

Spirituality in Family-Centered Practice: Parents' and Practitioners' Views

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DEDICATION

To Bruce, my husband, Chelsea and Reed, our children. You have been patient, giving, and understanding through this personal journey. You have accepted my fatigue, impatience, and lack of time with grace. I offer this work to my Higher Being, and to those who read it, may it provide an opportunity for insight and reflection.

“For the soul walks upon all paths. The soul walks not upon a line, neither does it grow like a reed. The soul unfolds itself, like a lotus of countless petals.” Kahlil Gibran

ABSTRACT

This exploratory study used a qualitative research approach to acquire parents' and practitioners' views of spirituality within family-centered practice. Outcomes of this study were to a) gain an understanding of parents' and practitioners' views of spirituality and religion b) determine if these constructs are valued within family-centered practice and c) explore necessary practitioners' competencies based on participants' perceptions of the constructs.

Parents (N= 6) and practitioners (N=7) participated in either individual interviews or focus groups to investigate their perceptions of formal and informal supports, the individual family service plan process, the family quality of life indicator of spirituality, and requisite practitioners' competencies. Parents and practitioners actively engaged in the debate and reflection process pertaining to the integration of the constructs of spirituality and religion into family-centered practice. Results indicated that parents' and practitioners' views reflected the multifaceted nature of spirituality and the complexity of family-centered practice as outlined in the literature. Participants value the integration of spirituality and religion within family-centered practice. Highlighted was the fundamental nature of making spirituality and religion overt and distinct constructs to be discussed within family-centered practice. Emphasized was the strength giving nature of spirituality and religion in addition to the importance of following, honouring, and respecting the family's beliefs. Furthermore, the data indicated that practitioners' competencies need to be inclusive of skill, knowledge, and reflection regarding the constructs. Implications and future research directions are discussed.

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CHAPTER I

Introduction

A. Statement of Problem

The fledgling science of early intervention has grown quickly in the past 30 years (Bailey, Aytch, Odom, Symons & Wolery, 1999; Dunst, 2000; Guralnick, 1991). As a relatively new player within the social sciences, early intervention's models of practice have moved from child-focused to parent-focused to family-focused (Guralnick, 2000; Shonkoff & Phillips, 2000).

Current state-of-the-art practice espouses the use of family-centered practice in order to support the child with developmental needs within the framework of the family. This ecological system's approach to family-centered practice encourages early intervention professionals to integrate informal and formal support systems in order to build capacity within the family unit (Bruder, 2000; Guralnick, 1991).

The individual family service plan (IFSP) serves as the framework for guiding practice with families. Embedded within this framework are formal and informal support systems (Gallagher & Desimone, 1995; McWilliam, Ferguson, Harbin, Porter, Munn & Vandivere, 1998).

Early intervention researchers and practitioners must continue to examine the formal support system but also investigate the informal support system to better understand how to integrate the two systems in order to better support families and children. The early childhood intervention field is at the point of having a generally agreed upon family-centered practice philosophy and an IFSP framework to guide practice. Therefore, it is essential to begin to investigate the indicators of family quality

of life within the formal and informal support systems. This entails moving from a macro understanding of research and practice to a micro understanding of the indicators that provide families with a substantial system of support. This includes the indicator of spirituality, which is embedded in the emotional well-being category of family quality of life.

A review of the early intervention literature demonstrates beginning research regarding family quality of life (Brown, Anand, Isaacs, Baum, & Fung, 2003; Cummins & Baxter 1997; Poston, Turnbull, Park, Hannan, Marquis & Wang, 2003; Poston & Turnbull, 2004). Conversely, research on family quality of life, which includes the indicator of spirituality, is limited (Brown et al., 2003; Poston et al., 2004). Therefore, this research will investigate how parents and practitioners view spirituality within the context of family-centered practice. This research will pursue the topic of spirituality, which is an established indicator of individual and family quality of life (Cummins & Baxter, 1997; Felce, 1997; Gardner, Nudler, and Chapman, 1997; Hughes & Hwang, 1996; Park, Hoffman, Marquis, Turnbull, Poston, Mannan, Wang, & Nelson, 2003). Spirituality is embedded within the informal family support system, which is an essential component to be integrated into family-centered practice. The driving question is, “Do parents and practitioners view spirituality as a valued or necessary entity to overtly integrate into family-centered practice?”

