups (Qualitative) -**Focus group** with key stakeholder group representatives in order to establish content structure and content validity (Qualitative) -Pre-launch **survey** of a group of potential course participants to learn about their specific professional backgrounds, needs, wants, preferred learning styles, and main FCC challenges (mixed methods)
Phase 2	Course start	- **Pretest MPOC standard questionnaire** is administered in two forms: a parent-report on the participant and a self-assessment of the participant (quantitative) -**Course assignment grades** on course assignments, according to specific guidelines and rubrics to ensure consistent grading -"**Mini surveys**" / quizzes after each module to assess learner comprehension of course content -**Self-evaluation** by each participant of his or her implementation of family-centered care in practice as observed in a video of himself or herself (quantitative + qualitative reflection), compared to **expert rating** (course instructor grading).
Phase 3	Course end	-Post participation course evaluation **survey** (mixed method) -**Posttest of MPOC questionnaire:** parent report and self-report -**Interview** with some participants (qualitative)
Phase 4	3-6 months after course end	Long-term summative study of participant and client outcomes (Including: change in FCC implementation; client satisfaction; client outcomes; care management policies) Data will be collected using mixed methods of **interviews, trained observations, and administration of MPOC** to practitioners and clients in the workplace.

Research design and methods

The evaluation program will utilize a combined approach including qualitative and quantitative methods. Table 2 (p. 10) elaborates on the data collection measures and approaches that were depicted in Figure 1 (p.3). A main component of the research design to be employed into BT course evaluation is a fixed-effects design for longitudinal evaluations (Henry, 2010), also described as a prospective quasi-experimental repeat measures study (Watson et al, 2010). This design includes a pretest-posttest methodology with the MPOC to measure FCC skills, with participants serving as their own controls and no comparison group. By comparing individuals to themselves, fixed- effects models eliminate any bias in the effect estimates that is attributable to differences between students that do not vary over time.

Data management plan

Quantitative information will be organized electronically on the main evaluator's personal computer in spreadsheets. Some information will be entered by the evaluator (such as course assignment grades) and some will be automatically organized and sent to the researcher via survey software (including MPOC and satisfaction survey). Qualitative information will be organized electronically by means of video or audio recordings of interviews and focus groups, Word documents will contain transcriptions of the recordings, and verbal information from open-ended survey questions. Accurately and systematically naming and numbering participants and their corresponding data will be imperative to ensure confidentiality, compare pre-post scores, and identify change in

skills. In order to prevent loss, all data will be stored virtually in a cloud system (i.e. Dropbox software) and on flash drives.

Data analysis and reporting

Due to the wide range of quantitative and qualitative analyses needed, the primary investigator will have professional statistical and qualitative guidance. A statistician will be hired prior to data collection to consult on best statistical analyses and how to run them. Qualitative data (from focus groups, interviews, and open ended questions in surveys) will be transcribed, coded and analyzed for themes. Triangulation and cross-checking will be used to enhance reliability and validity. The researcher will check back with interviewees and a hired research consultant for feedback on accuracy and quality of the interpretation (Kruger & Casey, 2010).

Effectively reporting and communicating the evaluation findings will be an essential component of the program's future success and its adoption in additional settings. Grob (2010) suggests that, in order to make an impact, report writers should attend to three main elements. The first pertains to the message: What should people remember after reading the report, and how can the "take away" points be made clear and actionable? The second has to do with identifying the audience, and tailoring the information provided according to the audience's needs, wants, and interests, and practicalities. The final element to make an impact is the medium by which the message is delivered. The medium may include verbal or written reports, graphics, slides or lecture. The impactful report must be clear and concise to highlight the most important, relevant, and actionable information. Using visuals (tables, charts, boxes) and an

organized and professional layout is also helpful to convey the main findings, conclusions, and required actions.

Single Subject Study Proposal

The purpose of this single-subject research study is to measure change in a practitioner's implementation of family-centered behaviors following participation in the BT course. The study is designed to answer the research question: do practitioners' family-centered behaviors change following participation in a professional development course?

Participants

Study participants will include 3 or more occupational therapy or other practitioners who work with children and their families, and who will be willing to participate in the continuing education on-line professional development course intervention. Preferably, practitioners will represent different clinical settings, for example school based, inpatient and outpatient, for higher generalizability. Inclusion criteria will include licensed practitioners currently working at a full-time position with families and children, with at least two years of prior experience in their clinical field. No standard screening methods will be used.

Setting

The setting for the repeated assessments will be the participants' clinical environment, namely their workplace, where each participant will have opportunities to implement lessons learned from the course. The setting of the BT course, the intervention, will be virtual, as the course is delivered in an on-line format.

Dependent variable

The dependent variable is family-centered behaviors (FCB) applied in daily practice. The operational definition of FCB will be a score on The Measure of Processes of Care (King et al., 1995) which is a standard questionnaire used to evaluate a practitioner's family-centeredness; multiple versions are available. The scale evaluates 5 domains: enabling and partnership; providing general information; providing specific information about the child; coordinated and comprehensive care; respectful and supportive care. Responses are made on a 7 point scale, with 7 representing "to a great extent", 4 representing "sometimes" and 1 indicating "never". According to Cunningham and Rosenbaum (2014), in the past 20 years since its development, the MPOC has been reported in 107 studies, used in various settings in 11 countries and translated into 14 languages. Psychometric information including reliability, validity and sensitivity to change over time have been found to be high in numerous studies (Cunningham & Rosenbaum, 2014). No specific training is needed to score the MPOC and it can be completed by parents or practitioners.

The MPOC-Service Provider version (MPOC-SP; Woodside, Rosenbaum, King, & King, 1998) is a 27-item self-assessment. Since the completion of the MPOC-SP may be cumbersome for participants and less effective as a repeated measure, a modified checklist version containing 22 MPOC-SP items was developed to be utilized in the single subject study (see Appendix I for sample checklist).

The MPOC-56 will be used as a pretest-posttest measure of FCB. This is a 56-item questionnaire used to evaluate parents' perceptions of the services they and their

children receive. The purpose of using the MPOC-56 in this study is twofold: (a) to collect pre-post measures of the subject's family-centered behaviors as measured from a parent's perspective; and (b) to obtain validation of the repeated self-report measures performed by study participants (on the modified MPOC checklist).

Independent variable (the intervention)

The independent variable is the Better Together on-line professional development course. Course content was developed according to findings from an extensive literature review examining factors leading to challenges with FCC enactment and effective means for remediating the problem and preparing practitioners for successful implementation (American Academy of Pediatrics, 2012; King & Chiarello, 2014). The course will include 4 weekly modules that will include reading materials and videos of case studies, virtual conversations via videoconferencing, written ongoing on-line discussion, and individual assignments to apply the theoretical learning into participants' daily practice. The majority of instruction will be provided by a trained instructor and supplemented with guest lecturers, stories told by family members (parents and siblings), and readings. The instructor must possess the following qualifications: (a) a certified and licensed professional; (b) ample experience working with families and with inter-professional teams; (c) trained and experienced in on-line teaching; and (d) demonstrate proficiency in course manual.

The course manual has been developed according to current best practices for adult learning and recent evidence on essential elements of FCC (Brown & Woods, 2012; Dunst & Trivette, 2009; Dunst, Trivette, & Deal, 2011). The manual provides a clear

course protocol and all needed theoretical background, lesson outline and content, exercises, assignments, grading rubrics, announcement to students, etc. In order to remain faithful to the protocol, the instruction process will be fully documented (including written correspondence with student, recorded live chats, provided feedback on assignments) and be viewed by the course developer and other content experts to determine faithfulness to the core elements of the course structure and knowledge base.

While adherence to protocol is important, personalized instruction that takes into account the learners needs and abilities is also essential for effective learning. One chief aspect of single study design is the ability to modify the intervention. Thus, based on performance on the different assignments and repeated measures, the instructor will be able modify the plan to add support according to areas of need, or provide less focus on areas that have been mastered by the participant.

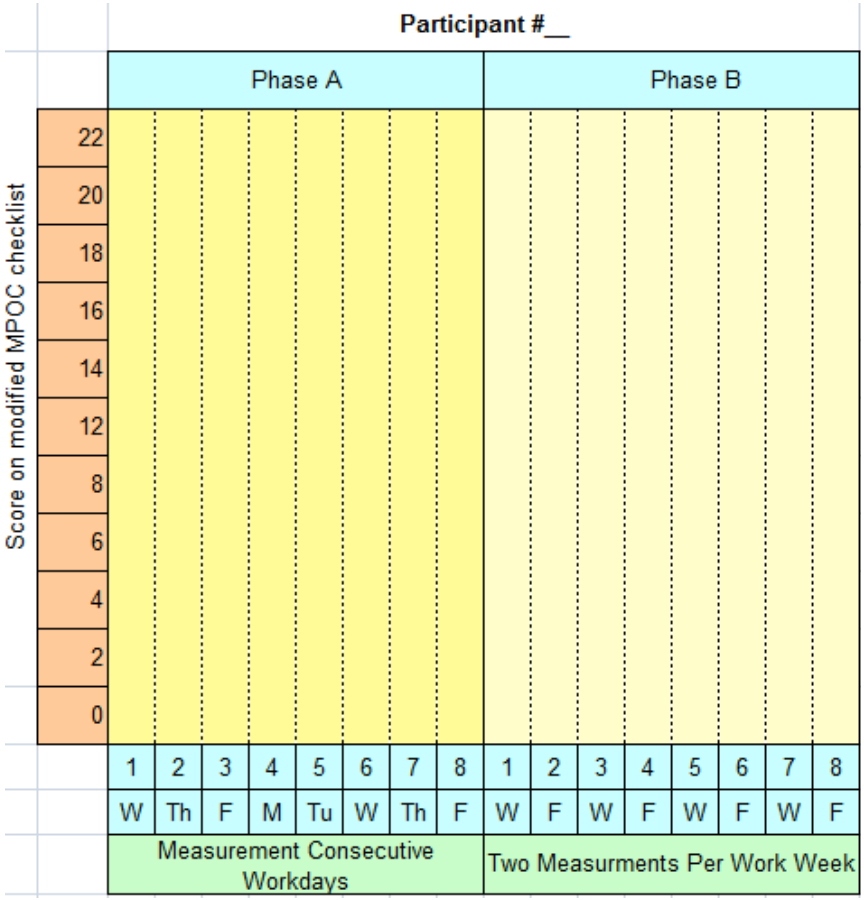
Research design

A Single-Subject AB design with multiple subjects was designed to assess the impact of the BT professional development course on participants' application of FCB into their practice. For establishing a baseline (the A phase), participants will complete the modified MPOC-SP measure at the end of each work day for 5-8 days prior to the course (the intervention) by placing a check mark next to every family centered behavior they recall making use of that day. During the intervention (B phase), participants will take part in eight weeks of the BT on-line course. In this phase participants will check off the list once every work week (for example, every Wednesday– with reference to the day of checklist completion) for the duration of the intervention. Additionally, MPOC-56 will

be administered pre-and post- intervention to the parents of participants' clients. Figure 1 provides a visual representation of the process.

The hypothesis is that participation in the course will enhance the number of FCB implemented in the workplace. Although an upward trend during the baseline phase is conceivable due to learning from the instrument, I hypothesize that course participants will show significant improvement in the implementation of FCB during phase B.

Figure 4.2: *Graphic Representation of SSD Design*



Internal validity and experimental control

The current study design is exposed to three main threats to internal validity, namely *history, repeat testing,* and *instrumentation*. Christ (2007) explains that "threats to internal validity are typically ruled out as a function of *both* the design of a study and the results of a study" (2007, p.452). In this section each threat will be defined along with experimental concerns to identify and mitigate these threats.

First, the history threat recognizes intervening events that influence measurement outcomes; any personal or professional event that could take place during the baseline experiment has the potential of impacting the behaviors that a practitioner exhibits with his or her clients (as with any other person). Christ (2007) suggests that the use of a Multiple Baseline single subject design as well as repeating the experiments with different subjects as useful to control all of the above threats. The current study will therefore include a minimum of eight baseline measure across at least three subjects (this will also support more advanced statistics). Based on the study results, lack of an abrupt change in the baseline will rule out the influence of history. An unexpected change in the trend can then be further explored and assessed to identify if indeed there were extraneous factors (history) impacting the participant's performance. History can be an influence on learning during the intervention phase as well. Factors to consider are personal illness, family illness or emergency and travel.

Second, the testing threat to internal validity refers to the influence of testing or measurement on the dependent variable. In this study, the repeated measure is a self-assessment using a Family Centered Behavior (FCB) checklist on a frequent basis. It

should be expected that simply the exposure to the components of FCB will elicit reflection and greater awareness of FCB practice and potentially will change the participant's behaviors even without an intervention. Again, using multiple baseline data points across a few subjects can indicate the influence of the testing. The magnitude of this threat will become evident when plotting the data and identifying trends. While testing is indeed a threat, improvement beginning at the baseline is not an undesirable outcome as it is change in the right direction. Hopefully, participation in the course will provide participants with the knowledge and mechanisms needed to make a significantly greater change in their FCB implementation. If not, it will be useful to know that testing by itself is sufficient.

Third, the threat of instrumentation refers to inconsistencies in the measurement devices that are used in a study. Although the MPOC-SP is a valid and reliable widely-used standard measure, the modified version has not been tested, which will reduce the confidence in its psychometric soundness. Additionally, no information about the sensitivity to change of the modified version nor a possibility of a ceiling effect have been assessed. There is much room for subjectivity and bias in the modified self-assessment and completion may not be consistent across the data points. Christ (2007) recommends making the instrument and condition as similar as possible for maximal consistency. Therefore, the measure, completion timing and location will be controlled to remain the same across all data points.

Data analysis plan

This hypothesis of this study is that significant change will be found between

phase A and B trends. The first step in data analysis will be to plot findings according to the graph presented in Figure 2. Change in level and amount or variability can then be visually examined. The appearance of possible trends will guide decisions regarding the appropriate statistics for data analysis. Any possible trend in the baseline data will be confirmed with the C and Z statistic. Once a trend is confirmed, celeration lines will be analyzed to identify significant change from phase A to B. If there is no significant trend in the baseline data, then a 2 SD band and/or binomial test can be used to identify significant change from phase A to B. Another option for confirming significant change from phase A to phase B, given that there will be an equal number of data points in the A and B phases, is the C and Z statistic for comparison of trends..

Practical issues to be considered

One practical issue that may impact the truthfulness of the study is the risk that participants may feel a need to report a certain level of FCB that they assume is expected by the researcher or course instructor, particularly as the course instructor will also be grading their course assignments and determining eligibility for certification. Therefore, the course instructor must be blind to the MPOC results and possibly to the identity of the study subjects to reduce biases both from the instructor and participants. In order to allow that, an uninvolved research assistant will be responsible for all study-related communicating with participants. The role will include explanation of confidentiality (and lack of instructor knowledge of their participation or reports) and data collection.

Another important issue is to assure the collection of at least 8 data points at baseline and intervention phases in order to perform statistical testing. Therefore,

sufficient time should be allotted for baseline data collection prior to scheduled course start for make-up in the case of missing data points.

Chapter 5: Funding Plan

Family-centered care (FCC) is recommended as "best practice" across a variety of pediatric service settings. However, providers in multiple healthcare fields report an ongoing struggle with translations of FCC concepts into their practice (Bamm & Rosenbaum, 2008; Graham, Rodger, & Ziviani, 2008; Lawlor & Mattingly, 1998; MacKean, Thurston, & Scott, 2005). The proposed program, *Better Together* (BT), was developed to address this need and to better prepare providers to effectively integrate best practice FCC in their daily interactions with clients. BT is an eight week, on-line professional development course offered to interprofessional practitioners and administrators who work with children and their families. The course content and structure are based on findings from an extensive literature review that critically examined factors that hinder and facilitate implementation of a FCC approach (American Academy of Pediatrics, 2012; King & Chiarello, 2014), and best practices in professional development education (Brown & Woods, 2012; Dunst, Trivette, & Deal, 2011; Knowles, Holton III, & Swanson, 2011).

The presented funding program reflects resources and funds required for BT course development, evaluation, delivery, and dissemination. Available local resources, budgets of needed resources, and potential funding sources are described next. Funding opportunities are presented according to two phases of BT course implementation. In Phase 1, the pilot phase, the BT course will be evaluated to examine the effect the course on enhanced implementation of FCC and overall quality of care provided by course participants. The implementation and evaluation study may take place in the Tri-city area

of Michigan, USA, and/or in Haifa, Israel. In Phase 2, BT will be offered as a commercial continuing education (CE) professional development course sponsored by an approved CE company (such as Dynamic Learning On-line Inc. or Educational Resources Inc.) or by an open on-line education company (such as the Open School of the Institute for Healthcare Improvement).

Available local resources

The following local resources have expressed their willingness to make pro bono (with no cost) contributions to the BT project:

- Volunteer friends and colleagues, including practitioners working with families (novice and experienced), administrators, and family members of clients, who will review and provide feedback on different aspects of the course.
- Ellen Cohn, ScD, OTR/L, has been essential in the conceptualization and creation of the course content and structure.
- Poonam Kumar, PhD, a colleague and an expert in on-line teaching, will review the course to provide guidance regarding course design.
- Yochai Gafni, MBA, expert in strategic planning and marketing in the global market, will provide guidance on marketing and dissemination approaches.
- Saginaw Valley State University Information Technology support team will provide guidance and support using educational software and technologies needed for the course.

Resources needed

Course development, instruction, publication, and delivery require additional

resources, as presented in Table 5.1.

Table 5.1: *Budget Needs*

Resource	Phase 1 *(pilot)*	Phase 2 *(sponsored by on-line teaching company)*	Explanation
Course developer	0.00	0.00	Course and material development has been done as part of the occupational therapy doctorate studies and will continue according to course feedback and new evidence on FCC. Ongoing course development will be a component of the course instructor job description and compensation.
Course instructor	$4,800.00		In Phase 1, course instruction, grading, and content development is estimated at $30.00 per hour x 10 weekly hours for each of the 8 weeks of the course ($2,400.00 per course). In phase 2, course instructor compensation will be paid by CE company as a percentage of registration proceeds.
Consultation	0.00 $500.00 $1,000.00	0.00	Consultation provided by local resources at no cost. On-line course development and adaptation to different learning styles will be provided by Dr. Nancy Doyle, 4 hours at $125.00 = $500.00. A copy editor will be hired to review all course materials in order to enhance the quality and clarity of content, and suggest additional teaching exercises and activities; 10 hours at $100.00 = $1000.00
Equipment	0.00	0.00	Equipment needed for on-line teaching includes a personal computer and webcam (available to instructor)
Software	0.00		A free teaching platform, UDEMY teach (https://www.udemy.com/teach/course-

			creation/), will be used for pilot course delivery. Various teaching technologies are available with no cost (for example, Jing, Animoto, and Google on-air). In Phase 2, the teaching platform and software will be provided by CE company.
Communication	0.00 $186.00	0.00 0.00	Written communication with course participants will be conducted via email. Verbal and visual communication will be conducted via video conferencing using GoToMeeting.com with a monthly subscription of $49.00 per month, 2 months per course, at $98.00 per course. Communication during Phase 2 will be done via CE company purchased resources.
Supplies and materials	0.00	0.00	No physical supplies needed for the course.
Travel	0.00	0.00	No travel is required for on-line course implementation
Rental of facilities	0.00	0.00	No facilities are required for course implementation.
Evaluation	$2,276.00		Program evaluation costs: -Focus-group facilitator: 10 hours at $100.00 = $1000.00 -Research assistant salary: 50 hours at $15.00 = $750.00 -Survey software one year subscription (Survey Monkey): $228.00 -Assessment tool purchase (Measure of Processes of Care): $298.00
Dissemination		$3,650.00	In phase 2, the majority of marketing and promotion of the course will be conducted by CE company professionals. Dissemination via scholarly and professional venues will be conducted by the course developer. Please see breakdown in Chapter 6, Table 1.
Total	$8,762.00	$3,650.00	

Funding Opportunities

As presented in Table 5.1, Phases 1 and 2 of the course implementation will require different funds. Therefore, each phase requires separate identification and application to potential funding sources. Sources for the pilot phase may include grants from federal, foundation, institutional, and local sources, as well as fundraising using crowdfunding. Phase 2 will be funded using participant's paid course tuition. Course participants may use personal continuing education funds to cover their participation costs.