B. Personal Reflection

As a dedicated early intervention professional who has spent 15 years providing early intervention services for children with developmental needs and their families, I have gained many experiences and insights along this professional journey.

Being at the mid-point of my life, I reflect upon the needs of individuals and families to be encompassed in a holistic fashion. Often the spiritual domain of families is neglected and unspoken when we begin to support and work with children and their families. As a constructivist practitioner who utilizes a relationship-based approach of working with families, I realize and understand that we often enter into discussions with families that reflect their spiritual philosophies and quests. These reflections or quests are in relation to understanding the families' grief, acceptance, joy, anger, or denial in the context of having a child with developmental needs.

Within the field of early intervention, formal and informal systems of support are espoused as needing to work together to support families. At times it has been difficult to meld the two systems; they are often not coordinated in a unified fashion in the ways that enhance family-centered practice. Spirituality is embedded in the informal support system, often clad within the emotional support system for families.

As a practitioner who continues to grow and develop spiritually, I am curious to investigate whether this is a domain which families and practitioners feel comfortable in discussing within the framework of family-centered practice. How do families utilize their spirituality as a source of support when facing difficult circumstances with their child who has developmental needs? How do practitioners react to and integrate the

families' spiritual beliefs in an overt, caring, and respectful fashion into the framework of family-centered practice?

C. Purpose and Aim

The purpose of this research was to explore the views of parents and practitioners regarding the concept of spirituality in relation to family-centered practice. Families and practitioners who are involved in early intervention programs and guided by the Individual Family Service Plan (IFSP) were asked to share their perceptions of this topic. While there is much research on early intervention and family-centered practice utilizing the IFSP, minimal attention has been given to integrating formal and informal support systems, specifically family spirituality. Early intervention research is moving from examining and developing broad standards of practice to examining indicators of family quality of life and how these manifest in measurable outcomes for service provision.

Spirituality is unique and personal to each family - as unique as each family's culture. As practitioners we are called to work closely with families and to value and honour their belief systems. Because of relational-based practice and the apparent gap that exists regarding spirituality in family-centered practice, this research provides early intervention professionals and families with an opportunity to begin addressing spirituality within the framework of early intervention services. Ultimately, the research provides an opportunity to reflect upon and practice competencies in family-centered practice in order to serve families better. The desired outcome is a practice-based shift to integrating formal and informal supports within the IFSP process and encouraging families and practitioners to engage in discussions about spirituality, which is a foundational element of humanness. As integration of spirituality in family-centered

practice is important based on parent and practitioner views, the dimension of spirituality can be embraced as an additional component to incorporate into competencies and outcome measures in family-centered practice.

D. Research Questions

- 1) Is spirituality a topic of conversation parents deem important to discuss with the early intervention practitioner?
- 2) Is spirituality a topic of conversation that early intervention practitioners deem important to discuss with the parents?
- 3) Is spirituality a valid concept to be integrated into the Individual Family Service Plan?
- 4) What types of innuendos are used in early intervention practice that promote/disclaim discussion of spirituality?
- 5) What supports, resources, or early intervention competencies are needed to integrate the concept of spirituality in family-centered practice?

E. Definitions

For the purpose of this research the following definitions and terms will be utilized:

Parent- biological, adoptive, foster, or legal guardian who is the primary caregiver of a child with developmental needs.

Early Intervention Practitioner- an individual professionally trained at the undergraduate or graduate level in a field or fields related to early childhood development.