Table 5.2: *Funding Opportunities*

Funding type	Funding source and description
Phase 1: Pilot	
Federal grants	US federal grants offered by the Health Resources and Services Administration and the Agency for Healthcare Research and Quality, are designed to support research focused on health quality. Specific grants that may be applicable for the evaluation of the Better Together (BT) course include: • HRSA-15-054: Primary Care Training and Enhancement Awards: this grant is intended "to strengthen the primary care workforce by supporting enhanced training for future primary care…[O]utcomes may include change in quality of care provided by graduates/program completers; patient service provided by trainees and faculty". (http://www.grants.gov/search-grants.html?fundingCategories%3DHL%7CHealth • HRSA-15-074: Maternal and Child Health (MCH) Interdisciplinary Education in Pediatric Pulmonary Centers (PPCs): "The purpose of the PPC program is to improve the health status of infants, children, and youth with chronic respiratory conditions" and to engage with families "as full partners to support family-centered practice, policies, and research" (http://www.grants.gov/search-grants.html?fundingCategories%3DHL%7CHealth).

	• K12 HS22986-01: Mentored Career Development for Child and Family Centered Outcomes Research, is focused on creating a "learning health system" to improve child health by work directly aligned with the expressed needs of patients, providers, and healthcare systems on child and family centered practices (http://gold.ahrq.gov/projectsearch/grant_summary.jsp?grant=K12+HS22986-01).
State grant	• The Michigan Department of Community Health offers health innovation grants to encourage projects that demonstrate an innovative approach to improving the efficiency and effectiveness of the delivery of Michigan's health services. BT offers an innovative family-centered approach for the local community that has been demonstrated to improve healthcare outcomes and satisfaction with services. Applicants for this grant are encouraged to provide matching funds in the form of a cash or in-kind match for their project, and therefore this grant would be applicable along with additional fundraising (http://www.michigan.gov/mdch/0,4612,7-132-2946_43858-335463--,00.html).
International Collaboration grant	The Israeli Ministry of Health offers several annual grants to support health related research that is conducted in collaborations from researchers from overseas to enhance the quality of care. BT was developed in the US and supported by an advisory board in the US and Canada. Implementation in Israel will realize the Ministry of Health's vision of worldwide collaboration. (http://www.health.gov.il/Subjects/Research/Pages/Research-Foundation.aspx).
Foundation grants	Application for foundation grants dedicated to promote health services: • The Bloorview Children's Hospital Foundation has funded several intervention programs and studies focused on promotion of family centered care (i.e., King et al., 2011; Law et al., 2005), and therefore may have an interest in supporting BT which was developed according to lessons learned from previously founded projects (http://www.hollandbloorview.ca/Home#). • Large healthcare insurance companies, such as Aetna and Blue Cross Blue Shield of Michigan, as well as Maccabi Healthcare in Israel, have foundations that are dedicated to fund endeavors that research and promote wellness, health and high-quality health care. Insurance companies may find BT an appealing project as there is evidence that effective implementation of FCC saves cost in healthcare and malpractice lawsuits. (http://www.aetna-foundation.org/foundation/index.html;

	http://www.bcbsm.com/content/dam/microsites/foundation/investigator-initiated-program.pdf; http://www.maccabi4u.co.il/25805-he/Maccabi.aspx). • The mission of the Rotary foundation is to advance world understanding, goodwill, and peace through the improvement of health, the support of education, and the alleviation of poverty. FCC has been suggested as a way to enhance provider's understanding, support, and quality of delivered care, especially to populations living in poverty and are prone to greater heath disparities (Andrulis, 2005; Berdahl et al., 2010; Lindsay, King, Klassen, Esses, & Stachel, 2012) (https://www.rotary.org/myrotary/en/learning-reference/about-rotary/rotary-foundation).
Local foundation	• Local foundations in the tri-city area in Michigan offer grants to support local endeavors for the promotion the health of the community. Among the major foundation is the Alden & Vada Dow Foundation with its primary aim to enhance the quality of life of Michigan residents through funding of programs in the areas of the arts, the environment, education, health and human services, and youth programs. BT aimes to enhance the quality of life of the children of Michigan, their families, and healthcare providers working with them (http://www.avdowfamilyfoundation.org/). • An active and influential local foundation in Israel is the Boston-Haifa Connection, which funds a variety of endeavors and initiatives annually, including support programs for young parents (http://www.haifa-boston.com/index.php?option=com_k2&view=item&layout=item&id=14&Itemid=9&lang=en).
Professional organization foundation	• The American Occupational Therapy Foundation (AOTF) awards Intervention Research Grants as part of its mission to "advance the science of occupational therapy to support people's full participation in meaningful life activities". BT offers a client-centered and interprofessional intervention fully aligned with the core values and guiding principles of occupational therapy, and can promote our role as leaders in supporting health and participation of children and their families (http://www.aotf.org/scholarshipsgrants/aotfinterventionresearchgrantprogram).
Internal institutional grant	Different institutions offer internal grants to support projects and personnel that will promote the reputation and standing of the institution. My place of employment, Saginaw Valley State University, offers an Internal Research Grant for full time faculty for the purpose of research leading to publication or presentation.

	Additionally, an institution that is interested in implementing BT for enhancing quality of care may utilize internal grants: • Covenant Healthcare is one of the main health providers in the tri-city area region, and was identified as a potential location to conduct the pilot study of BT. Covenant Foundation was established to support projects within the hospital such as programs for improvement of quality of care and patient satisfaction (http://www.covenanthealthcare.com/Main/CovenantFoundation.aspx • Rambam Healthcare Campus is a major hospital in Haifa, Israel, and is a second potential location for the pilot study. Studies focused on quality of care conducted at Rambam are often funded by the Technion R&D Grant (http://www.trdf.co.il/eng/fundinfo.php?id=2404).
Fundraising	Crowdfunding is a process by which individuals pool money and other resources to fund different projects. Different crowdfunding platforms provide a platform for promoting the project and pledging funds. This platform can be used to match or supplement grant funding if needed. Examples of companies that have supported projects similar to BT are FundAnything (FundAnything.org), Experiment (experiment.com), and Ralley (ralley.org).
Phase 2: commercialized course	
Course tuition	Tuition collected from participants will be used to cover course implementation costs. Remaining funds will be used for dissemination and ongoing course development.
Continuing education funds	Many organizations offer funds for professional development and training: • Individual funds: participants may apply for individual continuing education allowance to pay for registration. • Departmental funds: departments may purchase BT as a course for a group of employees as a means to train staff and enhance quality of care in the unit.

Chapter 6: Dissemination Plan

Family-centered care (FCC) is recommended as "best practice" across a variety of pediatric service settings. However, providers in multiple healthcare fields report an ongoing struggle with translations of FCC concepts into their practice (Bamm & Rosenbaum, 2008; Graham, Rodger, & Ziviani, 2008; Lawlor & Mattingly, 1998; MacKean, Thurston, & Scott, 2005). The proposed program, *Better Together* (BT), was developed to address this need and to better prepare providers to effectively integrate best practice FCC in their daily interactions with clients. BT is an eight week, on-line professional development course offered to interprofessional practitioners and administrators who work with children and their families. The course content and structure are based on findings from an extensive literature review that critically examined factors that hinder and facilitate implementation of a FCC approach (American Academy of Pediatrics, 2012; King & Chiarello, 2014), and best practices in professional development education (Brown & Woods, 2012; Dunst, Trivette, & Deal, 2011a; Knowles, Holton III, & Swanson, 2011). BT course implementation will take place in two phases. In phase 1, the pilot phase, BT course will be evaluated to examine the effect the course on enhanced implementation of FCC and overall quality of care provided by course participants. This phase may take place in the Tri-city area of Michigan, USA, or in Haifa, Israel. In phase 2, BT will be offered as a commercial continuing education (CE) professional development course sponsored by an approved CE company (such as Dynamic Learning On-line Inc. or Educational Resources Inc.), or by an open on-line education company (such as the Institute for Healthcare Improvement Open School).

Dissemination activities will begin in phase 2, following pilot study completion and confirmation of the course's utility to enhance the quality of care provided by participants.

The presented dissemination plan will first specify the dissemination goals and target audiences. Second, the main interests and needs of each target audience will be discussed, followed by the appropriate key messages tailored for the audience's distinct interests and challenges. Next, sources to deliver these messages and activities to best communicate the key messages will be identified. Finally, a budget and evaluation plan for dissemination activities will be presented.

Dissemination Goals

Long term goal: Improve the quality of care and client outcomes by integration of family-centered care into everyday practice.

Short term goals:

- BT course will be implemented and piloted with a group of 20 participants. The Pilot phase course practitioners will show evidence of having enhanced confidence and proficiency in implementing best practice FCC in everyday interactions with clients.
- Course evaluation outcomes will be disseminated via scholarly healthcare communication (conference presentations, peer-reviewed article) and professional trade magazines, websites, and social media.
- Course will be commercially offered via sponsorship of a CE-approved company to a growing number of providers.

- Ongoing course evaluation will be conducted to improve the course and monitor outcomes for continued dissemination.

Target Audience

The dissemination plan is designed to reach two main audiences. The primary target audience consists of providers (i.e. practitioners and administrators) who work with children and their families. The secondary audience includes organizations providing pediatric healthcare services.

Primary audience: practitioners and administrators. Although many practitioners and administrators agree that FCC is important and beneficial, professionals in multiple healthcare fields are reporting an ongoing struggle with the implementation of the core principles of family-centered care in their practice. (Bamm & Rosenbaum, 2008; Graham, Rodger, & Ziviani, 2008; Lawlor & Mattingly, 1998; MacKean et al., 2005). Some challenges are related to a lack of training and expertise in FCC (Campbell, Chiarello, Wilcox, & Milbourne, 2009; King et al., 2011). Other challenges result from an increasing administrative pressures for productivity and revenue that conflict with independent clinical judgment for appropriate patient care (AOTA, APTA, ASHA, n.d.). Consequently, this audience may be interested in ways to develop strategies that increase the effectiveness of their interventions while maintaining and promoting the appropriateness of care and reducing stress and burnout. FCC implementation has been found to increase practitioner satisfaction and reduce burnout (Hemmelgarn, Glisson, & Dukes, 2001).

Knowles' theory of adult learning (Knowles et al., 2011) is also helpful to better

understand the needs and preference of any potential group of course participants. Knowles and his colleagues (2011) identified six principles of adult learning: (1) Adults are internally motivated and self-directed; (2) Adults bring life experiences and knowledge to learning experiences; (3) Adults are goal oriented; (4) Adults are relevancy oriented; (5) Adults are practical; (6) Adult learners like to be respected. Additionally, Dunst and his colleagues (Dunst, Trivette, & Deal, 2011) reported that practitioners perceive more training time as being more beneficial for and influential on their practice. These elements are all integrated into the BT course to best meet the needs of the professional adult learner.

Finally, practitioners report that participation in professional development courses and workshops is often restricted due to obstacles such as timing and scheduling, location and commute, and costs associated with time off and travel to courses. On-line learning , as offered in BT, presents an ideal solution for these problems while providing high quality learning opportunities (Brown & Woods, 2012; Chen, Klein, & Minor, 2009; MacPherson-Court, McDonald, Drummond, Kysela, & Watson, 2005). The components that shape the target audiences' needs and preferences were infused to the key messages below:

Key messages.

1. Family-centered care is the best practice when working with children and their families and it yields better health and wellness outcomes to clients, and greater work satisfaction for practitioners and administrators.

2. BT is an on-line course that will teach you the practicalities of how to implement family-centered essentials into your everyday work, according to your individualized professional development goals, in a flexible format to fit your busy life.
3. BT presents the most recent literature and evidence from the highest authorities in the field of family centered care, offered in a dynamic, interactive, and learner-oriented stimulating course.

Sources/Messengers. The most credible spokespersons will be previous BT course participants. An honest and credible testimony regarding the personal and professional benefits of the course and the level of satisfaction with the content, structure and instruction may be the most influential on making a decision to register and commit to the course. It will therefore be important to collect testimonials through the pilot phase and beyond. In addition to individuals, organizations that may communicate the course value or advertise it include three groups:

(1) Professional associations that advertise approved continuing education programs. These include professional associations such as American Occupational Therapy Association (AOTA), American Speech-Language-Hearing Association (ASHA), American Physical Therapy Association (APTA), National Social Work Association (NSWA), and others.

(2) Interprofessional FCC organizations, such as CanChild Centre for Child Disability, Sensory Processing Disorder Foundation, Beach Center, Institute for Patient and Family Centered Care, Institute for Healthcare Improvement, Interdisciplinary

Council on Child Development and Learning, and the Interprofessional Education Collaborative. Other organizations include professional websites and forums such as OT4OT, and parent-professional forums that are dedicated for specific diagnoses such as SPD, autism, coordination disorders.

(3) Approved continuing education providers, accredited by various professional associations, which have a marketing department to conduct a market analysis and advertise accordingly.

Dissemination activities. Activities are presented according to the chronological sequence of implementation. All presented activities will be conducted by the course developer, with supports from local resources (see chapter 5) and collaborators.

1. Person-to-person: presentations in conferences, such as International Patient and Family Centered Care; Annual IHI International forum on Quality Improvement in Health care; the Interdisciplinary Council on Development and Learning.
2. Written information: a paper or electronic brochure including key messages will be developed and mailed / emailed to potential participants.
3. Electronic media: create short videos starring parents, children and past course participants working together to present FCC and the course, to be posted in a designated YouTube channel. Links to the YouTube channel and videos will be posted in different professional and parenting group websites and in all promotional materials.
4. Person-to-person: conducting short workshops for workplace teams as an introduction to the full course.

5. Written information: Advertisement of BT in a newsletter / journal published by a professional group.
6. Written information: Publish an article in a peer-reviewed journal describing the utility of the BT course for quality of care within 6 months of phase 1 completion.

Secondary target audience: parents of children receiving healthcare services. Parents want the best care and outcomes for their child and family. Qualitative studies have shown that parents want to collaborate with the healthcare team to decide and implement a dynamic care plan to best fit their family's needs (MacKean et al., 2005). Parents value health-care providers who cared about them, who understand that each child and family is unique, and who understand that a collaborative relationship involves negotiation of the respective roles played by each partner in the relationship (MacKean et al., 2005). When parents are involved in treatment, the intervention is better aligned with their needs and priorities, and results in a greater level of satisfaction (American Academy of Pediatrics, 2012). Often parents still expect a medical model approach in which the healthcare professional is the expert and authority to be obeyed without question (Lindsay, King, Klassen, Esses, & Stachel, 2012). However, many parents today do recognize the important role of their involvement and advocacy on the health outcomes of their child and family.

Key messages.

1. Family-centered care is the best practice for children's healthcare. That means that you, the parents, should feel encouraged to express your thoughts, concerns, and priorities, and receive a respectful and collaborative response to fit your

family's unique needs. Children and families that receive family-centered care report better health outcomes and higher levels of satisfaction with the care they received.

2. You, as parents, have an enormous impact on your child's care. By encouraging your healthcare provider and the administration to be family-centered you will enhance the quality of care that your child receives, as well as the care of other children and families who get services in the same place.
3. Although providers have your best interest in mind, sometimes it is difficult for them to be truly centered on your family. If that is the case, they can obtain training to enhance their expertise. The training is convenient, inexpensive, and will lead to higher levels of satisfaction both for families and providers. As a parent and a healthcare consumer you can suggest such training to providers or administrators.

Sources / messengers. The primary spokespersons for this target audience are other parents of children with similar healthcare needs. Parent-to-parent support is a process by which parents share their knowledge and expertise to support other families who are facing similar issues (Law, et al., 2003). Experienced parents are often perceived as more credible sources than providers because they share similar first-hand experience and can establish a bond of fellowship and empowerment (Law, et al., 2003). Parent-to-parent support can take place informally or formally, face-to-face or virtually, via numerous websites, forums, and Facebook groups that offer parenting information regarding healthcare. These relationships offer an opportunity for parents to share their

experiences of FCC and empower each other to expect it.

A second credible source is providers who practice from an FCC approach and advocate for it. Parents who experience FCC typically value it and continue to seek it. Providers can empower parents to expect and demand FCC in all of their child's healthcare settings.

Dissemination activities. Dissemination activities are presented according to their priority and chronological order:

1. Person to person: the BT course includes a lesson on parent-to-parent support group. All course participants will be required to identify existing relevant groups to refer their clients to, or to establish new ones. Providers should encourage parents to join appropriate groups and within them share their own experiences with FCC. If parents share their thoughts and experience regarding FCC and how they have obtained it, it may empower other parents to pursue it.
2. Electronic Media: personally join special interest forums, as a parent and provider, to respond to posts regarding relationships with providers, barriers to setting personalized goals, or dissatisfaction with services. The goal will be to empower parents to express their needs and wants with providers or administration and to request FCC. The on-line posts will include links to the BT YouTube channel featuring parents and children describing FCC outcomes and their role in making it happen. Examples of forums include websites for the general population (for example, Babycenter.com, Webmed.com), and special interest groups (for example, asdfriendly.org for parents of children with

Asperger's syndrome, and dystalk.com for parents of children with Dyspraxia / Developmental Coordination disorder).

3. Person to person: BT will include a module on advocating for FCC to prepare and encourage all course participants to become ambassadors of FCC within their social networks (in person and on-line) and with their clients. Encouraging providers to engage in the suggested on-line forums and special interest groups will also promote their professional standing and help with their self-marketing as experts.
4. Written communication: develop brochures to distribute in healthcare practices that describe FCC and its benefits, guiding parents on how to become more active and involved in the decision-making regarding their child's care.

Tertiary target audience: organizations providing pediatric care. Workplace factors have a major impact on the development of clinical behaviors and expertise including implementation of FCC principles (King et al., 2010). Healthcare organizations seek opportunities for growth, efficiency and profitability, typically in a competitive environment. Many organizations recognize the importance of the enhancing the human capital of their employees and the satisfaction of their customers as a means to realize their vision and strategic plans. Therefore, organizations may have an interest to promote their employees and customers satisfaction utilizing cost-effective and evidence-based ways: FCC. Another important aspect that impacts healthcare business is healthcare policies. Current healthcare policies in the US emphasize the importance of the patient-centered medical home delivery model which is designed to improve quality of care

through team-based coordination of care, treating the many needs of the patient holistically at once, increasing access to care, and empowering the patient to be a partner in their own care (U.S. Department of Health and Human Services, Health Resources and service administration, n.d.). FCC is an evidence-based approach that is appropriate to meet this significant demand in all pediatric care settings.

Organizations may misperceive FCC to require a greater investment of time in each patient, without feasible results. Therefore, it is important to inform key decision-makers in organizations of the accumulating evidence proving that organizations that correctly integrate FCC into their processes enjoy many positive outcomes, such as improvements in practitioners' job performance, less staff turnover, and a decrease in costs for the organization (Hemmelgarn et al., 2001); enhanced patient safety, reduced risk of medical errors, and improved risk management processes (Johnson, Ford, & Abraham, 2010); better utilization of health services (Kuo et al., 2012); and better communication and relationships associated with decreased numbers, severity, and costs of legal claims (Beckman, Markakis, Suchman, & Frankel, 1994; Levinson, Roter, Mullooly, Dull, & Frankel, 1997). In addition, involving families in key roles in an organization's management was found to yield positive results. Hospitals and community-based services that included family members in key decision-making roles (for example, in institutional quality or safety committees, staff education, program planning, and resource allocating) received high patient, family, and staff satisfaction scores, which translated into a more competitive position in the healthcare marketplace (Britto et al., 2006; Jones, Fournier, & Moore, 2002; Sodomka, Scott, Lambert, & Meeks,

2006).

Key message. Offering and encouraging FCC training to multiple staff (including interprofessional practitioners and administrators) can yield numerous benefits to the organization including enhanced consumer outcomes and satisfaction, enhanced employee satisfaction and retention, reduced costs related to errors, reduction of ineffective use of resources, and reduced law suits. All of these will lead to increasing competitive positions in the healthcare marketplace.