Knowledgeable in child development, in the provision of family-centered practice, and collaborative practice (British Columbia Infant Development Program, 1997).

Early Intervention- the provision of support to families of infants and young children from members of informal and formal social support networks that impact both directly and indirectly upon parent, family, and child functioning (Dunst, 2000).

Family-Centered Practice- collaborative relationship between families and professionals, in which parents are empowered to set service priorities for the well-being of their young child, professionals are responsive to the priorities and choices of the families, and parents are recognized as experts on their own children (Bruder, 2000).

Spirituality- finding meaning in our existence, for fulfilling relationships between oneself and others, the universe, and reality as one views and understands it. May include components of religious devotion, being fully aware of one's species being, being aesthetically or ethically aware (Hay & Nye, 1998).

Religion- belief in a superhuman controlling power, especially in a personal God or Gods entitled to obedience and worship. Religion is associated with a particular system of faith and worship; a thing that one is devoted to; life under monastic vows. Associated with churches, mosques, bibles, prayer books, religious officials, weddings and funerals (Hay & Nye, 1998).

Dogma- a strongly held opinion or belief that is accepted without question (Kozeny, 2004)

Individual Family Service Plan- a document developed in partnership with families and practitioners. The needs of the child and family drive the development of the document. The document defines formal and informal family support systems (Minke & Scott, 1993).

Formal Support- paid supports that are provided to a family who has a child with developmental needs (e.g., early intervention, speech and language services, medical services) (Dunst, 2000).

Informal Support- unpaid supports that are provided to a family who has a child with developmental needs (e.g., family, friends, neighbours, spiritual group) (Dunst, 2000)

Centered-Based- child-related services that are offered and implemented in a location outside the home environment (e.g., medical offices, hospitals, childcare centres).

Home-Based- child-related services that are offered and implemented in the child's home environment.

CHAPTER II

Literature Review

The literature review begins with a global perspective of early intervention, its philosophy and its process and then moves to a more refined micro perspective of indicators of quality of life and family quality of life, in which spirituality is embedded in the emotional domain of quality of life. Research that informed the inquiry of spirituality within family-centered practice will then be presented.

While spirituality in family-centered practice has not been well researched, extensive research has been conducted and published in regard to spirituality in the health care, social work, and mental health professions (Canda, 2004; Elkins & Cavendish, 2004; Faver, 2004; Kelly, 2004; Mellon, 2002).

A. Early Intervention

The term “early intervention” applies to any type of intervention in the early stages of a defined problematic developmental issue. Early intervention is utilized to create programs and services for such diverse areas as autism, Alzheimer’s disease, schizophrenia, psychosis, traumatized children, reading, multiple sclerosis, back pain, or asthma.

In terms of child development, “early intervention applies to children of school age or younger who are discovered to have or be at risk of developing a handicapping condition or other special need that may affect their development” (Kidsource, 2004).

Dunst (2000) defined early intervention as “the provision of support to families of infants and young children from members of informal and formal social support networks that impact both directly and indirectly upon parent, family, and child functioning” (p. 96). This social systems approach to early intervention emphasizes a set of principles for structuring the provision of social support, and a social systems framework for understanding the influences of social support on the child, parent, and family functioning, is essential. The most radical feature of the definition is that interventions should emphasize mobilization of supports from informal network members rather than relying solely or primarily on formal supports from professionals and professional helping agencies. This includes mobilizing supports from normal socializing agents such as family, neighbourhood, church, and other community institutions.

Conversely, Guralnick (1998) sees early childhood intervention more as a concept than a specific program. He comments,

Much of the diversity of early intervention is due to the range of differences related to specific target groups, which include broad-based agendas of health promotion, disease prevention, early child care, preschool education, developmental disabilities, economic hardships, family violence, mental health problems, child psychopathology, maternal depression, and parental substance abuse (Shonkoff & Phillips, 2000, p. 338).

Early intervention programs reflect diversity in the marked heterogeneity of service formats. These formats may include variations and combinations of home-based, center-based, and child-focused or family-focused philosophies. Included in this range of

service formats is also a blend of staffing configurations which range from highly professionalized services delivered by educators, developmental therapists, social workers, and nurses to personalized supports provided by community workers with limited formal education or training.

The common underpinning of all early childhood intervention programs is a concern for the child's development or behaviour, regardless of the cause, and a belief that formalized services increase the probability of a more positive outcome (Guralnick, 1998).

B. History and Evolution of Early Intervention

Scientists, researchers, and practitioners have had a long-standing interest in the process of early childhood development. As Shonkoff and Phillips (2000) noted, "the systematic study of infant behaviour can be traced back to the early to mid-19th century, when researchers in both embryology and evolution raised fundamental questions about the origins and course of human development across the life span"(p. 19). This quest continued into the 1920s with the blending of the professions of paediatrics, education, social work, and psychology within the field of child study. This process created a vibrant, multidisciplinary scientific discipline, blending the theories, empirical investigations, and professional experience of each. Over the last three decades, the explosion of information due to theoretical and conceptual advances, technological and computer-based analytical capacity, and behavioural and biological sciences has been phenomenal. The current trend of collaboration among neurobiologists, geneticists, and

social scientists offers an exciting enhancement of the understanding of the process of human development during early childhood (Shonkoff & Phillips, 2000).

In order to understand current early intervention practices, a brief historical overview provides insight into state-of-the-art practice.

A number of theoretical foundations provided the current grounding for early intervention, one of which is the “nature vs. nurture” debate. In the 1920s and 30s, “Dr. Arnold Gesell espoused an ardent belief in the biologically based unfolding of behaviour as a child matured, regardless of experience” (Farrell-Erickson & Kurz-Riemer, 1999, p. 3). Gesell’s well-documented developmental sequences derived from a maturational perspective on development continue to influence practice in early intervention.

Providing the opposing view in the nature vs. nurture debate was Dr. John B. Watson who assumed a “blank-slate” perspective on child development, which highlighted the influences of environment and experience. This perspective led to many later behaviourists extending Dr. Watson’s position and advocating for programs that would provide children with stimulation (Farrell-Erickson & Kurz-Riemer, 1999). During the 1970s a full appreciation for the impact of both biological and environmental factors on development was realized and articulated in Sameroff and Chandler’s transactional model. This model highlights the sophisticated interplay between a child’s biological, social, and environmental influences on a child’s development.

In the late 1970s and early 80s Bronfenbrenner’s “ecological” model provided a “systems” perspective to take into account many formal and informal social units and networks that affect what happens in a child’s life. These units examine immediate influences such as family and extended family, move to networks of friends and

neighbours, churches, agencies, and expand further to policy and socio-cultural networks. This model provides an interdependent network model that considers how events in one unit may affect other units (Farrell-Erickson & Kurz-Riemer, 1999).

The overlay of developmental theories with models of family functioning is a key ingredient to early intervention practice; a number of approaches are identified and have implications for early intervention practice. The systems theory described by Von Bertalanffy (as cited in Beckman, Robinson, Rosenberg, & Filer, 1994) maintains, “that all living systems are composed of interdependent parts; that is, factors affecting one part of the system are likely to affect other parts. Interaction among the parts creates features of the entire system that are not present individually in any of the parts” (Beckman et al., 1994, p15).

An additional theory or approach to the study of families involves the study of family stress. Children with developmental disabilities place emotional, physical, and time demands on family members that impact the level of stress a family experiences. The “ABCX Model,” developed by Hill in the late 1940s has four components. “The stressor event (A) interacts with the family’s resources (B) and the family’s perception of the event (C) to determine the extent to which the event becomes a crisis for the family (X)” (Beckman et al., 1994, p. 16).