Sources/messengers. Sources of effective spokespeople include the organization's clients (parents) and employees (healthcare providers); other organizations that have experiences success following implementation of BT and FCC; objective evidence (numbers) indicating the cost effectiveness of FCC; professional marketing companies; professional associations; and policy makers. Information from these various sources needs to be brought to the attention of the key decision-makers, in order for them to appraise BTs potential contributions to the organization's mission and strategic plan.

Dissemination activities. Once dissemination activities for primary and secondary target audiences have been successfully implemented (please see the Evaluation section below for indication of "success"), the following activities will take place:

1. Written information: Develop written fact sheet presenting evidence supporting BT with testimonials from families, and providers, and managers sharing their perspective on the value of BT.
2. Person to person: Network to establishing relationships with influential key persons, including professional associations (i.e., AOTA, APTA, ISOT,

CanChild) and policy makers (i.e., representatives in Michigan Health department or the Israeli Ministry of Health) to endorse BT as a recommended program.

3. Person to person: Develop and deliver a presentation ("pitch") to present the BT course, supportive evidence, and how it can support the organization's strategic plan. This may be conducted by the course developer or by a professional marketing company, such as Dynamic Learning On-line Inc., (potentially a distributer of BT) which specializes in marketing directly to businesses.

Budget

The implementation of the dissemination activities requires resources of time and money. The anticipated budget plan includes the financial costs for scholarly dissemination and marketing activities that will be conducted by the course developer. Once the BT course is commercialized and offered by a certified CE company, the majority of marketing and dissemination costs will be covered by the company. However, continued dissemination via scholarly and professional venues will continue by the course developer.

Table 6.1: *Budget Needs*

Dissemination activity	**Cost**	**Explanation**
Conference presentations (i.e. International Patient and Family Centered Care Annual Conference, International forum on Quality Improvement in Health care (held by the Institute for Healthcare Improvement); Interdisciplinary Council on Development and Learning Annual Conference; American Occupational Therapy Association Annual Conference and Expo; or the Biennial Conference of the Israeli Society for Child Development and Rehabilitation)	$2,600.00	Includes two conferences at $1,300.00 each, with expected costs of registration ($300.00) travel ($400.00) accommodations ($600.00)
Brochure / fact sheet / presentation handouts	$50.00	Color printing: $30.00 Mailing to selected healthcare facilities: $20.00
Video clips production	$1,000.00	Included fee for video photographer and equipment for 10 hours at $100.00 an hour
Advertisements in professional magazines and websites	0.00	Coordinated and paid for by CE company
Published peer-reviewed article	0.00	Time only
Written posts in parent and provider groups	0.00	Time only
Networking with others interested in promotion of FCC	0.00	Time only
Total:	$3,650.00	

Evaluation

The overall success of dissemination efforts will be evaluated according to the following criteria:

1. Increasing number of registered learners.
2. 95% satisfaction with course.
3. Reported positive change in daily practice of FCC and client outcomes.

4. Adoption of BT course by a healthcare organization to be offered to employees.

An assessment of the effectiveness of specific dissemination activities include:

- Conference presentations: proposal will be accepted for presentation in two conference.
- Brochure / fact sheet / presentation handouts: will be requested by presentation audiences and by healthcare providers; informational sheets will be used to register for the course.
- Video clips on YouTube channel will receive increasing numbers of views, "likes" (positive feedback), and will be shared in other social media.
- Peer reviewed article: paper will be accepted within 1 year following BT Pilot Phase completion.
- Written on-line posts on FCC: posts will be followed and shared, parents and providers will continue to develop communication threads mentioning elements of FCC as a means to enhance care.
- Networking: relationships with key leaders in the realm of FCC will be initiated and maintained through different collaborative projects.

Chapter 7: Conclusion

Family-centered care (FCC) is recommended as "best practice" across a variety of pediatric service settings (American Academy of Pediatrics, 2012). Although there is strong research evidence documenting the benefits of FCC and resources to support implementation of FCC, providers continue to encounter difficulties translating FCC principles into practice (Bamm & Rosenbaum, 2008; Graham, Rodger, & Ziviani, 2008; Lawlor & Mattingly, 1998; MacKean, Thurston, & Scott, 2005). Therefore, the aim of this doctoral project was to understand the barriers to FCC implementation, and to propose solutions to support practitioners to enact FCC on their practice.

Better Together (BT) was developed to educate and empower health care providers to implement and advocate for FCC in their daily interactions with clients. Better Together is an on-line course offering learners a synthesis of the recent literature and evidence related to FCC. Using a flexible format to fit learner's individual needs and goals, the course is designed to enable practitioners to translate family-centered principles into their everyday work.

The BT course content and structure are based on findings from a literature review of core skills and knowledge essential to effectively practice FCC, as well as the best practices for professional development and on-line learning. These essential skills include: effective communication (King & Chiarello, 2014), cultural sensitivity (Beach et al., 2005; Lindsay, King, Klassen, Esses, & Stachel, 2012), collaborative goal-setting and coaching (American Academy of Pediatrics, 2012; AOTA, 2014; King & Chiarello, 2014; Woods, Wilcox, Friedman, & Murch, 2011), and knowledge of strategies to

support families and implement FCC assessments and processes (Dunst, Trivette, & Hamby, 2007; King & Chiarello, 2014). Promoting interprofessional teamwork and supportive workplace policies are also imperative for delivery of FCC (King & Chiarello, 2014). The BT content addresses all of these identified skills.

The BT course design incorporates best practices for professional development based on teaching/learning principles related to adult learning theory (Knowles, Holton III, & Swanson, 2011), reflective inquiry (Cohn, Schell, & Crepaeu, 2010; King et al., 2011; Schell, 2013), and ongoing mentorship (Brockbank & McGill, 2012; Campbell, Chiarello, Wilcox, & Milbourne, 2009; King, 2009a; Myall, Levett-Jones, & Lathlean, 2008). All of these principles can be applied to in-person learning experiences or on-line instruction (Brown & Woods, 2012; Chen, Klein, & Minor, 2009; MacPherson-Court, McDonald, Drummond, Kysela, & Watson, 2005). Most importantly, learning must be meaningful and relevant to the learners (Brown & Woods, 2012; Dunst & Trivette, 2009). Meaningful learning can be achieved by engaging the learner in all stages of learning from self-identified learning goals and their relevance to daily practice, through implementation and self-appraisal of skills, and to planning of future learning goals. Instruction must include multiple options for practice and implementation of FCC behaviors in different settings. Dunst, Trivette, & Deal (2011) recommend that programs, provide ongoing mentoring to support continued learning with a dosage of at least 10 hours. All of these elements were incorporated into the BT course design and structure.

Family-centered care yields better health and wellness outcomes for clients, and greater work satisfaction for practitioners and administrators (American Academy of

Pediatrics, 2012). Family-centered collaborative care is a fundamental concept in occupational therapy (AOTA, 2013, 2014), and is now more important than ever with the emergence of healthcare policies guided by the Affordable Care Act and Patient Centered Medical Home. These policies highlight the value of patient- and family-centered collaboration for quality care. Expertise in FCC will enable providers to shape service delivery and the environments in which services are provided.

Summary

Family-centered care goes beyond client-centered care and requires attention to multiple interacting factors. It is recommended that providers and organizations that offer healthcare services to children and their family evaluate their ability to provide respectful, personalized, culturally sensitive services that include effective information exchange for empowered decision making, and utilize the family's strengths. Better Together offers providers an opportunity to gain the knowledge and confidence needed to enact FCC principles to deliver quality care that benefits families, providers, and organizations.

Appendix A: Evidence to Support the Proposed Explanatory Model

1. Evidence to understand and explain family-centered care:
- **1.1. Is there evidence to support a systems perspective for FCC, and the relevance of the systems presented in the explanatory model (family, professional, organizational policies and overall cultural and societal perceptions) to FCC enactment?**
- **1.2. Is there evidence identifying the essential features of FCC, and what is considered good/effective FCC?**

Reference	Report type	Study design	Key findings	Application
Committee-on-hospital-care-and-institute-for-patient-and-family-centered-care. (2012). Patient- and family-centered care and the pediatrician's role. *Pediatrics, 129*(2), 394-404.	Review	Extensive literature review examining over 200 studies. This is AAP's policy statement which specifically defines the expectations of patient- and family-centered care.	Essential components of FCC: 1. Listening to and respecting each **child and his or her family** *(indicating Microsystems)* 2. Flexibility in **organizational policies**, procedures, and **provider practices** so services can be tailored to unique client and family's needs and **cultural background** *(indicating exosystem and macrosystem).* 3. Sharing information. 4. Providing and/or ensuring formal and informal support. 5. Collaborating with patients and families at **all levels of health care**: (direct care, education, policy making, program development, implementation, facility design) *(indicates importance of a multi-level approach)* 6. Recognizing and building on the strengths.	Article provides information regarding consensus of main FCC components according to AAP. These main components further support the main causal factors presented in the proposed doctoral explanatory model.

Reference	Report type	Study design	Key findings	Application
King, S., Teplicky, R., King, G., Rosenbaum, P. (2004). Family-centered service for children with cerebral palsy and their families: a review of the literature. *Seminars in pediatric neurology, 11*(1), 78-86.	Review	Overview of FCC, definitions, benefits, and ways to enhance FCC enactment.	Essential components of FCC: 1. Parental involvement in decision making. 2. Collaboration and partnership. 3. Mutual respect. 4. Acceptance of the family's choices. 5. Support. 6. Focus on strengths. 7. Individualized and flexible service delivery. 8. Information sharing. 9. Family empowerment.	This article further supports main FCC components for this doctoral project to follow. Authors describe assessment tools (self-assessment and parent assessments) to measure quality of provided FCC.
Dunst, C. J., Trivette, C. M., & Hamby, D. W. (2007). Meta-analysis of family-centered helpgiving practices research. *Mental retardation and developmental*	Meta-analysis on research on the relationship between FCC helpgiving and different aspects of parent, family, and child behavior and	47 studies which together included more than 11,000 participants from seven different countries. The meta-analysis was guided by a practice-based theory of family-	FCC is characterized by 1. practices that treat families with dignity and respect. 2. information sharing so families can make informed decisions. 3. family choice regarding their involvement in and provision of services. 4. parent/professional collaborations and partnerships as the context for intervention.	This article further supports main FCC components for this doctoral project to follow.

Reference	Report type	Study design	Key findings	Application
disabilities research reviews, 13(4), 370-378.	functioning.	centered helpgiving.		

2. Evidence to support the understanding of the term Family:

2.1 **Is there evidence that the values (and cultural background) that families and parents bring to the encounter impact if the encounter is family-centered?**

Reference	Report type	Study design	Key findings	Application
Coker, T. R., Rodriguez, M. A., & Flores, G. (2010). Family-centered care for US children with special health care needs: who gets it and why? *Pediatrics, 125*(6), 1159-1167.	Survey of 38,902 households with a child with special needs in 50 states + DC	Bivariate and multivariate logistic regression analyses of data from the 2005–2006 National Survey of children with special health care needs; The goal was to examine racial/ethnic and language disparities in family-centered care (FCC) and in FCC components for children with special health care needs.	Survey results indicate significantly lower odds of FCC provision for Latino, African-American, and other backgrounds, compared with white children, and for children in households with a non-English primary, compared with those in households with English as the primary language. These disparities persisted after adjustment for child health, socioeconomic factors, and access to services. Parents in these groups reported lower scores on provider performance compared to white parents for feeling that providers spent enough time, provided culturally sensitive care, listened carefully, provided needed information, and helped them feel like a partner in care.	This study provides alarming evidence of the impact of culture/ethnic background on an FCC and occupational injustice. Authors recommend enhanced time for therapeutic encounters and enhanced cultural sensitivity.

Reference	Report type	Study design	Key findings	Application
Lindsay, S., King, G., Klassen, A. F., Esses, V., & Stachel, M. (2012). Working with immigrant families raising a child with a disability: challenges and recommendations for healthcare and community service providers. *Disability and Rehabilitation, 34*(23), 2007-2017.	Qualitative study	In-depth interview with 13 providers working with immigrant families raising a child with a disability	Providers reported challenges providing care to immigrant families raising a child with a disability due to: (1) lack of training in providing culturally sensitive care; (2) language and communication issues; (3) discrepancies in conceptualizations of disability between healthcare providers and immigrant parents; (4) building rapport; and (5) helping parents to advocate for themselves and their children. *Recommendations: • providers should engage in training and education around culturally sensitive care to better meet the needs of clients. • More time is needed when working with immigrant families to build trust and rapport. • Clinicians need to be sensitive to gender issues and try to involve both parents in the decision making regarding the care for their child. • Healthcare providers should enhance awareness of resources available in the hospital and in the community.	This study provides evidence of the impact of culture/ethnic background on therapeutic encounters. Authors recommendations can be used in the professional development workshop design.
2.2 Is there evidence that families yield better outcomes when FCC is provided?				
Kuo, D. Z., Mac Bird, T., & Tilford, J. M. (2011). Associations of family-centered	Survey (secondary to 2005–2006 National	Participants: 40,723 families that completed phone interviews, of which 38,915 (96%) had data on receiving FCC.	Odds ratios were used to describe the association between FCC and **family burden**. Overall positive **health** and family outcomes were associated with FCC. Families with FCC reported: • improved health service access	This article provides strong evidence of favorable health outcomes of FCC.

Reference	Report type	Study design	Key findings	Application
care with health care outcomes for children with special health care needs. *Maternal and child health journal, 15*(6), 794-805.	Survey of Children with Special Health Care Needs)	Receipt of FCC was determined by five questions regarding how well health care providers addressed family concerns in the prior 12 months. *Family burden* was measured by reports of delayed health care, unmet need, financial costs, and time devoted to care; health status, by stability of health care needs; and emergency department and outpatient service use.	• fewer direct caregiving hours • reduced financial burden. • decreased odds of delayed medical care and unmet service need during the previous 12 months • improved care coordination and fewer delays of received care which may have translated into more appropriate utilization of services. • greater odds of receiving each of 18 needed services, including preventive care, specialty care, dental care, and mental health care; prescription medications, therapies, home health care, and medical supplies; and technology aids, including eyeglasses, hearing aids, mobility aids, and communication devices. • Family-centered care was found to be positively associated with stable child health status and decreased emergency room utilization.	
Kuhlthau, K. A., Bloom, S., Van Cleave, J., Knapp, A. A., Romm, D., Klatka, K., . . . Perrin, J. M. (2011). Evidence for family-centered	Systematic review	Twenty-four studies met the review criteria. Eight were cross-sectional studies from the National Survey of Children With Special Health Care Needs, and 7 were reports of randomized, controlled trials.	Authors found positive associations of FCC with improvements in efficient use of services, health status, patient satisfaction, access to care, communication, systems of care, family functioning, and family impact/cost. There was little available evidence for cost effectiveness and transition out of service.	Article provides evidence to support health outcomes associated with FCC.

Reference	Report type	Study design	Key findings	Application
care for children with special health care needs: a systematic review. *Academic pediatrics, 11*(2), 136-143. e138.				
Bailey, D. B., Raspa, M., & Fox, L. C. (2012). What Is the Future of Family Outcomes and Family-Centered Services? *Topics in Early Childhood Special Education, 31*(4), 216-223.	Literature review / opinion/ critical appraisal of topic	Authors discuss challenges and gaps in measuring and reporting family outcomes, program efficacy, and accountability evaluation	"Understanding, promoting, and measuring outcomes for families of young children with disabilities have been relatively ignored" The authors show that early intervention and preschool programs are not held accountable for family outcomes; instead, they are limited only to showing that families are **satisfied** with services, with little else. Authors suggest several lines of work needed to advance the field toward making an informed policy decision about documenting family benefit.	Lack in non-health related outcomes: This is important when considering how outcomes and benefits are measured and demonstrated in different treatment settings.

3. Evidence to understand health care providers:
3.1. Is there evidence that providers experience difficulties implementing family-centered care?

Reference	Report type	Study design	Key findings	Application
Fingerhut, P. E., Piro, J., Sutton, A., Campbell, R., Lewis, C., Lawji, D., & Martinez, N. (2013). Family-centered principles implemented in home-based, clinic-based, and school-based pediatric settings. *American Journal of Occupational Therapy, 67*(2).	Qualitative study (Grounded theory)	28 OTR interviewed in three different settings: home based, school based, and clinic based.	Main barriers to FCC implementation result from multiple systems and the interactions among them. Therefore FCC is manifested differently in each setting. Factors that impact FCC implementation include: (1) characteristics of the family: language, socioeconomic status, culture, and personal stressors. (2) characteristics of the practice setting: work culture, time and schedules, agency specialty and types of goals set for a child.	FCC implementation will need to be specifically tailored to each setting where program will be implemented (there is no "one-size-fits-all service delivery model").
Campbell, P. H., Chiarello, L., Wilcox, M. J., & Milbourne, S. (2009). Preparing therapists as effective practitioners in early intervention. *Infants & Young Children, 22*(1), 21-31.	Literature Review	A discussion of OTs, PTs, and SPLs preparation to work in EI settings. Authors cite multiple surveys.	-Authors claim that pre- and post-graduate preparation for FCC provision in Early Intervention (EI) settings is inadequate. -OTs, PTs, and SPL report lack of confidence and preparation for FCC implementation even though they are mandated to partake in pre-professional and post-professional training. -Reasons for challenges in educating therapists as well as suggestions are discussed: In **pre-professional education**, lack of time and recourses, as well as the load of credits and fieldwork obligations limits student exposure and formal	Article highlights the importance of supervision/mentoring for change in practice, beyond one-day workshops. According to recommendation, OTD project should include a fieldwork experience to promote better

Reference	Report type	Study design	Key findings	Application
			preparation to work with families. Authors cite evidence of benefits derived from family observations, with related reflective journaling and mentoring. Professionals indicated that most preferred **post-professional education** activities are a "one-shot" training opportunity (such as workshop or conference). While these are important to keep professionals up to date these were not found to lead to significant change in practice. Mentoring, supervision, or expert consultation (e.g. by parents as experts) were seldom reported. Authors recommend that these methods of professional preparation should be further evaluated.	understanding of families.
Bamm, E. L., & Rosenbaum, P. (2008). Family-centered theory: origins, development, barriers, and supports to implementation in rehabilitation medicine. *Archives of physical medicine and rehabilitation, 89*(8), 1618-1624.	Literature Review of FCC theory and practice	Extensive literature review describing foundations and application of FCC.	Ongoing struggles with FCC implementation are experienced by professionals in various health care fields. Questions raised by these professionals include the following: How do they provide essential information to each family? How can they avoid being just "the expert" and become a partner? How will they know when they are expected to guide and when just to listen?	FCC challenges are interprofessional and thus the proposed workshop should address the challenges in an IP approach.

3.2 Is there evidence of mechanisms that enhance effective FCC enactment (such as use of FCC assessments and intervention guidelines, enhanced self awareness and cultural sensitivity, or specific professional development programs)? **3.3 Is there evidence of mechanisms that hinder FCC enactment?**				
King, G., Tam, C., Fay, L., Pilkington, M., Servais, M., & Petrosian, H. (2011). Evaluation of an occupational therapy mentorship program: effects on therapists' skills and family-centered behavior. *Physical and Occupational Therapy in Pediatrics, 31*(3).	Pre-post intervention questionnaires (OT FCC mentorship program) and focus groups	Self- and peer-report measures of family-centered behavior, critical thinking ability, listening/interactive communication skill, and clinical behavior were collected before and after an 11-month facilitated, collaborative group mentorship intervention.	Significant pre–post changes associated with intervention were found on 9 of 12 outcome measures, including information provision, respectful treatment, self-confidence, and listening and clinical skill. Practitioners attributed changes to reflective practice enhanced in mentorship. Changes were not found on the more trait-like variables of open-mindedness, interpersonal sensitivity, and interpersonal skill. Experienced therapists had higher scores than new therapists on most variables, including family-centered behavior, listening skill, and clinical skill.	A peer mentoring program should be included as part of the professional development workshop (to support application into daily practice).
Bamm, E. L., & Rosenbaum, P. (2008). Family-centered theory: origins, development, barriers, and supports to implementation in rehabilitation medicine. *Archives of physical medicine and rehabilitation, 89*(8), 1618-1624.	Literature Review: the development and evolution of family-centered theory as conceptual foundation for contemporary health services	The focus includes key concepts, accepted definitions, barriers, and supports that can influence successful implementation, and discussion of the valid quantitative measures of family-centeredness currently available to evaluate service delivery.	Barriers or supports to FCC enactment can be found in multiple levels and systems, which include 1. Political, managerial, and conceptual factors (e.g. how does an organization / society see care, what is the prominent model of care – medical or social). 2. Financial factors (is it cost effective?). 3. Attitudinal factors within providers (do providers feel confident in their ability to provide FCC, how is it viewed by families).	Factors described in various systems should be assessed and addressed within the OTD project.

Woods, Wilcox, Friedman, Woods, J. J., Wilcox, M. J., Friedman, M., & Murch, T. (2011). Collaborative consultation in natural environments: Strategies to enhance family-centered supports and services. *Language, speech, and hearing services in schools, 42*(3), 379.	Literature review on theory and evidence based practice (EBP) in FCC	This article presents current information on recommended practices related to the delivery of FCC in Early intervention (EI). *although this paper focuses on SPL role in EI, the information presented can be valuable for any professional working with families.	• The authors describe and summarize main models for FCC collaborative work. These various strategies are often used in service delivery approaches described as collaborative consultation (Buysee & Wesley, 2004), coaching (Hanft et al., 2004; Peterson et al., 2007), or participation based (Campbell & Sawyer, 2007). Although the approaches have distinct differences, they also have many similarities that support increased performance and outcomes for caregivers. • The authors discuss the principles and applications of adult learning principles supported by EBP, "A bidirectional teaching and learning relationship between the SLP and caregiver is the basis for a truly individualized family-centered approach". The three key Elements according to Donovan, Bransford, and Pellegino (1999): (1) new material is more easily learned by adults when it has direct relevance to the learner's knowledge and interests. (2) for mastery to occur, application in multiple contexts must be provided, with opportunities for evaluation and feedback. (3) self-reflection and goal-setting help adult learners apply their knowledge and skills to novel situations. • Specific techniques such as modeling, reflective listening, questioning, performance feedback, prompting, and problem-solving are specific strategies	Important practical information for intervention guidelines that should be used in proposed workshop.

			described in an emerging literature base. These are explained and demonstrated with helpful examples.	
Dunst, C. J., Trivette, C. M., & Hamby, D. W. (2007). Meta-analysis of family-centered helpgiving practices research. *Mental retardation and developmental disabilities research reviews, 13*(4), 370-378.	Meta-analysis on research on the relationship between FCC helpgiving practices and intervention outcomes.	47 studies which together included more than 11,000 participants from seven different countries. The meta-analysis was guided by a practice-based theory of family-centered helpgiving.	Practices important for effective FCC can be categorized in the following groups: **relational practices** (e.g., active listening, compassion, empathy, collaboration and respect). **participatory practices** (individualized, flexible, and responsive practice to family concerns and priorities; family involvement in achieving desired goals and outcomes).	This information will be incorporated into FCC practices learned in intervention program.

4. Evident to support the understanding of the influencing factors in the workplace:

4.1. Is there evidence of policy implementation that facilitated FCC provision and enhanced client outcomes?

4.2. Is there evidence to indicate that organizations benefit from FCC enactment? (e.g. cost effectiveness, patient satisfaction with services, patient goal attainment, other)?

Reference	Report type	Study design	Key findings	Application
DiGioia III, A. M., Fann, M. N., Lou, F., & Greenhouse, P. K. (2013). Integrating Patient-and Family-Centered Care With Health Policy: Four Proposed Policy Approaches. *Quality Management in Healthcare, 22*(2), 137-145.	Description of a model and implement-tation	Authors describe the Patient- and Family-Centered Care Methodology and Practice (PFCC M/P), designed specifically for health care, to establish and sustain patient-centeredness in any care setting.	While the definitions of patient and family-centered care have evolved, actual models to apply them are lagging behind. The authors present a model for Patient and Family-Centered Care (PFCC) implementation methodology which has been implemented at over 60 different healthcare units with measurable improvement in patient and family care experience and decreasing waste and cost. The steps for implementation of this model are clearly described: **Step 1:** Select a care experience for improvement and define the beginning and end points of the care experience on which to focus **Step 2:** Establish a PFCC Guiding Council **Step 3:** Evaluate the current state through Shadowing, Care Flow Mapping, and other tools from the PFCC Co design Toolkit **Step 4:** Establish a PFCC Care Experience Working Group **Step 5:** Create a shared vision by writing the ideal care story from the patient and family's viewpoint **Step 6:** Form PFCC Project Improvement Teams to close the gaps between the current state care experiences and the ideal.	Article provides evidence and practical suggestions for FCC policies that can be taught to course participants and implemented in the workplace.

Reference	Report type	Study design	Key findings	Application
			Authors specify four optional policy options to support model implementation and discuss the benefits of adopting these policies.	
Committee-on-hospital-care-and-institute-for-patient-and-family-centered-care. (2012). Patient- and family-centered care and the pediatrician's role. *Pediatrics, 129*(2), 394-404.	Literature review		This review presents multiple studies that provide evidence to support cost effectiveness of FCC. Authors agree that to appropriately incorporate FCC concepts professionals must invest extra time, which should be Paid without undue administrative complexities since it will save money in the long run. Examples for cost effectiveness are: • More efficient use of health care resources (e.g., more care managed at home, decrease in unnecessary hospitalizations and emergency department visits, more effective use of preventive care). • A practice environment that enhances professional satisfaction in both inpatient and outpatient practice, and thus reduces turnover. • A possible decrease in the number of legal claims, claim severity, and legal expenses. • A more competitive position in the health care marketplace. *no actual $ values were provided to support quantitative appraisal of cost effectiveness.	Article supports the proposed explanatory model and the importance of organizational policies. Examples provided can be used to illustrate FCC benefits for workshop marketing.
Britto, M. T., Anderson, J. M., Kent, W. M., Mandel, K. E., Muething, S. E., Kaminski, G. M., .	Case study	Program description	Family members were an integral part of safety and quality improvement teams. As a result, the hospital achieved excellence in quality, safety, and patient experience, and was the recipient of multiple honors and awards.	Workshop participants will learn about benefits of including families

Reference	Report type	Study design	Key findings	Application
. . Kotagal, U. R. (2006). Cincinnati Children's Hospital Medical Center: transforming care for children and families. *Joint Commission Journal on Quality and Patient Safety, 32*(10), 541-548.				in quality assurance team.
Sodomka, P., Scott, H., Lambert, A., & Meeks, B. (2006). Patient and family centered care in an academic medical center: informatics, partnerships and future vision. *Nursing and Informatics for the 21st Century: An International Look at Practice, Trends and the Future. Chicago, IL: Healthcare Information and Management Systems Society*, 501-506.	Paper presentation in conference	Program description	Families participated in design planning for the new hospital, and they have been involved in program planning, staff education, and other key hospital committees and task forces. In recent years, this children's hospital has consistently received among the highest patient and family satisfaction scores in a nationwide survey of comparable pediatric facilities. Furthermore, it has demonstrated decreased length of stay, reduced medical errors, and improved staff satisfaction.	Workshop participants will learn about benefits of including families in different committees in their organization / agency.

5. Evidence to understand the influence of societal perceptions

5.1 Is there evidence to indicate how implicit notions impact behaviors and communication between parents and service providers in a community?

Reference	Report type	Study design	Key findings	Application
Harkness, S., Super, C. M., Sutherland, M. A., Blom, M. J., Moscardino, U., Mavridis, C. J., & Axia, G. (2007). Culture and the construction of habits in daily life: Implications for the successful development of children with disabilities. *OccupationalTherapy Journal of Research, 27*, 33S.	Presentation of a model illustrated by two Case studies	Qualitative in-depth interviews conducted in Italy, the Netherlands, and the United States.	Parent ethnotheories (implicit, taken for granted ideas and notions related to culture) lead to specific beliefs that are translated to daily practices and eventually to outcomes both in child development and family function. The authors demonstrate how different ethnotheories lead to different daily practices and priorities. The authors discuss consideration of cultural variability in parents' ideas of "successful development," which either challenges or supports to the work of the occupational therapist.	The article provides evidence to the impact of the Macrosystem, including societal perceptions on FCC. Course participants will be directed to examine and reflect on their own enthnotheories and those of the parents they work with.

Appendix B: Evaluative Summary of Effective Mechanisms to Promote FCC

1. Evidence of best practice and effective FCC mechanisms

Reference	Study design	Theoretical grounding	Active ingredients	Empirical support	Application to OTD project
King, G., & Chiarello, L (2014). Family-centered care for children with cerebral palsy: Conceptual and practical considerations to advance care and practice. *Journal of Child Neurology*. *Journal of Child Neurology*, (August Special Issue Section 4).	Review of evidence from recent research on FCC in various professions.	-FCC refers to how health care professionals interact, provide services, and involve clients and their family in their care. -The key elements of family-centered practice include an emphasis on child and family strengths rather than deficits, facilitating family choice and control, and creating a therapeutic environment that optimizes the development of a collaborative family-provider relationship (Espe-Sherwindt, 2008). -there is still a lack in theoretical understanding of FCC provider behaviors and the contextual support	-Service provider **family centered (FC) behaviors** linked with successful outcomes include communication, information sharing, collaboration, fostering family involvement and choice, building on strengths, and providing support. More information on specific ingredients is presented below:		Remediating challenges and enhancing the mentioned FC behaviors will be the objectives of the intervention. -challenges with implementation include lack of understanding, inadequate guidance to direct providers' behaviors and practices, and marginal implementation (Kuo et al., 2012)

Reference	Study design	Theoretical grounding	Active ingredients	Empirical support	Application to OTD project
		needed to ensure translation of FCC to practice **FCC principles and approach transcend disability type, but may be specific to an organizational system.			
		Joint goal-setting can build a sense of partnership, enhance feelings of competency, and encourage client engagement in therapy (Øien, Fallang, & Østensjø, 2010).	**Collaborative goal-setting** is recognized as a key component of the partnership aspect of family-centered care.	A substantial body of research in psychology demonstrates that clear and functional goals enhance motivation and lead to improved outcomes (Eccles & Wigfield, 2002; Locke & Latham, 2002)	Models mentioned in the article can be useful in promoting collaboration.
		Good communication allows service providers to understand clients' worldviews, needs, and priorities, thereby enabling providers to tailor information, advice, and	**Effective communication** is strongly linked to client satisfaction and is an essential aspect of high-quality care.	Numerous studies point to the integral role of communication in the therapeutic encounter and in establishing a strong, ongoing	Intervention must include training for effective communication

Reference	Study design	Theoretical grounding	Active ingredients	Empirical support	Application to OTD project
		recommendations to the unique circumstances, resources, day-to-day concerns, and routines of families(Bedell, Khetani, Cousins, Coster, & Law, 2011; Gillian King, Baxter, Rosenbaum, Zwaigenbaum, & Bates, 2009). Moreover, Communication can create and define relationships among participants (King, Servais, Bolack, Shepherd, & Willoughby, 2012).		client-practitioner relationship (King & Chiarello, 2014)	
		Patient-centered care is a central notion in the growing literature on interprofessional education and collaborative practice. Services are now being delivered more frequently by interprofessional teams, creating additional complexities to being family-centered.	**Interprofessional teamwork or team coordination.**	Studies indicate increased recognition that collaboration among service providers is necessary for the successful implementation of family-centered care(Wright, Hiebert-Murphy, & Trute, 2010).	Workshop should address core competencies of IPE/IPC.

Reference	Study design	Theoretical grounding	Active ingredients	Empirical support	Application to OTD project
		FCC behaviors influence parental self-efficacy, and parents' self-efficacy can affect children's outcomes (Dunst, Trivette, & Hamby, 2007). According to Dempsey and Keen's FCC model (Dempsey & Keen, 2008), FCC behaviors focused on building parent control attributions (e.g., locus of control, self-efficacy) . These are a central mediating variable. Influencing parents' own judgments and capabilities in providing development-enhancing learning opportunities to their children. Participatory practices are what sets family-centered care apart from other intervention approaches and led to better satisfaction and outcomes.	**Care-giving behaviors:** (a) relational or **interpersonal** practices (active listening, compassion, empathy, and respect ,focus on family strength); b) participatory, instrumental, or **goal-oriented practice**s (informed family choices and family involvement in achieving desired goals) (Dunst & Trivette, 2009a; Forry, Moodie, Simkin, & Rothenberg, 2011).	FCC practices enhance client engagement, parent empowerment, self-efficacy, control, and capacity (Dunst & Dempsey, 2007; Dunst et al., 2007).	Caregiving behaviors can be self-assessed prior to workshop, and participants can set personal goals for development of needed skills. ***Important take away message to emphasize in program: respectful and supportive family-provider relationship is important but not enough on its own to optimize outcomes. Being satisfied with care is often based on the characteristics of people who make the services positive, but this does not always*

Reference	Study design	Theoretical grounding	Active ingredients	Empirical support	Application to OTD project
					translate to good client outcomes, for a host of reasons.
			Supportive work culture: service managers' supportive policies and behaviors enabled therapists to implement collaborative goal setting. The extent to which family-centered care is valued, supported through policies and resources, and expected by administrative leadership appears to be a key determinant of its actualization. Improved **service coordination, interagency collaboration, and integrated systems of care** are needed to effectively FCC (Kuo et al., 2012; Nolan, Orlando, & Liptak, 2007; Wright et al., 2010).	A growing number of studies indicate the importance of organizational culture and administrative factors on service providers' ability to deliver family-centered care (Kuo et al., 2012; Law et al., 2003; Wright et al., 2010)	Participants' work culture should be explored and addressed during the workshop. Learning about how participants can promote FCC culture would be imperative for implementing newly learned FC behaviors.

Reference	Study design	Theoretical grounding	Active ingredients	Empirical support	Application to OTD project
			Hindering factors in the workplace included high caseloads, supervisors who did not support family-centered care as a priority, limited professional development education, and lack of collaborative policies, lack of resources, particularly finances.		
			FCC implementation requires continuity across all aspects of care, from initial contact with a family, through examination, diagnosis, intervention planning, intervention, and discharge from services. Providers should have sufficient opportunities to hold conversations with families to clearly establish the extent and focus of service. Assessments and treatment will be provided according to the agreed upon		These ideas of a continuum should be emphasized in the workshop. Participants should be encouraged to consider how FCC would be enacted in each milestone of the continuum.

Reference	Study design	Theoretical grounding	Active ingredients	Empirical support	Application to OTD project
			goals and expectations. Assessment tools that can be used to evaluate the level of FCC provided include the MPOC.		
Woods et al. (2011). Collaborative consultation in natural environments: Strategies to enhance family-centered supports and services. *Language, Speech, and Hearing Services in Schools*, *42*(3), 379-392.	Review of theory and evidence based practice in FCC *although this paper focuses on SPL role in EI, information presented is highly relevant	Commonly used theoretical models for FCC collaborative work are: • collaborative consultation (Buysee & Wesley, 2004), • coaching (Hanft et al., 2004; Peterson et al., 2007), • participation based (Campbell & Sawyer, 2007). Each approach has distinctive features, but all share similar premise and intention to support increased performance and outcomes for caregivers. Principles of adult learning are presented as key for bidirectional family-professional teaching and learning relationship.	Specific techniques described in collaborative consultation and coaching models include **modeling, reflective listening, questioning, performance feedback, prompting, and problem solving** all specific strategies described in an emerging literature base. These are explained and demonstrated with helpful examples in the paper.		Modeling, reflective listening, questioning, performance feedback, prompting, and problem solving strategies should be introduced and practiced in the OTD intervention

Reference	Study design	Theoretical grounding	Active ingredients	Empirical support	Application to OTD project
Lindsay et al. (2012) Working with immigrant families raising a child with a disability: challenges and recommendations for healthcare and community service providers. *Disability and Rehab*	In-depth interview with 13 providers working with immigrant families raising a child with a disability.		Recommendations for key aspects of training, based on participant's comments: • providers should engage in training and education around culturally sensitive care to better meet the needs of clients. • **More time is needed when working with immigrant families to build trust and rapport**. • Clinicians need to be **sensitive to gender issues** and try to **involve both parents in the decision making** around the care for their child. • Healthcare providers should enhance awareness to resources available in the hospital and in the community.	Providers reported challenges providing care to immigrant families raising a child with a disability due to: (1) lack of training in providing culturally sensitive care; (2) language and communication issues; (3) discrepancies in conceptualizations of disability between healthcare providers and immigrant parents; (4) building rapport; and (5) helping parents to advocate for themselves and their children.	Enhancing cultural sensitivity must be addressed in one the modules/content areas of the program. Recommendations are useful and should be incorporated into program content.

2. Means to prepare professionals to enact FCC

Reference	Study design	Theoretical grounding	Active ingredients	Empirical support	Application to OTD project
King, G., & Chiarello, L. (2014). Family-centered care for children with cerebral palsy: Conceptual and practical considerations to advance care and practice. Journal of Child Neurology.	Review of evidence from recent research on FCC.	The authors suggest several practice models that can be used as a guide to FCC enactment. Their strength is infusing family-centered care principles with ideas about collaborative practice and intervention in real-world settings. The models highlight therapists as collaborators, consultants, facilitators, educators, and coaches.	All models were developed by practitioners, are strength based, relational, and foster change through collaborative goal setting and client empowerment. The Occupational Performance coaching model (Graham, Rodger, & Ziviani, 2009) highlights enablement and interventions in real-world settings. The Transdisciplinary model of solution-focused coaching for pediatric rehabilitation (SFCPeds) (Baldwin et al., 2013) emphasizes am exploration of a preferred future and utilized solution focused strategies rather than collaborative problem solving. Therefore, main methods include working with resources and strategic questions to construct intervention. Foster, Dunn and Lawson (2013) highlight the elements of change by reflection of parent-coach relationship and the child's engagement.	Emerging evidence points to effectiveness of coaching models to assist families to achieve meaningful goals of child's participation and help parents to feel more competent.	These models are very useful and can offer structure and orientation to the workshop.

Reference	Study design	Theoretical grounding	Active ingredients	Empirical support	Application to OTD project
		Theoretical foundations for the role of reflection in expertise development can be found for example in (Cohn, Schell, & Crepaeu, 2010; King, 2009; Schell, 2013).	Reflection on **own beliefs and behaviors** is essential in order to develop expertise as a practitioner (King & Chiarello 2014).	A systematic review examined 29 studies of reflection in healthcare professionals concluded that reflection leads to deeper learning, stronger social connections, and better linkage of theory and practice (Mann, Gordon, & MacLeod, 2009).	Reflective inquiry and development of reflective practice should be included as a main skill to be develop in workshop and subsequent mentoring.
Madsen, W. C. (2013) Applications of Collaborative Helping Maps: Supporting Professional Development, Supervision and Work Teams in Family-Centered	Description of a self-assessment that is useful to enhance reflection, collaboratio n, and goal setting. Case studies illustrate how maps can be	Formal theoretical background is not presented, yet it could be inferred that reflection and collaboration are impacted by cognitive behavioral theories and goal setting theories. It also appears to draw from management/ business models as it resembles a SWOT	The Collaborative Helping Map requires that the **professional or family identify their vision** ("Where do you want to be headed in your life or work?"), **Obstacles** (What gets in the way of your Vision?), **Supports** ("who and what support you in moving towards your vision?") and **Formulating an action plan** ("How can we draw on supports to address obstacles to help you move towards your Vision?").	*no empirical evidence is provided, but there are abundance of examples of application which promotes reflection and collaboration.	The Collaborative Helping Map will be integrated into the workshop as a simple and helpful mechanism that can be used to enhance professional's reflection,

Reference	Study design	Theoretical grounding	Active ingredients	Empirical support	Application to OTD project
Practice. Family Process, 53(1), 3-21.	useful in supervision and working with families.	analysis. Madsen provides multiple examples of application of this tool to conversation with parent and mentoring practitioners.			facilitate discussion and goal setting with parents, and be used and a tool to enhance teamwork and shared vision and goal setting.
Beatson, J. (2006). Preparing speech-language pathologists as family-centered practitioners in assessment and program planning for children with autism spectrum disorder. Seminars In Speech & Language,	Paper describes teaching principles of a grant-funded program to prepare IP/ SLP students for FCC provision for families with a child with ASD	Theoretical foundation not mentioned but there is an abundance of support to incorporation of ingredients: *while this is a "pre-service" program, author indicates that the key elements can be used as a guide for practicing professionals seeking professional development opportunities. The research indicates that the essential training elements	-Family-centered values must be embedded in all aspects of the curriculum in preparing health professionals. **-Families must be involved in the preparation of service providers**, both in the classroom and in the families' own homes: university programs should incorporate ''family faculty'' to teach alongside their regular faculty (see below). -Students must acquire **technical and leadership skills** (assessment and intervention in specific conditions, **interdisciplinary collaborative teaming and conflict resolution**, and **evidenced-based practice**). "With an	Research indicates that the essential training elements required to transform pre-service SLPs from understanding family-centered care to being family-centered practitioners includes a focus on technical and leadership skills as well as a variety of experiences with families who have children with special needs.	OTD workshop should include "family faculty"; assure that there is abundant experience with families (perhaps between two sessions of the workshop), and address ways to enhance participants technical (or-specific clinical) and leadership skills.