The “family life cycle model” developed by Duval (1957) is a third approach to understanding families. “This model addresses the issue of family change over time”(Beckman et al., 1994, p. 17). Functions of the family and roles played by family members are believed to change based on the family’s stage in the life cycle. Transitions from one stage of the cycle to another offer the most potential for stress within the family

unit. Turnbull, Summers, & Brotherson (1986) studied the effects that children with disabilities have on families. Findings include additional family stress associated with delayed and lengthy transitions, failure of the child to achieve milestones, and children hospitalized for long periods of time.

The blending of theories and models has impacted, articulated, diversified and grounded early childhood intervention. Models of service delivery have continued to evolve over the last several decades.

C. Models of Service Delivery

During the last 4 decades there have been tremendous developments in the field of early intervention. These developments have led to a variety of models of service delivery that may still be considered as contemporary approaches. Two driving theoretical assumptions provide the underlying rationale for early intervention programs. The first assumption is that genetic and biological problems or deficits can be overcome or attenuated and secondly, early experiences are important to children's development (Bricker & Veltman, 1990). In order to understand the acceptability of family-focused intervention we must examine how the field of early intervention evolved and arrived at this generally accepted consensus.

i. Child-focused.

Child-focused early intervention programs were developed based on three assumptions. First, that children with developmental problems require more and/or different early experience from nondisabled age-mates. Second, that formal programs

with trained personnel are necessary to provide the required early experience to compensate for developmental problems. Finally, that developmental progress is enhanced in children with handicaps who participate in early intervention programs (Bricker & Veltman, 1990, p. 374). Therefore, the essence of a child-focused program is one of a formal structure of instructional strategies derived from developmental theory and applied systematically by trained interventionists to facilitate behaviour change in the child.

Bricker and Veltman (1990) expanded further on the theoretical and program components of child-focused programs. Child-focused programs advocate a number of guidelines for infant and child learning, such as: the central system must be aroused, attention must be focused, active participation must occur, and learning is facilitated through environmental manipulation that produces disequilibrium in children. The majority of child-focused programs operate within a three-phase context. Phase one, entry, encompasses finding, identifying, and referring children to programs for services. This includes the two rigorous exercises of screening and diagnostic evaluation. These two activities are present within many health, education, and social service networks to ensure that young children with developmental needs are discovered early and provided with services. Phase two, program implementation, includes activities relevant to service delivery, including program assessment, individual education plan (IEP) development, development and implementation of an instructional program, and evaluation. Phase three, exit, focuses systems on the transition of children from the early intervention program to the next setting. This phase includes the systematic sharing of information between exit and entry agencies to satisfy the child's individual needs.

ii. Caregiver-focused.

Caregiver-focused models concentrate early intervention efforts on the child's caregivers. A grounding premise within this model is the importance of the parents' role for the health, well-being, and development of the infant and young child. It is the parents who protect the child's health, social, and cultural traditions. Parents guide the young child's development in thinking, acting, and feeling as a person. They enable the child to experience intimacy, security, and love. It is essential that professionals support parents and other caregivers through the skilled use of knowledge about development, health, physical, emotional, and intellectual well-being.

The ideal outcome of a caregiver-focused model occurs when the service providers are successful in creating a working partnership with the caregivers on behalf of the child. Through the evolution of early intervention it has become known that professionals cannot be the only source of expertise and wisdom, so a partnership with parents and caregivers is the ideal outcome.

Seitz and Provence (1990) suggest that there are three basic principles that enhance successful early intervention with caregivers: competence, continuity, and partnership.

Competence refers to the competence of service providers. It is essential that professionals provide parents with basic knowledge and practical skills that match the needs of the child and family. The team of persons providing the services should also have special skills and knowledge in different areas and understand how to work with parents. The competence principle is applicable to a wide range of professionals in the

health, mental health, education, social service, legal system, daycare, foster care, and residential care settings, and with paraprofessionals and lay home visitors.