Reference	Study design	Theoretical grounding	Active ingredients	Empirical support	Application to OTD project
27(1), 1-9.		required to transform pre-service SLPs from understanding family-centered care to being family-centered practitioners includes a focus on technical and leadership skills as well as a variety of experiences with families who have children with special needs.	increase in competence comes an increase in confidence allowing the SLP to naturally assume a leadership role when advocating for evidenced-based programs". -Students should have a variety of experiences with families to understand the context in which families live and support their children with special needs.		
Whithead et al. (1998). Weaving parents into the fabric of early intervention interdisciplinary training: How to integrate and support family involvement in training. *Infants & Young Children*, *10*(3),	Program evaluation description: three imple-mentations of a year-long program for preparing professionals for FCC in EI -program was		Four main aspects of the program: 1. Participants obtaining diverse clinical experiences (different setting, patients, etc.). 2. **Seminar: didactic teaching by professional and family faculty: (parents & siblings) involving families in teaching** and **advisory committee** (design and ongoing evaluation of curriculum), invaluable info and also models collaboration. 3. **Family mentor**: students spend time with the family W/O treating (See A Family Mentor Handbook references) – to sensitize students	Quantitative evidence indicates high levels of trainee satisfaction and sense of learning. Reflections were important to share emerging FCC views as well as to reframe judgmental or negative view of families.	Very important ideas to include in intervention, specifically the roles of family faculty and mentor in design, providing and evaluating the intervention.

Reference	Study design	Theoretical grounding	Active ingredients	Empirical support	Application to OTD project
44–53	evaluated using qualitative and quantitative self-reports completed by trainees to indicate level of usefulness of each activity/ environment.		to the reality of everyday life (i.e.: dinner, birthday party, doctor visit, therapy session…). 4. **Interprofessional team**: participation in IEP process and team meetings.		
Sewell, T. (2012). Are we Adequately Preparing Teachers to Partner with Families? Early Childhood Education Journal. pp. 259-263.	Literature review to assess teachers preparedness for partnering with families (perceptions and training mechanisms)	Teachers see FCC as a daunting and unman-ageable task due to lack of preparation and training. All too often preparation does not emphasize the importance of part-nering with families enough to enable pre-service teachers to practically apply the knowledge	-For students: even one course will make an impact, but infusion of content across coursework is ideal. **Including families as teachers** and offering practical experiences are effective. -For practicing professionals: **ongoing in-service training** is imperative in order to not only educate practicing teachers, but to support them in their daily practice with families.		This paper offers additional support for family involvement in education and the need for ongoing professional development.

Reference	Study design	Theoretical grounding	Active ingredients	Empirical support	Application to OTD project
King et al. (2011). Evaluation of an occupational therapy mentorship program: effects on therapists' skills and family-centered behavior. *Physical and Occupational Therapy in Pediatrics*, *31*(3), 245–62.	Description of evalua-tion of 11 month program to enhance 25 OTs FCC behaviors and expertise in different departments in one hospital in Toronto. Assessments included self-and peer-report on Effective Listening and Interactive Communicat ion, MPOC, Self-nomination	Based on King's 2009 model, therapists' engagement in deliberate practice generates feedback, which in turn is instrumental for processing and reflecting on the experience. Effective reflection will lead to further engagement in deliberate learning opportunities. The cycle is presumed to enhance therapists' knowledge and behaviors, which will ultimately lead to enhanced expertise.	**-diverse learning activities** **-feedback from self-reports, supervisor and peers** **- reflection** **-group and individual mentoring**	Positive changes were found for information provision, respectful treatment, self-confidence, and listening and clinical skill. Changes were not found on variables of open-mindedness, interpersonal sensitivity, and interpersonal skill. Experienced therapists had higher scores than new therapists on most variables, including family-centered behavior, listening skill, and clinical skill.	Program structure and assessments will be useful in designing the mentorship components and pre-post testing.

Reference	Study design	Theoretical grounding	Active ingredients	Empirical support	Application to OTD project
	Scale of Expertise				
Hanna & Rodger (2002). Towards FCC in paediatric occupational therapy: parent–therapist collaboration. *AOTJ*, *49*(1), 14–24.	Literature review of parent-professional collaboration and practices in USA, Canada and Australia.	(*this is not an actual program/intervention – only ideas based on current literature).	Authors suggest FCC elements to consider to enhance collaboration: • **Reflection on culture and unique background.** • **Establishing supportive policies at the organizational level.** • **Setting goals with parents and working hand in hand on goal-attainment.** • **Realizing that medical model is still prominent and seek ways to enact more collaborative approaches.**		Reminder of the need for supportive policies in the organizational level and cultural sensitivity.
Beach et al. (2005). Cultural Competency: A Systematic Review of Health Care Provider Educational Interventions. *Medical Care*, *43*(4), 356–373.	Systematic review of 34 studies describing outcomes of program to enhance cultural competence.		Cultural competence training shows promise as a strategy for improving the knowledge, attitudes, and skills of health professionals. However, evidence that it improves patient adherence to therapy, health outcomes, and equity of services across racial and ethnic groups was lacking.	Excellent evidence that cultural competence training improves the knowledge of health professionals; good evidence that cultural competence training improves the attitudes and skills of health	

Reference	Study design	Theoretical grounding	Active ingredients	Empirical support	Application to OTD project
				professionals. Good evidence that cultural competence training impacts patient satisfaction Interestingly, no studies have evaluated patient health status outcomes, and cost-effectiveness of training was not determined.	

3. Best practices for effective professional training/ development

Reference	Study design	Theoretical grounding	Active ingredients	Empirical support	Application to OTD project
Brown, J. A., & Woods, J. J. (2012) Evaluation of a multicomponent online communication professional development program for early interventionists. Journal Of Early Intervention, 34(4), 222-242.	Evaluation of an online professional development (PD) online course to enhance com-munication in EI settings. Participants included 25 EI providers	As the literature demonstrates limitations of workshops and supports comprehensive PD systems, time and resource challenges become paramount. Technology-supported PD is gaining momentum to flexibly meet training needs (Chen, Klein, & Minor, 2009). Program was designed with opportunities to build on content through observation, practice, reflection, and contextual application (Buysse, Winton, & Rous, 2009; Dunst & Trivette, 2009c) The R.O.P.E. (Read, Observe, Practice, Exhibit) is an instructional method that provide multicomponent	- promising impact of **online multicomponent PD** programs - **situated learning was supported by annotated video examples, narrated presentations**, video camera access, specific content organization (R.O.P.E.) and practice video examples. R.O.P.E. Each unit was structured using the R.O.P.E. (Read, Observe, Practice, Exhibit) instructional method. R.O.P.E. is congruent with Johnson and Aragon's (2003) recommended principles for effective online learning: address individual differences, create a real-life context,	Pre-post evaluation of participants' learning indicated significant change in knowledge on application and self-report measures of knowledge, along with participant's satisfaction and perceived benefit from PD.	-Perhaps some parts / all of the workshop could be done online -Program (online or face to face) should be based on a sequence of observation, practice, reflection, and contextual application (more helpful and practical info in article) -Videos of different situations to discuss would be supportive of learning. -Assessments to evaluate participants learning can include video to record and analyze practitioner's sessions with families, analyze notes, and reflective papers.

Reference	Study design	Theoretical grounding	Active ingredients	Empirical support	Application to OTD project
		situated learning opportunities to increase knowledge and skills. It is based on current online learning, principles for adult learning (Bransford, Brown, & Cocking, 2000) and online instruction (and effective early childhood PD components (Dunst & Trivette, 2009b).	motivate the learner, provide hands-on activities, avoid information overload, encourage social inter-action, and encourage student reflection. Students read assigned content, then engage in diverse opportunities to observe, practice, apply, and reflect on skills in the context in which they will be using in actual practice. Students' learning is then evaluated according to how they exhibit their skills and knowledge in real life settings.		
MacPherson-Court, L., McDonald, L., Drummond, J., Kysela, G. M., & Watson, S. (2005). Issues in developing an internet	Evaluation of online graduate/undergraduate course on FCC	(This article mainly describes aspects related to online teaching and learning, with less emphasis on FCC content or structure. Also, focus in on students and not on practicing professionals).	Course materials: included **self-study modules** focusing on family-centered practice and the assessment of family strengths and needs; natural teaching strategies; and family problem-solving. Assignments: Case study		More support for the feasibility and possibility of on-line teaching.

Reference	Study design	Theoretical grounding	Active ingredients	Empirical support	Application to OTD project
course for family-centered practice in early intervention. Developmental Disabilities Bulletin, 33(1-2), 154-175.		Online teaching and learning can resolve two problems: the first is obstacles of on-campus instruction such as timing, location and travel, and different personal situations. The second is that students are not able to learn all there is to learn on the pre-service programs and there is a desire for life-long learning opportunities.	reports on experiences with families, participation in discussions.		
Dunst, Trivette & Deal (2011) Effects of in-service training on early intervention practitioners' use of family-systems intervention practices in the USA, Professional Development in	Survey: 473 participants self-rated the usefulness of the training and change in their behaviors on a researcher-developed questionnaire, 1 month and 4 months post FCC training. Training was		-Key features of in-service training associated with positive learner benefits included **active practitioner involvement in the learning opportunities (application, reflection, self-assessment,** etc.), which occurred on **multiple occasions over time** -The elements of field based in-service include: Trainer introduction of the **practice**; Trainer illustration of use of the	-Results showed that field-based training was associated with greater benefits compared with the other types of training, and that the enhanced field-based training was associated with optimal participant benefits. -Field-based training provided	-Consider ways to provide ongoing field based in-service. The idea of meeting teams at their work place may be the best way to personalize the training to their settings, challenges, and opportunities, and enhance active learning and application. This approach can be

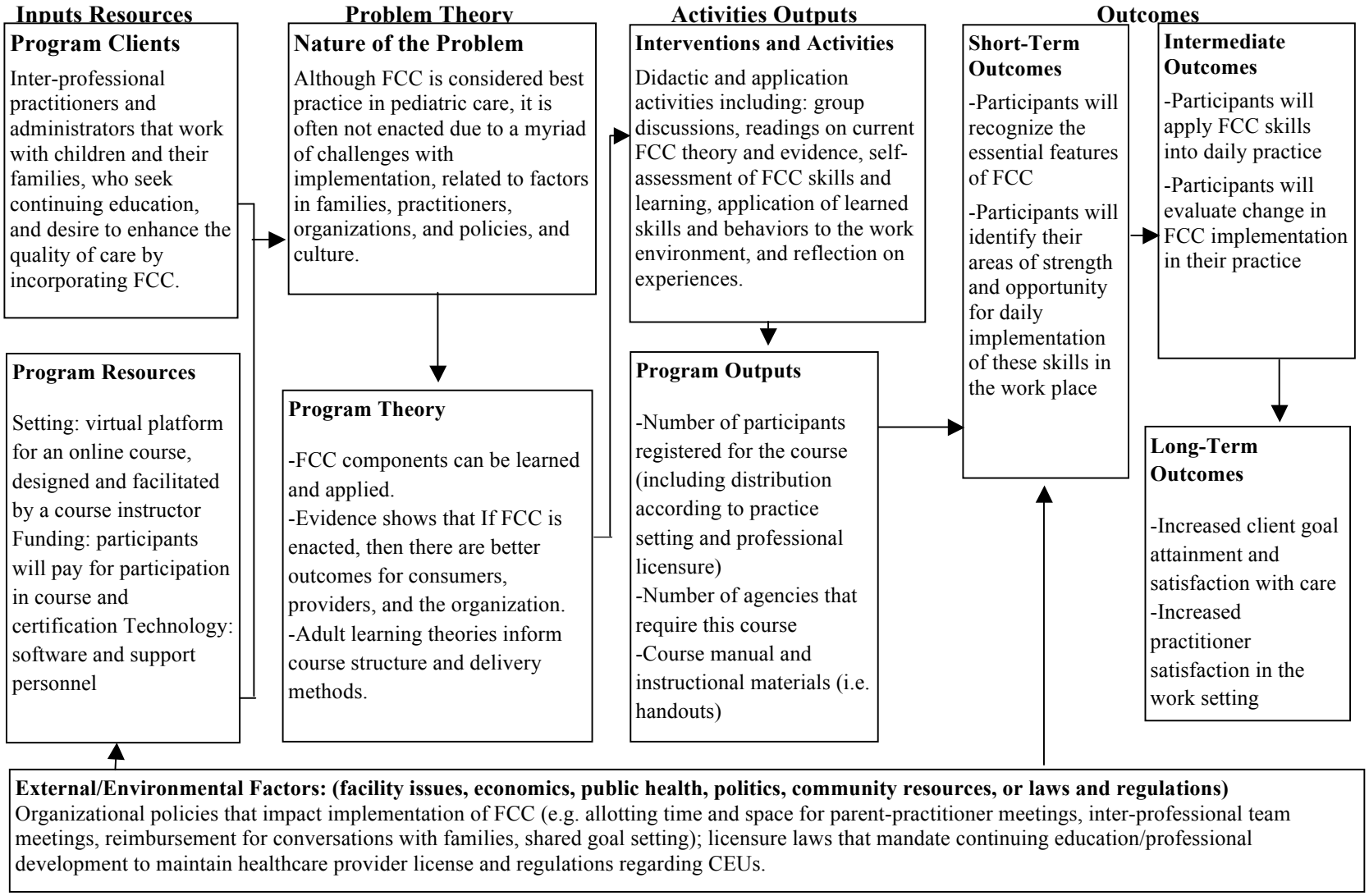
Reference	Study design	Theoretical grounding	Active ingredients	Empirical support	Application to OTD project
Education, 37:2, 181-196	offered in one of 3 categories: conference presentations; workshops (half day/full day or multi-day); or on-site, field-based training (basic and enhanced).		practice; Trainee application/use of the practice; **Trainee evaluation of his/her use of the practice**; Trainee **reflection on his/her learning** ; Trainee assessment of learner mastery ; Multiple learning sessions. - Instruction or training was provided on multiple occasions and lasted more than 10 hours.	on multiple occasions over time increases the likelihood that the characteristics that optimally affect changes in practitioner behavior are more easily incorporated into the training (as also mentioned in Trivette et al, 2009 – below).	delivered in a blended/hybrid format, where students gain field experience and reflect and analyze OL.
Trivette et al.,(2009). Characteristics and consequences of adult learning methods and strategies [online]. Practical evaluation	Meta-analysis of 79 studies of four different adult learning methods (accelerated learning, coaching, guided design and just-in-time	Trivette et al. defined six adult learning characteristics, which included methods and procedures for : (1) introducing and (2) illustrating the practice that was the focus of instruction or training; (3) learner use of the practice of his or her experiences and (4) evaluate implementing the practice; and (5) learner reflection on	Optimal benefits occur when: - learners were actively involved in all aspects of learning and mastering the use of the practices constituting the focus of instruction or training. - Effective learning occurs via multiple learning experiences, large doses of learner self-assessment of	Practices associated with largest effect sizes were the use of learner input to illustrate a target practice, learner role-playing and simulations, learner self-assessment of mastery, and learner reflection on the use of a	Clinical implications for professional development are clearly stated in this paper (p. 10). Using multiple opportunities for practicing, incorporating all different learning methods, active participation and self-assessments are key for

Reference	Study design	Theoretical grounding	Active ingredients	Empirical support	Application to OTD project
reports, 2 (1), 1–32.	training), to identify the particular characteristics of these methods associated with optimal learner benefits.	and (6) self-assessment of mastery of the focus of instruction or training. Length of training (as well as other moderators) was also examined to determine their influence on the effectiveness of the adult learning methods. Results from the research synthesis showed that all six adult learning method characteristics were associated with positive learner outcomes, and that there were value-added benefits when the majority of the six characteristics were incorporated into the instruction or training.	their experiences, and instructor facilitated learner assessment of his or her learning against some set of standards or criteria (Table 3).	target practice and judgments of the consequences of application.	learner success and implementation.
Dunst, C. J., & Trivette, C. M. (2009b). Let's Be PALS: An Evidence-Based Approach to Professional Development.	Description of an evidence based approach to professional development.		Key elements of PALS (Participatory Adult Learning Strategy), are based on active learner involvement in all phases of the learning and capacity building process. The PALS is a 4-phase process	Based on the Trivette et al. 2009 meta-analysis, this is a theoretically and evidence based "protocol" for designing in-service delivery and	PALs structure will be used as the "blue print" for program/workshop delivery.

Reference	Study design	Theoretical grounding	Active ingredients	Empirical support	Application to OTD project
Infants & Young Children, 22(3), 164–176.			includes: (1) introduction and illustration of targeted knowledge or practice, (2) application of the knowledge or practice, (3) evaluation understanding by reflection and assessment of mastery of the knowledge or practice, and (4) collaboration on continued steps in the learning process to further develop learner understanding, use, and mastery. (see fig. 3 and table 3 in the article for more details)	evaluation.	
Kolehmainen, N., & Francis, J. J.(2012). Specifying content and mechanisms of change in interventions to change professionals' practice: an	The paper describes an exemplar of a theoretical based and systematic of program to change professional practice.	Theories on professional change *See: Michie S, Johnston M, Francis J, Hardeman W, Eccles M: From theory to intervention: mapping theoretically derived behavioral determinants to behavior change techniques. Appl Psychol Meas 2008,	Techniques are (1) selecting and defining the intervene-tion techniques: Specific techniques are presented and defined on p. 5. (2) operationalizing the techniques and deciding on their delivery: Advisory board of senior OTs was involved to "translate" the	Program evaluation was not reported on this paper: only the theoretical foundations and hypothesis for change. Authors emphasize importance of choosing	-OTD project should include the three main ingredients -Goals identified in this intervention program are highly relevant to the current OTD project. Justification and definition could be

Reference	Study design	Theoretical grounding	Active ingredients	Empirical support	Application to OTD project
illustration from the Good Goals study in occupational therapy. *Implementation Science*, *7*(1), 100.	(specifically: OTs caseload management).	57:660–680.	theoretical ideas to operational and context relevant implementation. (3) formulating hypotheses about the mechanisms through which the thought to result in change: see chart on p. 8 of article. A two day workshop was followed with weekly staff meeting to continue monitor and implement concepts (see p.7 – structure of intervention).	theoretically relevant outcome measures (which exist for FCC!).	easily adopted. - An advisory board should be included and consulted with regarding the acceptability and relevancy of intervention techniques to the specific context. Culture, and needs. -Develop workbook for a team to independently work on as a group after the workshop may be useful.

Appendix C: Logic Model



Appendix D: Sample Lesson Plans

Module 1: Introduction to Family Centered Care (FCC)

Timeframe. 2 weeks for module completion.

Materials and planning needed. Access to online module; schedule interview and observation with a family.

Method of delivery and completion due dates.

Independent reading (lesson 1.1)	By day 5
Virtual chat (lesson 1.2)	Day 6, 9:00pm EST (tentative)
Discussion-board post of assignment	By day 11
Response to at least two peers on discussion board	By day 14
Peer-mentoring meeting (lesson 1.3)	By day 14

Lesson 1.1: Essential Features of FCC

Objectives. By the end of this session, participants will be able to:

1. Identify strengths and areas of opportunity in learner's FCC practice.
2. Identify the essential features of FCC
3. Describe ways to identify cultural diversity and modify care to meet family's values.
4. Apply strategies to promote parents' self-efficacy, empowerment, and engagement.
5. Practice active listening skills and strategies for effective information exchange according to family's needs and capacities.

Participatory Adult Learning Strategies components.

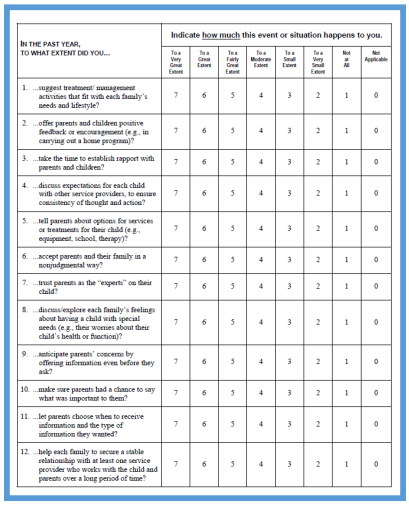
- Introduction: FCC essential features, and identification of personal goals for learning and enhancement.
- Application: Family observation and interview to apply FCC principles discussed.

- Informed understanding: reflective assignment to evaluate learning and skill mastery, responses to peers to facilitate mutual learning and understanding. Repetition and identification of next steps in the learning process: in self-assessment and peer-mentoring activity.

Measure of Processes of Care
(Woodside, Rosenbaum, King, & King, 1998)

Please complete the MPOC-SP now. You will analyze it later in this module to identify your areas of strength and the areas on which you wish to focus on during this course.

Once you have completed the assessment, please keep it and we will review your answers after learning some more about FCC.



IN THE PAST YEAR, TO WHAT EXTENT DID YOU...	Indicate how much this event or situation happens to you.							
	To a Very Great Extent	To a Great Extent	To a Fairly Great Extent	To a Moderate Extent	To a Small Extent	To a Very Small Extent	Not at All	Not Applicable
1. ...suggest treatment/ management activities that fit with each family's needs and lifestyle?	7	6	5	4	3	2	1	0
2. ...offer parents and children positive feedback or encouragement (e.g., in carrying out a home program)?	7	6	5	4	3	2	1	0
3. ...take the time to establish rapport with parents and children?	7	6	5	4	3	2	1	0
4. ...discuss expectations for each child with other service providers, to ensure consistency of thought and action?	7	6	5	4	3	2	1	0
5. ...tell parents about options for services or treatments for their child (e.g., equipment, school, therapy)?	7	6	5	4	3	2	1	0
6. ...accept parents and their family in a nonjudgmental way?	7	6	5	4	3	2	1	0
7. ...trust parents as the "experts" on their child?	7	6	5	4	3	2	1	0
8. ...discuss/explore each family's feelings about having a child with special needs (e.g., their worries about their child's health or function)?	7	6	5	4	3	2	1	0
9. ...anticipate parents' concerns by offering information even before they ask?	7	6	5	4	3	2	1	0
10. ...make sure parents had a chance to say what was important to them?	7	6	5	4	3	2	1	0
11. ...let parents choose when to receive information and the type of information they wanted?	7	6	5	4	3	2	1	0
12. ...help each family to secure a stable relationship with at least one service provider who works with the child and parents over a long period of time?	7	6	5	4	3	2	1	0

Do I practice family centered care?

To begin this lesson please obtain and complete a copy of the Measures of Processes of Care (MPOC) self-assessment *(to be electronically available)*. This is a standard questionnaire to evaluate a practitioner's family-centeredness with multiple versions. Two versions (long and short) were developed for parents. We will be using the third version developed for service providers (MPOC-SP). The MPOC-SP survey takes 10-15 minutes for most service providers to complete. For each item, you will be asked to respond to a common question: "In the past year, to what extent did you...". A 7-point response scale is used, with the following response options available: 7 indicated that the service provider engaged in this behavior "to a very great extent", 6 = "to a great extent",

5 = "to a fairly great extent", 4 = "to a moderate extent", 3 = "to a small extent", 2 = "to a very small extent", and 1 = "not at all". A score of 0 indicated that the item was "not applicable".

Introduction to Family-centered care

The following video clip was developed by the Institute for Patient-and Family-Centered Care (http://www.ipfcc.org/), one of the leading organizations in Family-Centered Care. The video provides an overview of family-centered care from healthcare professionals and family members' perspectives: http://www.aha.org/content/00-10/patient_family_centered_care.wmv

Definition of FCC

Based on findings from over 200 studies conducted in recent decades, in 2013 the American Academy of Pediatrics (AAP) published a policy statement to explain the core principles of Family-centered care (FCC). AAP defines FCC as an innovative approach to the planning, delivery, and evaluation of health care that is grounded in a mutually beneficial partnership among patients, families, and providers that recognizes the importance of the family in the patient's life. When FCC is practiced it shapes health care policies, programs, facility design, evaluation of health care, and day-to-day interactions among patients, families, physicians, and other health care professionals. Health care professionals who practice patient- and family-centered care recognize the vital role that families play in ensuring the health and well-being of children and family members of all ages. These practitioners acknowledge that emotional, social, and developmental support are integral components of health care.

They respect each child and family's innate strengths and cultural values and view the health care experience as an opportunity to build on these strengths and support families in their caregiving and decision-making roles. Patient- and family-centered approaches lead to better health outcomes and wiser allocation of resources as well as to greater patient and family satisfaction. Practitioners of FCC are becoming aware that positive health care experiences in provider/family partnerships can enhance parents' confidence

in their roles and, over time, increase the competence of children and young adults to take responsibility for their own health care, particularly in anticipation of the transition to adult service systems (APP, 2013).

FCC is grounded in collaboration among patients, families, and healthcare professionals in clinical care as well as for the planning, delivery, and evaluation of health care, and in the education of health care professionals and in research, as well. These collaborative relationships are guided by the following principles:

Benefits of FCC: for children, families, professionals, and organizations. Family-centered approaches have been found to lead to better intervention outcomes for children and their families, professionals, and organizations and are summarized below (American Academy of Pediatrics, 2012). Recent literature reviews and meta-analyses of research across medical and early intervention service sectors have examined the extent to which FCC practices are related to wide variety of child and family outcomes. Research evidence suggest that FCC practices have positive effects in a diverse array of child and

family domains, such as more efficient use of services, family satisfaction with services, family well-being, parenting practices and psychosocial components, reduced family burden and financial stress, and improved health or developmental outcomes for children (Bailey, Nelson, Hebbeler, & Spiker, 2007; Gooding et al., 2011; S., Teplicky, R., King, G., Rosenbaum, P. King, 2004; Kuhlthau et al., 2011; Kuo, Mac Bird, & Tilford, 2011; McBroom & Enriquez, 2009; Piotrowski, Talavera, & Mayer, 2009; Raspa et al., 2010).

Studies that described the impact of FCC practices on professionals identified that staff members who engaged and collaborated with families felt it was valuable to their work (Heller & McKlindon, 1995), created positive change in their perceptions of people with disabilities (Widrick et al., 1991), and overall led to improved job performance, less staff turnover, and a decrease in costs for the organization (Hemmelgarn, Glisson, & Dukes, 2001). Opponents of FCC claim that this approach requires a greater investment of time in each patient. However, there is evidence to suggest that FCC is cost-effective. FCC enhances efficient use of health care resources such as home or community service and effective use of preventive care, which decreased unnecessary and costly hospitalizations and emergency department visits (Forsythe, 1997; Kuo et al., 2011; Solberg, 1996; Vander Stoep, Williams, Jones, Green, & Trupin, 1999). Moreover, better communication and relationships associated with FCC have the potential to decrease the number of legal claims and their severity, and associated expenses (Beckman, Markakis, Suchman, & Frankel, 1994; Levinson, Roter, Mullooly, Dull, & Frankel, 1997). Finally, FCC practices were found to enhance patient safety, reduce the risk of medical errors, and improve risk-management processes (Johnson, Ford, & Abraham, 2010).

In addition, involving families in key decision-making roles in an organization's management was also found to yield positive results. Hospitals and community-based services that included family members in key decision-making roles (for example, in institutional quality or safety committees, staff education, program planning, and resource allocating) received high patient, family, and staff satisfaction scores, which translated into a more competitive position in the healthcare marketplace (Britto et al., 2006; Jones, Fournier, & Moore, 2002; Sodomka, Scott, Lambert, & Meeks, 2006).

Barriers to FCC enactment. Although the importance and value of FCC has been documented in hundreds of studies in the past decades (AAP, 2012), professionals in multiple healthcare fields are reporting an ongoing struggle with the implementation of the core principles of family-centered care in their practice due to factors related to the families, to the organization, and to themselves (Bamm & Rosenbaum, 2008; Graham, Rodger, & Ziviani, 2008; Lawlor & Mattingly, 1998; MacKean et al., 2005).

Question: Have you ever witnessed or experienced any of these challenges? What do you think were the causes?

Your answer:

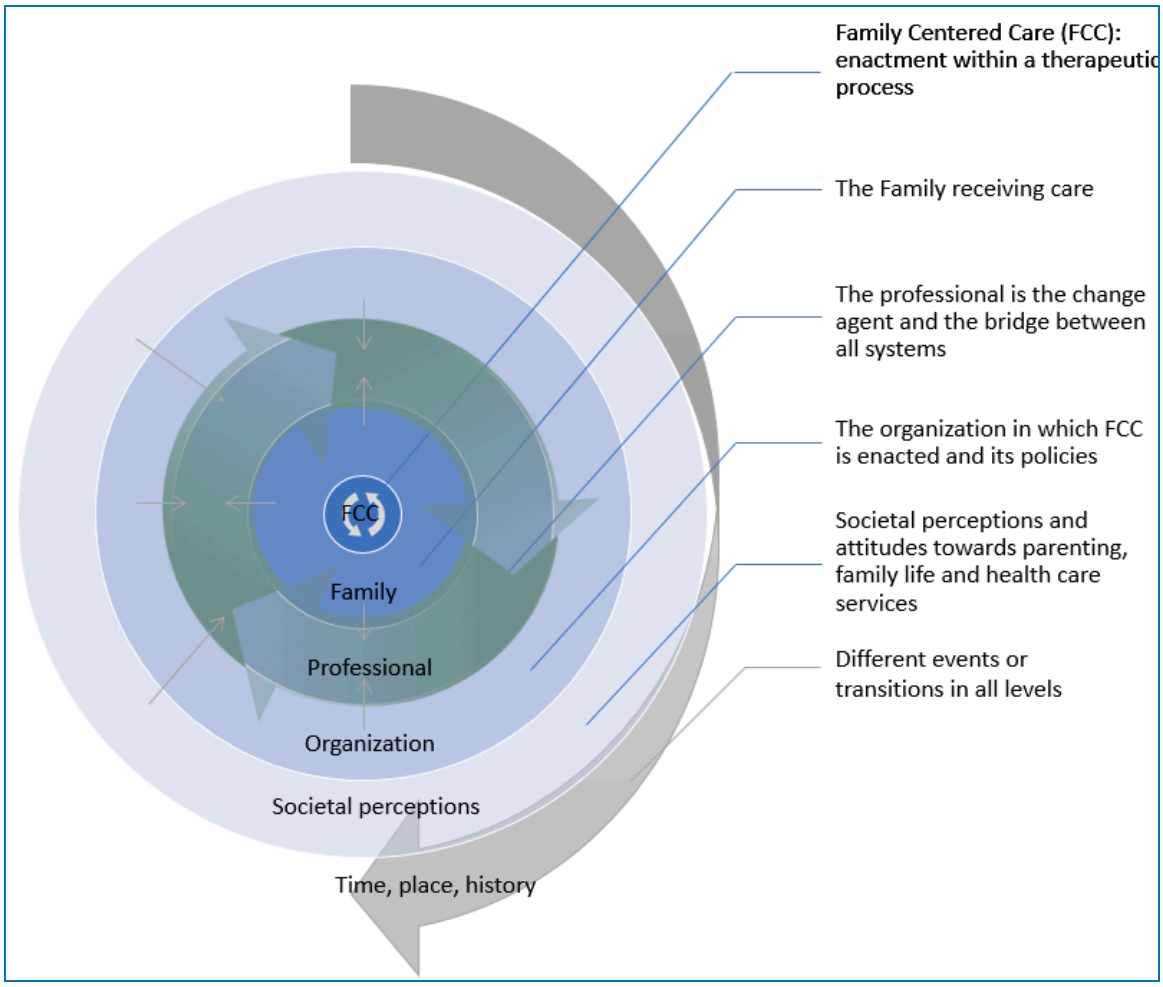
Barriers to FCC associated with families include communication and trust-building related to diversity in culture, language, socioeconomic status, and personal stressors (Fingerhut et al., 2013; Lindsay, King, Klassen, Esses, & Stachel, 2012). Fingerhut et al. (2013) found that characteristics of the organization create expectations regarding the roles of families and professionals. For example, professionals in home-based practices tend to view the parents' contributions as integral in the intervention while in school settings parent involvement was encouraged but not a central part of a child's intervention plan. Other barriers are related to organizational policies: these include evaluation processes (including the types of assessments and extent to which information is gathered with and from families), and availability for face-to-face meeting times in which to share and discuss information with parents.

Challenges related to the professionals include attitudinal factors such as how professionals view FCC and evaluate their confidence in implementing it (Bamm & Rosenbaum, 2008). Other reasons for challenges in family-provider collaboration mainly include misinterpretations of what FCC means (King & Chiarello, 2014). This may include practicing from a traditional medical model of care, such as compliance with therapist-driven goals, rather than adherence to collaboratively established goals and programs to implement them. Other examples include difficulties with exchanging

information according to the family's level of understanding and culture (Lindsay et al., 2012), or placing unwanted amounts of responsibility on parents. Finally, barriers also include lack of quality training (Campbell, Chiarello, Wilcox, & Milbourne, 2009).

The following visual model depicts the complexity of FCC due to the multiple levels that must work together in order to enable it:

Figure 1: *A systems approach to family-centered care*



This model views FCC as a result of multiple interactions between professionals and families; among professionals in interprofessional teams; and among professionals and families and the environment in which they work together. The environment includes the healthcare facility or organization in which healthcare encounter takes place, as well

as the surrounding society, its dominant culture, and impact of temporal factors. Recognizing the complexity of FCC helps to understand why, although it is considered best practice, it is challenging to implement this approach in daily practice.

MPOC assessment

Now let us return to the MPOC assessment. MPOC-SP does not measure service provider behaviors, in the objective sense of the word, but rather it measures the service provider's perceptions of his or her own behaviors. According to Cunningham and Rosenbaum (2014), in the past 20 years since its development, the MPOC has been reported in 107 studies, used in various settings in 11 countries and translated into 14 languages. Psychometric information including reliability, validity and sensitivity to change over time have been found to be high in numerous studies (Cunningham & Rosenbaum, 2014). No specific training is needed in order to score this measure and it can be completed by parents or practitioners.

A respondent's data yield 4 scores, one for each of the factors or scales. On the MPOC-SP there is no total score. Each scale score is obtained by computing the average of the relevant items' ratings. If you choose, it may be useful to pair the MPOC-SP with other FCC measurement tools such as the MPOC-56 or 20 to be completed by your patient families to obtain a multi-perspective analysis of your health care delivery.

Please review your answers to identify your areas of strength and areas that you may want to focus on in this course:

List your three strongest areas:

List your three weakest areas:

List three areas that you would like to work on during this course. What can you do to enhance each skill? The following sections may provide you some guidelines.

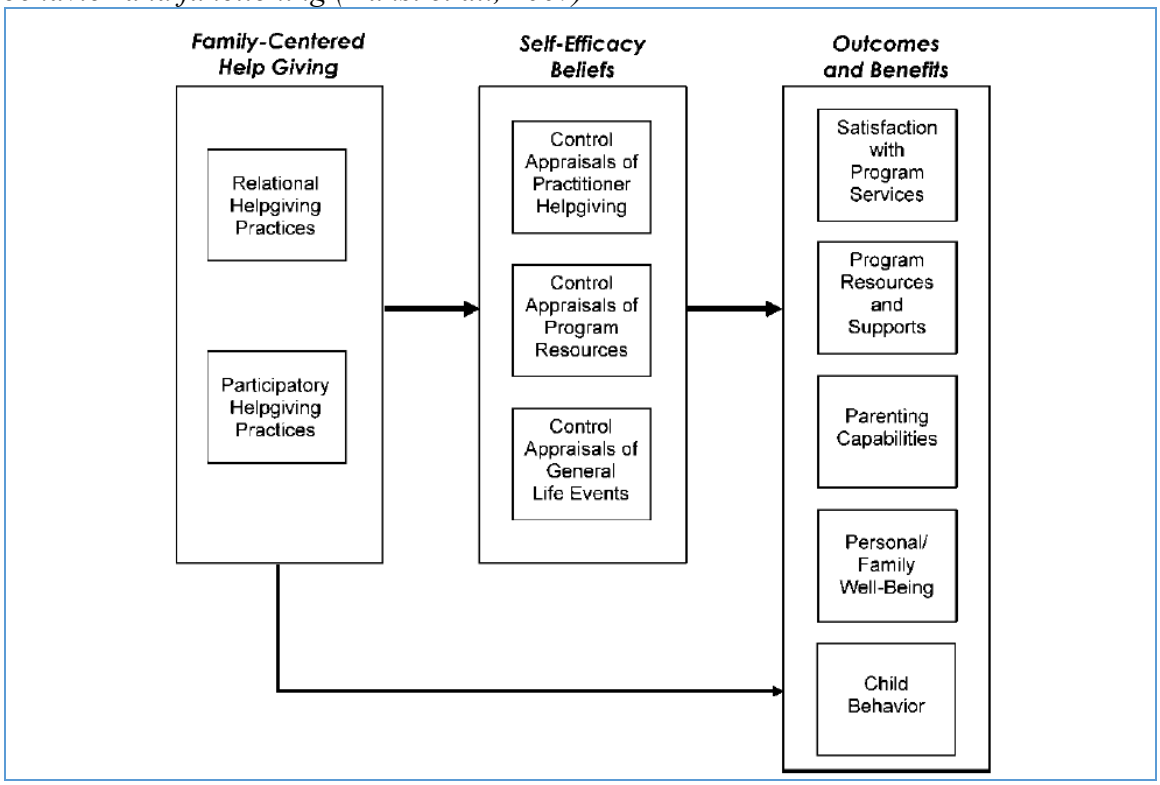
Delivering effective FCC

In the following part of the module we will explore three areas of skill that are essential for effective FCC delivery. Based on your identified areas of interest, click on the desired boxes to learn more about each skill:

Supporting families

Family-centered care is based on the premise that the family is central to the child's life, and is the child's primary source of strength and support (MacKean, Thurston, & Scott, 2005). The parent-professional relationship is viewed as a partnership in which the parents are recognized as the "experts" on their child. A growing body of research demonstrates that the nature of the relationship between parents and professionals and parents' judgments of their feelings of empowerment are closely linked (Dempsey & Keen, 2008; Dunst, Trivette, & Hamby, 2007). The quality of parent-professional relationship has been found to be correlated with parental empowerment and enhanced parenting capabilities. As seen in figure 2, specifically, effective FCC behaviors were found to influence parental self-efficacy and locus of control, which in turn can affect children's outcomes (Dunst & Trivette, 2009).