Continuity of care is more effective when service providers are supportive and know the parent and child well. “Utilization of services and the satisfaction of clients and patients are enhanced by parents’ ability to see and count on being seen by the same service providers over time” (Seitz & Provence, p .402).

There are four common models of intervention that are utilized when working with the parent and child. These are: parent as recipient of developmental guidance, parent and child models, parent as therapist, and parent as teacher (Seitz & Provence, 1990).

The parent as recipient of developmental knowledge is applicable when the child is the primary focus of attention, but the work goes on between the caregiver and practitioner. Providing advice about keeping children healthy, how to care for them when they are ill, hurt, or disabled, and providing developmental knowledge are strategies utilized. Information is imparted in a sensitive, caring manner when a parent is ready to hear and use it. The assumption is that information will have a beneficial influence on the caregiver’s ability to function comfortably and competently in the parental role.

“Parent and child” models operate on the premise of working with both parent and child, in the presence of a therapist, all of whom are participants in the therapeutic process. The effectiveness is determined by to the changes brought about in the parent. The child is present and participates primarily as a catalyst as his/her development,

actions, and reactions to parent and therapist facilitate and shape the direction of the work.

“Parent as therapist” enables parents to function as therapists, doing what professionals would do for their children. Nurses, speech, occupational, and physical therapists, as well as teachers have utilized this model. Parents are increasingly expected to learn and master techniques in the above therapies. This is in addition to understanding the needs of their child with complex health care needs such as respiratory, gastrointestinal, neurological, or urological problems. In order to utilize the parent as a therapist it is essential to assess that the child and parent appropriately to determine that the child does not need direct work and the therapy may be carried out through guiding the parent. The child’s well-being remains the central focus of the work between the clinician and parent. Practitioners need to be aware that something beyond the ordinary parent-child relationship is involved. The parent is being asked to assume a role that is task-oriented and the child is being requested to cooperate in the same way they would with the therapist. This may cause undue stress on the child and parent and emotional complications may escalate. Continual evaluation of the therapeutic plan is the responsibility of the professional.

When the child’s primary problem has been perceived as intellectual slowness due to a presumed lack of adequate cognitive stimulation, the “parent as teacher” model is utilized. A similar process as with “parent as therapist” is utilized; the intensity of the effort may be less in the “parent as teacher” model. This model “is likely to be imposed on parents by others who are concerned about the child’s development rather than

adopted because the parents perceive a problem and seek help” (Seitz & Provence, 1990, p. 406).

iii. Family-centered intervention.

Family-focused and family-centered intervention are synonymous labels that have emerged in the last several decades to encompass a broader model of working with children within the context of the family. Singer, Power, and Olson (1996) provide a comprehensive definition, “family-centered service delivery, across disciplines and settings, views the family as the unit of attention. This model organizes and delivers assistance in a collaborative fashion and in accordance with each family’s wishes, strengths, and needs” (p. 64).

One of the earliest forms of family-focused intervention focused on prescribed programs of stimulation or therapy administered to the infant by the practitioner, with the parent assuming a passive bystander role. Because the child is focus of the therapy and the parent is minimally involved, this could also be perceived as a child-focused model.

Simeonsson and Bailey (1990) highlight three alternate forms of family-focused intervention that have evolved. The first began in the early 1970s with the recognition of the importance of family involvement in programs on behalf of handicapped children. This recognition was formalized for school-aged children with the provisions of Public Law 94-142, which specified the rights of parents to participate in the educational planning process on behalf of their handicapped child (p. 428).

Within early intervention, the process of involving parents was less formalized, yet parents were encouraged to become involved in their child's program. In this method of early intervention, training family members to extend the teaching and therapist roles of the practitioner formalized parent involvement. Parents were encouraged to become the cotherapist with the interventionist, which could also be perceived as a caregiver-focused model.

During the early 1980s, "families began to be viewed as important recipients of services...this form of family involvement is currently gaining increased attention through the formal requirements for family assessment, family goals, and family services spelled out by the provisions of Public Law 99-457" (Simeonson & Bailey, 1990, p. 429) in the United States and through provincial policies in Canada.