Figure 2: *Practice-based theory of family-centered helpgiving depicting the direct and indirect influences of helpgiving on self-efficacy beliefs and parent, family, and child behavior and functioning (Dunst et al., 2007)*



Effective FCC - or *helpgiving*- behaviors include two types of practices. Relational helpgiving includes practices typically associated with good clinical practice (e.g., active listening, compassion, empathy, and respect) and help givers to develop positive beliefs about their family's strengths and capabilities. Listening to a family's concerns and asking for clarification or elaboration about what was said is an example of a relational helpgiving practice. Participatory helpgiving includes practices that are individualized, flexible, and responsive to family concerns and priorities, and which support informed choices and family involvement in achieving desired goals and outcomes. Engaging a family member in learning how to find information needed to make an informed decision about care for her child is an example of a participatory helpgiving practice (Dunst & Trivette, 2009; Forry, Moodie, Simkin, & Rothenberg, 2011). These participatory practices distinguish family-centered care from other

intervention approaches and, when enacted, lead to better satisfaction and performance outcomes (King & Chiarello, 2014).

More information and examples of behaviors to support parents can be found in these excellent articles:

Dunst, C. J., Trivette, C. M., & Hamby, D. W. (2007). Meta-analysis of family-centered helpgiving practices research. *Mental Retardation and Developmental Disabilities Research Reviews*, *13*(4), 370–378.

Woods, J. J., Wilcox, M. J., Friedman, M., & Murch, T. (2011). Collaborative consultation in natural environments: Strategies to enhance family-centered supports and services. *Language, Speech, and Hearing Services in Schools*, *42*(3), 379–392.

Time to reflect:

Which of the effective practices have you been using in your daily practice? What are two ways by which you can promote parents' capacities and self-efficacy in your work?

Your answer:

Cultural Sensitivity.

Culture is considered to be a core factor of the human experience, yet it has been notoriously difficult to define (Fitzgerald, 2004). Fitzgerald (2004) offers this working definition of culture: "*culture is the learned, shared, patterned ways of perceiving and adapting to the world around us (our environment) that is characteristic of a population or society"* (p. 949). Multiple studies have demonstrated that family members' roles, beliefs, and behaviors are influenced by culture (Harkness et al., 2007). Culture also impacts people's perceptions of health, illness, disability, normality, expectations about the role, and the rights and responsibilities of the people involved (Cohn et al., 2009;

Fitzgerald, 2004; Harkness et al., 2007; Lawlor & Mattingly, 2013; Lindsay et al., 2012). Professionals, which act as the instrument of intervention, are also the product of their own culture. They bring their own views of families, which are shaped by their past experiences and culture, into clinical interactions (Lawlor & Mattingly, 2013). A professional's tacit assumptions regarding the concept of "family" tend to be influenced by one's own personal experiences. More importantly, these assumptions have the potential to create differing expectations between the client's family and the professional which can hinder communication, trust, and goals in a therapeutic encounter.

Another important concept to explore within the work with families is ethnicity. Ethnicity is also a debatable term, that refers to a sense of shared identity that can be based on many things (such as geographical, national, or racial origin, for some examples), only one of which is shared culture (Fitzgerald, 2004). It is important to differentiate between these concepts since we cannot assume that people who share an ethnic background share the same cultural beliefs or vice versa. This confounding notion can lead to incorrect assumptions about a family's beliefs and values.

The first core principle in the AAP official policy for patient- and family-centered care guides professionals to respect the family's background, as follows: "Honor racial, ethnic, cultural, and socioeconomic background and patient and family experiences and incorporate them in accordance with patient and family preference into the planning and delivery of health care" (AAP, 2012, p. 395). While this statement represents an awareness of the importance of attending to cultural and ethnical background, studies have demonstrated that diversity may actually lead to disparities in FCC provision. Coker, Rodriguez, and Flores (2010) surveyed 30,902 households with a child with special needs in 50 states and reported alarming evidence of injustice. Survey results indicate significantly lower odds of FCC provision for people of Latino and African-American origins, and other ethnic backgrounds, as compared with white children. Higher incidences of disparities were also noted for children in households with a non-English primary language, compared with children in households with English as the primary language. These disparities persisted after adjustment for child health,

socioeconomic factors, and access to services.

King, Desmarais, Lindsay, Piérart, & Tétreault (2014) sought to understand reasons for such disparities. In-depth interviews were conducted with 42 health care providers to explore their perceptions of challenges related to delivering FCC to immigrant families raising a child with a disability. Providers reported challenges providing care to immigrant families raising a child with a disability due to: (1) lack of training in providing culturally sensitive care; (2) language and communication issues; (3) discrepancies in conceptualizations of disability between healthcare providers and immigrant parents; (4) building rapport; and (5) helping parents to advocate for themselves and their children. Providers discussed using four main types of strategies to engage immigrant parents, including understanding the family situation, building a collaborative relationship, tailoring practice to the client's situation and ensuring parents' understanding of therapy procedures. To learn more about recommendations for remediating these problems please review these articles:

Lindsay, S., King, G., Klassen, A. F., Esses, V., & Stachel, M. (2012). Working with immigrant families raising a child with a disability: challenges and recommendations for healthcare and community service providers. *Disability and Rehabilitation*, *34*(23), 2007–2017.

King, G., Desmarais, C., Lindsay, S., Piérart, G., & Tétreault, S. (2014). The roles of effective communication and client engagement in delivering culturally sensitive care to immigrant parents of children with disabilities. *Disability and Rehabilitation*, 1–10.

Law, M., Rosenbaum, P., King, G., King, G., Butke-Gaffney, J., Moning-Szkut, T., & Kertoy, M. (2003). ***FCS Sheet #9 -*** *Respectful Behaviors and Language in FCS*. Ontario, Canada: CanChild Centre for Childhood Disability Research, McMaster University.

Time to reflect:
Have you experiences an instance where your perspective was different from a family's? What are two ways to understand a family's perspective and adapt the intervention to that view?

Effective communication.

According to King and Chairello (2014), effective communication between families and providers is a growing area of research. The literature has moved from notions of information provision or one-way information giving, to information sharing, information exchange, and now effective communication. Effective communication is strongly linked to client satisfaction and is an essential aspect of high-quality care. Communication has an integral role in the therapeutic encounter and in establishing a strong, ongoing client-practitioner relationship: good communication allows service providers to understand clients' worldviews, needs, and priorities. This will enable providers to personalize information, advice, and recommendations to the unique circumstances, resources, day-to-day concerns, and routines of families (Bedell, Cohn, & Dumas, 2005). Communication functions not only to transmit information but also to create and define relationships among participants (King, Servais, Bolack, Shepherd, & Willoughby, 2012). Recent articles refer to the importance of communication regarding roles and goals (Corlett & Twycross, 2006; Egilson, 2011; Rosenbaum, 2011) which are aspects of the task-oriented functions of communication, and also to relationship building aspects, which involve building rapport and providing the mutual understanding that can engage parents in the intervention process.

An important aspect for practitioners to keep in mind as they enact participatory helpgiving behaviors is consideration of the parent's learning style. Adult learning refers to the complex process of change in behavior, knowledge, skills, and attitudes in adults. It includes acquisition and mastery, application of the meaning to one's own experience,

and the intentional use or variation of ideas to novel or relevant problems (Knowles, Holton III, & Swanson, 2012). Three key elements in the "science of learning" that have direct applicability to collaboration with caregivers. First, new material is more easily learned by adults when it has direct relevance to the learner's knowledge and interests. Second, for mastery to occur, application in multiple contexts must be provided, with opportunities for evaluation and feedback. Finally, self-reflection and goal setting help adult learners apply their knowledge and skills to novel situations.

For more information review these interesting papers:

King, G. A., Servais, M., Bolack, L., Shepherd, T. A., & Willoughby, C. (2012). Development of a measure to assess effective listening and interactive communication skills in the delivery of children's rehabilitation services. *Disability and Rehabilitation*, *34*(6), 459–469.

Rosenbaum, P. (2011). Communicating with families: a challenge we can and must address! *Physical & Occupational Therapy in Pediatrics*, *31*(2), 133–134. doi:10.3109/01942638.2011.563659

Law, M., Rosenbaum, P., King, G., King, G., Butke-Gaffney, J., Moning-Szkut, T., & Kertoy, M. (2003). ***FCS Sheet #8 -*** *Effective Communication in Family-Centred Service.* Ontario, Canada: CanChild Centre for Childhood Disability Research, McMaster University. Retrieved from http://www.canchild.ca/en/childrenfamilies/fcs_sheet.asp

Time to reflect:

Please describe two ways you have (or can) adapt an information exchange to a family's needs and capacities in your workplace:

a. Observe a family of your choice (preferably with a child with a disability) in their home or other typical environment (i.e. playground, doctor's office, birthday party, class, family activity). Spend an hour or two with the family to learn about their day-to-day behaviors.

b. Interview the parent to understand his or her cultural background, values and beliefs about family and parenting, and about the child. Inquiring about a typical day's schedule can be helpful to learn about how meaning is embedded in activities, habits and routines.

Possible interview questions may include (but not limited to) the following, followed up with your own questions to elaborate on the topics shared:

- Please tell me about a typical day
- Please describe family activities or customs that are important to your family, and ask follow up questions.
- Please share what brings you joy in your role as a parent; is there anything that you worry or are concerned about?

c. In up to one page, share your reactions to this encounter. You do not need to describe what you saw, but rather what you have learned from the experience, what questions arise, and how would you apply the ideas and insights that emerged in the experience to your work.

d. Post your response in the course discussion board, respond to at least two peers.

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American Academy of Pediatrics. (2012). Patient- and family-centered care and the pediatrician's role. *Pediatrics*, *129*(2), 394–404.

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Module 1: Introduction to Family Centered Care (FCC)

Lesson 1.2: Virtual Chat, Instructor Guideline

Introduction to course and to Family-Centered care

Objectives. By the end of this session, participants will be able to:

1. Define the terms "Family" and FCC.
2. Identify and explain key aspects of quality care and FCC in the participant's workplace.

Participatory Adult Learning Strategies components.

- Introduction and illustration of basic terms.
- Application: identification of concepts in case studies and personal experiences.
- Repetition and identification of next steps in the learning process: in virtual chat and peer-mentoring process

Materials.

All participants must have a working computer set up with course platform software, microphone, speakers and webcam. For this session participants need to have paper and writing utensils (colorful preferred).

Lesson outline.

1. Welcome all participants to the first meeting; self-introduction.
2. Identifying cultural background and perceptions of family.
   - 2.1. My family portrait: (reflective assignment and formative assessment): Each participant will draw their family portrait.
   - 2.2. Group sharing and discussion: Participants describe their drawing to the group.
     - 2.2.1. "How are our families the same and how are they different from each other?" Facilitator to address family size, members included, participants' roles in the family, family values, activities.
     - 2.2.2. "Tell me about the families you work with. What are some of the behaviors and values that you see?"; "What is similar and what is different compared to your family?"; "How to you make sense of these differences in relation to your daily work?"
   - 2.3. Group work:
     - 2.3.1. "Let's work together to define the term - Family". Facilitator requests that participants write their definitions in the chat-box. Facilitator reads the definitions aloud.

2.3.2. Present in a slide and read aloud definition by New Mexico's Memorial Task Force on Children and Families and the Coalition for Children (1990): *"We all come from families. Families are big, small, extended, nuclear, multigenerational, with one parent, two parents and grandparents. We live under one roof or many. A family can be as temporary as a few weeks, as permanent as forever. We become part of a family by birth, adoption, marriage, or from a desire for mutual support. As family members, we nurture, protect, and influence one another. Families are dynamic and are cultures unto themselves, with different values and unique ways of realizing dreams. Together, our families become the source of our rich cultural heritage and spiritual diversity. Each family has strengths and qualities that flow from individual members and from the family as a unit. Our families create neighborhoods, communities, states, and nations."*

2.3.3. "What do you think about this definition"?

3. Essential features of family-centered care (FCC):
   3.1. Identifying FCC features meaningful to group participants: "In your opinion, what is quality FCC?" Facilitator draws a concept map according to responses; Facilitator summarizes and highlights themes based on participants' answers.
   3.2. Sharing and analyzing narratives: "Please tell us about a successful experience you had working with a family?" Participants will share narratives and describe why they think the experience was successful. Participants will then identify which FCC principles were enacted in the success stories. Facilitator should encourage expression of opinions and positive feedback within the group. If there appears to be open communication and a sense of safety and support, facilitator will ask: "Please describe a time when you felt 'stuck' working with a family?"; unpack according to FCC principles: what were "missed opportunities"; how would increasing any of the principles help solving a similar situation? .

4. Summary: tonight we began to enhance our sensitivity to the diversity among families and uniqueness of each one. In this module's self-study you began to explore the essential elements of FCC. The assignment will help you apply this knowledge and gain new insights.

5. Reminder of timeframes and clarifications regarding assignments due.

6. Summative information – One Minute Paper including the following questions (to be sent to facilitator in private chat box or email):
   6.1. The most important thing I learn today was:

6.2. One question that remains unanswered is:
6.3. What I hope to learn in this course, or - the information that would be most valuable for me would be: _____

Module 1: Introduction to Family Centered Care (FCC)

Lesson 1.3: Peer-Mentoring Guidelines

Objective: By the end of this session, participants will identify personal goals and establish a collaborative learning process.

Tasks:

1. **Collaborative helpgiving map** (Madsen, 2013)**:**

<table>
<tr><td colspan="2">Vision
Where do you want to be headed in your life or work?</td></tr>
<tr><td>Obstacles / Challenges
What gets in the way of your Vision?</td><td>Supports
Who and what support you in moving towards your Vision?</td></tr>
<tr><td colspan="2">Plan
How can we draw on supports to address obstacles to help you move towards your Vision?</td></tr>
</table>

The Collaborative Helping Map (CHM) can be useful to enhance reflection, collaboration, and goal setting. It incorporates ideas from cognitive behavioral theories, goal setting theories, and business models (similar to SWOT analysis), and can be administered as a self-assessment or an interview. This map can be utilized as a tool to both help practitioners think their way through complex situations and to provide a guideline for constructive conversations between families and helpers about challenging issues. CHM requires that the professional or family identify their vision ("Where do you want to be headed in your life or work?"), Obstacles (What gets in the way of your Vision?), Supports ("who and what support you in moving towards your vision?") and Formulating an action plan ("How can we draw on supports to address obstacles to help you move towards your Vision?").
Please review Madsen (2013) p. 3-10 for sample questions and guidelines.

2. **Mentoring agreement**:

Discuss your roles as Peer Mentors; include how often you will meet to discuss your experiences with families and your professional development during the course. Include the setting (frequency, times, media) and types of feedback/guidance you anticipate.

Once completed, please post maps and agreements on your personal peer-mentoring discussion board.

Reference: Madsen, W. C. (2013). Applications of Collaborative Helping Maps: Supporting Professional Development, Supervision and Work Teams in Family-Centered Practice. *Family Process*.

Module 2: the Partnership

Timeframe. 2 weeks for module completion.

Method of delivery and completion due dates.

Independent reading (lesson 3.1)	By day 5
Virtual chat	Day 6, 9:00pm EST (tentative)
Discussion-board post of assignment	By day 11
Response to at least two peers on discussion board.	By day 14
Peer-mentoring meeting	By day 14

Lesson 3.1: Collaboration and Goal Setting

Objectives. By the end of this session, participants will be able to:

1. Identify strategies for collaboration
2. Apply collaborative strategies in the workplace
3. Establish Goal Attainment Scaling Follow-Up chart

Participatory Adult Learning Strategies components.

- Introduction and illustration of collaboration and shared goal setting.
- Application: apply concepts to past experiences and to current practice
- Informed understanding: reflection and evaluation of learning.
- Repetition and identification of next steps in the learning process: in peer-mentoring activity.

Partnering and collaborating

Please watch the following video clip of family members' personal accounts of they experience with family-centered care (FCC) and their thoughts about fostering communication, partnership and respect: https://www.youtube.com/watch?v=_09IRcnqark

Please review CanChild FSC number 10, 12, 13, and complete the following assignment:

FCS Sheet #10 - Working Together in Family-Centred Services

FCS Sheet #11 - Effective Negotiation for Family-Centred Service

FCS Sheet #13 - Setting Goals Together

Time to reflect: of the different strategies and guidelines presented in these FCS, please list the strategies that you believe will be most valuable for you to implement to reach your course goals:

Be prepared to discuss these with your peer-mentor.

The Family-Provider Partnership

Many health care providers and researches agree that client engagement is important for successful outcomes to occur. Client engagement requires a sharing of power and therapist skill in creating a therapeutic environment that is safe, open, and truly collaborative. Good family-provider relationships foster engagement, and are considered to be influenced by service providers' adoption of a role as partner, listener, facilitator, and consultant. Such customized, collaborative child and family-centered interventions create motivational climates that empower and enable children.

Question: Based on your experience, how does client engagement impact the intervention outcomes?

Your answer:

Family-provider partnership and collaboration are a fundamental principle of family-centered care (King & Chiarello, 2014; Kuhlthau et al., 2011). Collaboration is defined as developing effective relationships and shared goals (Hanna & Rodger, 2002), and has been found to be associated with family empowerment (i.e., parenting competence, confidence, and enjoyment of the parenting role) (Dunst & Dempsey, 2007). Collaborative goal setting and subsequent goal achievement has been identified as the cornerstone of effectiveness of family-centered care, since joint goal setting can build a Sense of partnership, enhance feelings of competency, and encourage client engagement in therapy (Øien, Fallang, & Østensjø, 2010).

In the following section new practice models that are helpful in establishing goals and a collaborative therapeutic environment will be reviewed.

Emerging practices in consultation and coaching, and collaboration

In their work, practitioners use a variety of strategies to engage and collaborate with families. Published literature offers us theoretical models that help analyze our therapeutic and collaborative processed and enrich it. Emerging models for supporting and collaboration include collaborative consultation (Wesley & Buysse, 2004), coaching (Hanft & Shepherd, 2008) or participation based (Campbell & Sawyer, 2007), and the collaborative Relational Goal-Oriented Model (King, 2009). Although the approaches have distinct differences, they also have many similarities that support increased performance and outcomes for caregivers. These various strategies are often used in service delivery approaches described as modeling behaviors, reflective listening, questioning performance, performance feedback, prompting, and problem solving are specific strategies described in an emerging literature base. To read more about practical

implementation and strategies please review Woods et al. (Table 1; Woods, Wilcox, Friedman, & Murch, 2011).

The *consultation model* is characterized by a triadic relationship among the provider as consultant, the caregiver, and the child. Consultation is a voluntary and reciprocal collaboration, with each participant contributing valued knowledge and experiences to achieve mutually defined goals (Wesley & Buysse, 2004). The goals of the consultation are bidirectional (parent-provider), and each step builds on the previous to inform the latter. General goals in EI consultation are to (a) scaffold learning for the caregiver that supports child development and interactions, and (b) provide resources to handle similar challenges in the future.

In *coaching*, the practitioner and caregiver identify goals and include learner observation of the clinician (modeling) and learner opportunities to practice the new skill while receiving feedback (scaffolding) in the process. Reflection and evaluation are important steps that encourage the parent or caregiver to think critically about his or her use of strategies. One coaching model, The Transdisciplinary Model of Solution Focused Coaching for Pediatric Rehabilitation (SFCPeds) (Baldwin et al., 2013) emphasizes an exploration of a family's preferred future and utilizes solution focused strategies rather than collaborative problem solving. The main methods include working with resources and asking strategic questions to construct customized interventions with families.

A *collaborative* model, the Relational Goal-Oriented Model (EGM; King, 2009) of optimal Service Delivery, addresses the components of effective communication and provides strategies to optimize outcomes. As depicted in Figure 1, the model recognized three main "players": the family, the practitioner, and the organization. The family-practitioner and practitioner-organization relationships and subsequent intervention processes can be enhanced through sharing knowledge and skill in joint decisions on goals and intervention. The model outlines six parallel elements of quality practice. The foundational three elements are the "what" and "why" to establish a relational goal-oriented process and includes identifying overarching goals; desired outcomes; and fundamental needs. The next three elements represent the "how" and include relational

processes; approaches, worldviews, and priorities; and strategies. Each of these essential elements is enacted by the three players (family, practitioner, and organization).
To read more about this model please view:
King (2009). A Relational Goal-Oriented Model of Optimal Service Delivery to Children and Families. *Physical and occupational Therapy in Pediatrics, 29*(4), 384- 408.

Goal Attainment Scaling

Collaborative goal setting is often recognized as a key component of the foundational family-professional partnership (American Academy of Pediatrics, 2012; AOTA, 2014; King & Chiarello, 2014; Woods, Wilcox, Friedman, & Murch, 2011). Evidence points to that fact that clear and functional goals enhance motivation and lead to improved outcomes (Eccles & Wigfield, 2002; Locke & Latham, 2002), and that joint goal setting can build a sense of partnership, enhance feelings of competency, and encourage client engagement in therapy (Øien et al., 2010).

Goal Attainment Scaling (GAS) is a method for writing personalized evaluation scales in order to quantify progress toward defined goals. GAS lends itself to family centered care as it can support realistic outcome expectations that can be negotiated with the client and family members, caregivers or teachers. This approach is attracting growing interest in clinical practice because it enables assessment of a treatment's efficacy in terms of goals set by the client him/herself (rather than on generic scales, which may not always include the problem that most severely bothers the client) (Krasny-Pacini, Hiebel, Pauly, Godon, & Chevignard, 2013). GAS is used in many fields, including medicine and especially in psychiatry, geriatrics, pediatrics, and rehabilitation fields in which setting precise goals is a fundamental part of treatment planning. In fact, GAS can be used to cover all the fields of the International Classification of Functioning, Disability and Health (ICF) by choosing goals that cover activity, participation, quality of life and environmental factors. Involving the child and his/her family and caregivers in the choice of treatment goals may enable better integration of these goals into activities of daily living by transforming goals related to ICF activity domain into participation goals

in the child's usual context. Clients undergoing intervention are more motivated when their goals are clearly defined and consistent with their own goals and values (Krasny-Pacini et al., 2013).

As we have discusses, intervention outcomes are better when the client is involved in setting his/her goals. Several literature reviews on GAS (such as Krasny-Pacini, 2013) have identified that GAS helps to plan rehabilitation programs by setting priorities; structure team meetings and multidisciplinary consultations around precise objectives; better quantify a client's progress; better communicate with the client, his/her family and rehabilitation funding bodies, better address ethical issues, and better to assess health care system functioning. Gas was found to be a valid and reliable tool that can be used to track client progress in practice and research.

How to set a Goal Attainment Scale?

Overall, GAS methodology consists in:

1. Defining a rehabilitation goal.
2. Choosing an observable behavior that reflects the degree of goal attainment.
3. Defining the client's initial (i.e. pretreatment) level with respect to the goal.
4. Defining five goal attainment levels (ranging from a "worse than expected" to ''no change'' to a ''much better than expected outcome''.
5. Setting a time interval for client evaluation.
6. Evaluating the client after the defined time interval.

A five-point scale is generally used: ''–2'' is the initial pretreatment (baseline) level, ''–1'' represents progression towards the goal without goal attainment, ''0'' is the expected level after treatment, (and therefore, the ''most likely'' level after treatment), ''+1'' represents a better outcome than expected, and ''+2'' is the best possible outcome that could have been expected for this goal. Since there may be several intervention goals for a given client, each goal will have its own GAS scale. Determining the goal is relatively easy in routine practice, as GAS is a formalization of the therapeutic objectives discussed on a daily basis with clients and their families. However, it is more difficult to draft a full

goal attainment scale, i.e. to precisely describe the five attainment levels.

Bovend'Eerdt, Botell and Wade (2009) developed a method for easily determining the various GAS levels once the main goal has been defined. The first step consists in identifying the client's expectations and the environmental factors influencing the performance of the activity in question (e.g. the client's house has two floors and thus the client needs to walk up and down stairs: (Table 1). The second step consists in determining the observable target behavior corresponding to the target activity (e.g. walking down 10 steps of the stairs). In the third step, the rehabilitation team works with the client and family to identify the assistance required to perform this activity: human assistance, technical aids, assistive devices, verbal guidance, cognitive assistance, etc. The fourth step consists in quantifying the initial performance at the target activity in terms of the time required, quantity (e.g. the number of steps) and frequency (e.g. frequency of falls) of the target behaviour. The five attainment levels are then written by adding or changing the ''assistance required'' and/or ''performance quantification'' categories. It is important to modify only one characteristic at a time.

Example: Danny

Danny is a sweet two year and 11 months old boy recently diagnosed with Pervasive developmental Disorder Not Otherwise Specified (PDD-NOS). He currently attends a part-time special education program and a mainstream daycare. Danny's parents expressed concerns regarding his delayed communication and learning skills, as well as challenges with sensory-motor, social-emotional, play and ADL performance. Based on evaluation findings, an in-depth interview with the parents, and a follow up conversation, Danny's parents identified their top goals as enhancing Danny's ability to: (1) attend to a task for longer, (2) show interest in play with peers and (3) be able to fall asleep faster at night (as it was taking him 90 minutes on average, and it was hypothesized that fatigue was partially related to poor performance during the day). Based on these priorities, a goal attainment follow-up guide was developed for a timeframe of three months as presented in Table 1.

Table 1: *Goal Attainment Follow-Up Guide*

Level of Attainment	Goal #1 Sustained attention in task	Goal #2 Social interaction in peer-play	Goal #3 Time for falling asleep
Much less than expected: Score of -2	Danny will sustain attention in a desired task for 1-59 seconds	Danny will not engage in spontaneous parallel play next to peers in daycare	Danny will fall asleep later than 90 minutes after lights out
Somewhat less than expected: Score of -1	Danny will sustain attention in a desired task for 1-4 minutes	Danny will engage in spontaneous parallel play next to peers in daycare once each school day	Danny will fall asleep within 31-89 minutes after lights out
Expected level of outcome: Score of 0	Danny will sustain attention (but not perseverate) in a desired task for 5-8 minutes	Danny will engage in spontaneous parallel play next to peers in day care twice each school day	Danny will fall asleep within 15-30 minutes after lights out
Somewhat more than expected: Score of +1	Danny will sustain attention in a desired task for 8-11 minutes	Danny will engage in spontaneous parallel play next to peers in day care 3-5 times each school day	Danny will fall asleep within 7-14 minutes after lights out
Much more than expected: Score of +2	Danny will sustain attention in a desired task for 12 minutes or more	Danny will engage in spontaneous parallel play next to peers in day care 6 or more times each school day	Danny will fall asleep within 6 minutes after lights out

Identifying meaningful goals

Mailloux and her colleagues (2007) suggested the following helpful guiding questions for parents during goal-setting interview:

1. Tell me about your child. What are his/her strengths, his/her weaknesses?

2. What has led you to seek services for your child?
3. What concerns you most about your child? Tell me more specifically about. . . .
4. What is a typical (day, week) like for him/her?
5. Tell me about your family's life. What kinds of things do you like to do? What is easy or hard for your family or its members?
6. Tell me about what you or other family members need to do to have things go smoothly for your child.
7. (Review the child's evaluation and ask questions regarding functional areas of difficulty.) For example: I notice that _____ (e.g., mealtime) seems to be hard for him/her. Can you tell me more about that?
8. (After functional areas are covered): Tell me more specifically about _____ (each specific sensory area identified as problematic from the evaluation).
9. (Ask if appropriate): Our evaluations showed some difficulties/delays with _____Is this something that has been of concern to you?
10. What are some goals you have for your child in the next 3 months or so? (Time frame may be variable.)
11. Looking ahead, what are some of the things you are hoping for your child?
12. Imagine we are sitting here talking 3 months [variable] from now. What changes would you like to see by that time?

Making your GAS effective

1. Each GAS level must be described accurately enough to allow a person not involved in the GAS-writing process to easily classify the client at one of the GAS levels described therein;
2. Each scale must represent a single dimension of change.
3. The levels must be measurable and thus defined in terms of observable behaviors.

4. The scales must correspond to goals that are important to the client and family. All the levels must be realistic and attainable. In particular, the +2 level must not correspond to an unexpected or miraculous goal;
5. The time scale within which goals must be attained and scales must be scored should be defined in advance.
6. The inter-level differences in difficulty must all be the same, i.e. it must be as difficult to go from –2 to –1, as from –1 to 0 or from 0 to +1, etc.

These criteria are based broadly on the idea that regardless of the GAS scale, all rehabilitation goals must be ‘‘SMART’’: specific, measurable, acceptable, realistic and defined in time.

Common mistakes to avoid:

Consequently, the most frequent mistakes in writing goal attainment scales are as follows:

1. Attainment levels that overlap or, in contrast, are not covered by any of the goals.
2. Unequal gaps between levels (although this problem can never be completely eliminated).
3. The use of multidimensional scales (e.g. standing up and walking).
4. Over-simple goals, the attainment of which does not correspond to a significant clinical difference.
5. Subjective criteria for goal attainment (i.e. based on opinions and interviews, rather than objective, quantifiable observations).

GAS training methods have shown that well-trained rehabilitation staff are able to draft realistic, pertinent GAS for their clients. One of the best ways of writing a goal attainment scale is to use existing scales, such as those published as illustrative examples by experienced research groups Teams wishing to learn more about GAS can follow published training modules [63] and the guides developed by McDougall and King (2007; http://www.mc.uky.edu/healthsciences/grants/ptcounts/docs/gasmanual2007.pdf)

and Bovend'Eerdt and group (http://cre.sagepub.com/content/23/4/352).

Summary

Setting precise goals, describing the client's initial status, defining the possible attainment levels and agreeing on how that goal can be attained: these steps themselves constitute a pedagogic process, that enables: to negotiate realistic goals; to discuss what is the most important for the client and the client's family; to obtain a truly informed consent for the rehabilitation plan proposed; and to actively involve the client and his/her family in the intervention project. In this sense, GAS is above all a tool for dialogue, client education and formalization of the client-caregiver contract.

- **Choose** one family that you work with.
- **Schedule** a meeting with the caregiver to review the goal attainment.
- **Prepare** prior to the meeting by reviewing the collaborative model and identify potential strategies to enhance your collaboration with the family representative.
- **Interview** the family member according to Mailoux et al (2007) - guiding questions for parents during goal-setting interview
- **Develop** two goal scales according to Bovend'Eerdt's guidelines on components of good GAS.
- **Reflect** on this experience: how did a collaborative GAS process impact the partnership? What was a challenge and success that you have encountered?
- **Post** your reflection and GAS chart for two goals on the course discussion board.
- **Respond** to a minimum of two other posts.

Appendix E: Executive Summary
Better Together: Advancing Family-Centered Care

Introduction

Family-centered care (FCC) is recommended as "best practice" across a variety of pediatric service settings. However, providers in multiple healthcare fields report an ongoing struggle with the translations of FCC concepts into their practice (Bamm & Rosenbaum, 2008; Graham, Rodger, & Ziviani, 2008; Lawlor & Mattingly, 1998; MacKean, Thurston, & Scott, 2005). The aim of this doctoral project is to understand the importance of and barriers to FCC implementation, and to propose solutions to this problem.

FCC is an innovative approach to the planning, delivery, and evaluation of healthcare. The essential elements of FCC include: (1) mutual respect between providers and families, (2) establishing collaborative partnerships among the parent and care team, (3) exchanging information to support family decision-making, and (4) providing flexible personalized service delivery and support according to each family's unique needs (American Academy of Pediatrics, 2012). Benefits of FCC practices include promising outcomes to children and their families, healthcare providers, and healthcare organizations. Children and their families benefit from more efficient use of services, enhanced family satisfaction and well-being, better parenting practices and psychosocial components, reduced family burden and financial stress, and improved health outcomes (Bailey, Nelson, Hebbeler, & Spiker, 2007; Gooding et al., 2011; Teplicky, King, Rosenbaum, & King, 2004; Kuhlthau et al., 2011; Kuo, Mac Bird, & Tilford, 2011;

McBroom & Enriquez, 2009; Piotrowski, Talavera, & Mayer, 2009; Raspa et al., 2010). Providers report enhanced relationships with families and interprofessional teams, improved job performance and satisfaction, and less staff turnover (Hemmelgarn, Glisson, & Dukes, 2001). Organizations have found that FCC contributed to enhanced patient safety and satisfaction, reduced risk of medical errors (Johnson, Ford, & Abraham, 2010), decreased numbers of legal claims and their severity (Beckman, Markakis, Suchman, & Frankel, 1994; Levinson, Roter, Mullooly, Dull, & Frankel, 1997), and enhanced reputation in the community (American Academy of Pediatrics, 2012).

However**,** although many providers desire to do so, multiple barriers impede their ability to practice from a FCC approach (Bamm & Rosenbaum, 2008; Graham, Rodger, & Ziviani, 2008; Lawlor & Mattingly, 1998; MacKean, Thurston, & Scott, 2005). These include challenges communicating with families due to lack of training and expertise in FCC, (Campbell, Chiarello, Wilcox, & Milbourne, 2009; King et al., 2011), combined with increasing administrative pressures for productivity (AOTA, APTA, ASHA, n.d.).

Barriers to family-centered care implementation are best understood from a dynamic systems perspective. The explanatory model presented in Figure 1 is helpful to conceptualize FCC as an outcome of

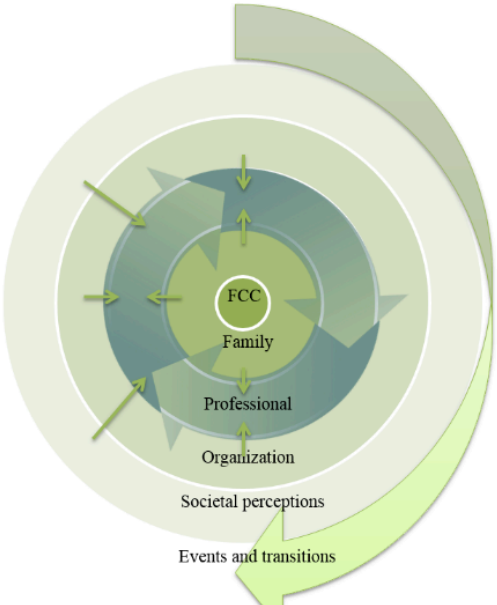

Figure 1: *an explanatory model of barriers to FCC implementation*

multiple connections that exists between professionals and families; among professionals in interprofessional teams; and among professionals and families and the environment in which they interact. The environments includes the healthcare facility or organization in which healthcare encounter takes place, as well as the surrounding society, its dominant culture, and impact of events and transitions on all systems. Recognizing the complexity of FCC helps to understand why, although it is considered best practice, it is difficult to implement this approach in daily practice. Better Together (BT), was developed to address the myriad of barriers and to empower providers to mitigate challenges and transform their daily practice and environments to offer best practice FCC to their clients.

Program overview

Better Together (BT) was developed to advance FCC by better preparing providers to work together to effectively integrate best practice FCC in their daily interactions with clients. The course content and structure are based on findings from a review of the literature specific to identifying core skills and knowledge that must be mastered in order to effectively practice FCC, as well as the best practices for professional development instruction. Agreed-upon capacities for FCC enactment include the skills essential for guiding a collaborative intervention process. These are: effective communication, cultural sensitivity, collaborative goal setting and coaching, and specific knowledge of ways to support families and implement FCC assessments and processes. Promoting interprofessional teamwork and supportive workplace policies are also imperative for delivery of FCC. BT content addresses all of the identified capacities.

Best practices identified for professional development instruction include adult

learning principles, enhancing reflective inquiry, and incorporating ongoing mentoring, all of which can be delivered via in-person or online instruction. Most importantly, learning must be meaningful and relevant to the learners. Making learning meaningful can be achieved by engagement of the learner in all stages of learning from self-identified learning goals and their relevance to daily practice, through implementation and self-appraisal of skills, and to planning of future learning goals. Instruction must include multiple options for practice and implementation of FCC behaviors in different settings. Longer programs (over 10 hours) with ongoing mentoring to support continued learning and expertise are recommended. All of these elements were incorporated in the course design and structure.

BT was therefore designed as an online professional development course to be offered to interprofessional providers who work with children and their families. The course content is delivered within eight weeks, and includes four modules. Table 1 presents module main topics, learning objectives, and learning activities.

Table 1: *Outline of Better Together course content and objectives*

Module and Topic	Learning objectives ***by the end of this lesson, learners will be able to:***	Sample learning activities
1. Family-centered care: Essential elements	• Identify and discuss the essential features of FCC. • Assess personal strengths and areas of opportunity in learner's FCC practice; devise a personal plan for developing expertise in FCC behaviors relevant to the workplace. • Apply strategies of active listening and effective information exchange to promote parents' self-efficacy, empowerment, and engagement.	• Reading and live group discussions. • Self-assessment using the Measures of Processes of Care (MPOC) to identify FCC behaviors. • Observe a family of a child with special needs in their home.
2. Implementing FCC: Processes and mechanisms for the work-place	• Choose and administer appropriate FCC assessments. • Discuss and implement an effective FCC intervention process.	• Review, compare and contrast FCC assessments. • Analyze case studies.
3. Partnership: Collaboration and goal-setting	• Apply strategies for collaboration with families. • Establish Goal Attainment Scaling follow-up chart.	• Simulate collaborative vs. division case scenarios. • Collaboratively set goals with one client's family.
4. The bigger picture: Promoting FCC in the workplace	• Appraise existing FCC process and collaborative work with families and teams. • Become an ambassador of FCC	• Develop a flow chart of the FCC processes in the workplace. • Develop an advocacy plan for the learner's workplace.

Each module includes an independent interactive learning section, a live group discussion, and peer-mentoring. Each learner determines his or her professional development goals for the course based on a self-assessment of FCC skills. Course content can be modified and selected by the learner to support personal goal attainment. Theoretical content is translated into practical application via course assignments

performed in the learner's natural environment (community or workplace) and reflected upon individually and within the group discussions. Ongoing peer-mentoring provides additional individualized support and opportunity for goal setting and reflection. Upon completion of the course all learners are invited to continue their participation in a monthly group mentorship with all course participants and the course instructor.

BT course implementation will take place in two phases. In phase 1, the pilot phase, BT courses will be evaluated to examine the effect the course has on enhanced implementation of FCC and overall quality of care provided by course participants. This phase will take place either in the Tri-city area of Michigan, USA, or in Haifa, Israel. In phase 2, BT will be offered as a commercial continuing education (CE) professional development course sponsored by an approved CE company (such as Dynamic Learning Online Inc. or Educational Resources Inc.,) or by an open online education company (such as the Institute for Healthcare Improvement Open School, or AOTA Learn). Dissemination activities will begin in phase 2, following pilot study completion and confirmation of the course's utility to enhance the quality of care provided by participants. Dissemination activities may include both a scholarly approach via professional conferences and publications and also direct marketing to providers, families, and organizations.

Conclusion

Family-centered care is the best practice when working with children. This approach yields better health and wellness outcomes to clients and greater work satisfaction for practitioners and administrators. Family-centered collaborative care is a

fundamental concept in occupational therapy and it is important now more than ever with the emergence of healthcare policies guided by the Affordable Care Act and Patient Centered Medical Home that highlight the importance of a patient- and family-centered collaboration for quality care. Better Together presents the most recent literature and evidence from the highest authorities in the field of family-centered care, offered in a dynamic, interactive, and learner-oriented stimulating course. This online course will provide education to providers on the practicalities of how to implement family-centered essentials into their everyday work, according to the learners' individualized professional development goals, in a flexible format to fit their busy lives. Expertise in FCC will enable providers to shape the service delivery and the environments in which it is offered to lead care teams and families to best health outcomes for the child, and to advance the professional reputation of occupational therapy and its practitioners.

Recommendation

It is recommended that providers and organizations that offer healthcare services to children and their family evaluate their ability to provide respectful, personalized, culturally sensitive services that include effective information exchange for empowered decision making, and utilize the family's strengths. Family-centered care goes beyond client-centered care and requires attention to multiple interacting factors as described above. Advancing providers' education is essential for enhancing their expertise, work satisfaction, and productivity along with reduction of staff burn-out. Better Together offers an opportunity to engage in the important emerging trend of family-centered care and deliver win-win-win benefits to families, providers, and organizations.

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