In the United States, Public Law 99-457 provides the federally legislated impetus for change; within Canada this is not so. It is upon the backs of those educating, practicing, and politicizing within the realm of early intervention to support the paradigm shift in order for family-centered intervention to become the "norm" of practice.

Two conceptual contributions that reinforced the importance of family involvement were the formulation of the transactional model of child development by Sameroff's and Bronfenbrenner's ecological systems model. The transactional model "views the family as the essential component of the care giving environment that influences and is influenced by the child over time, resulting in differential outcomes for child and family" (Simeonsson & Bailey, 1990, p. 430). The ecological model

"views the family as one system embedded in the larger ecological framework of systems. Two overriding implications of these models for

early intervention include 1.) Adoption of a systems orientation of intervention because the influence of family members is reciprocal.... and because the family system is embedded in a larger ecology, and 2.) Assessment and intervention should consider different levels of reciprocal effects involving the immediate family, the community, and the society in which the family is situated” (p. 430).

These findings and contributions have led to the diversification of approaches of family involvement in early intervention.

Families have become participants in the provision of services to their children, and families have become clients and recipients of services. Family involvement can be viewed as a continuum, varying in form, focus, and complexity depending upon the interaction of child, family, and program variables.

A number of principles underlie the philosophy of family-centered care. These include: that infants are dependent on their families, that families are diverse and must be respected, that families should determine involvement in services, that families and professionals must collaborate, that traditional practices must change, that normalization principles should guide practice, and that teamwork is critical. (B.C.I.D.P. Manual, 1997).

Trute, Hiebert-Murphy, Wright, and Levine (2004) define family-centered services in the field of childhood disability as being characterized by a focus on the family unit as a vital context of child development. Parents are viewed as partners with professionals in this service model, are recognized as experts on their own children, and are empowered to set service priorities for the well-being of their young children with

developmental delays or intellectual and physical disabilities. The emphasis on families has been guided by a number of findings. Turnbull and Turnbull (1982) found that one factor for increased family involvement was the general growth in parents' involvement on behalf of their children. Parents are becoming more sophisticated consumers of services and more knowledgeable about the dimensions of service. Simeonsson, Cooper and Schiener (1982) determined that questionable evidence of the effectiveness of early intervention resulted when programs focused on children alone. This led to an interest in family outcomes. Kaiser and Fox (1986), using behaviour modification, noted the success of parents in modifying their child's behaviour; this was another factor that led to supporting a family emphasis in early intervention. Finally, Bailey and Simeonsson (1988) reported on the formal and informal evidence that families have specific needs related to the presence of an infant or young child with disabilities.

The grounding essence of family-centered practice is the relationship and collaboration between families and professionals. Bruder (2000) cites a number of empirically-based practices that support family and child competence.

These practices include treating families with dignity and respect; being culturally and socioeconomically sensitive to family diversity; providing choices to families in relation to their priorities and concerns; fully disclosing information to families so they can make decisions; focusing on a range of informal, community resources as sources of parenting and family supports; and employing help giving practices that are empowering and competency-enhancing (p. 113).

Trivette, Dunst, and Hamby (1996) found that help-giving practices and staff disciplines were factors associated with the degree to which families indicated they had control over needed services, resources, and supports. Help-giving practices that actively involved families in making decisions and choices are perceived to give parents more control. It is important to note that help-giving practices, not help-giving behaviours (active listening, empathy), contributed to this perceived sense of control. It is also essential that practitioners employ the use of quality clinical help-giving behaviours, but also expand them to ensure that help-giving practices support the family.

Implanted within the practice of family-centered practice is the notion of empowerment, which “refers to a constellation of processes and activities that involve people in determining their own futures and, possibly, the future of their communities. People may perceive varying degrees of empowerment depending on the scope of the environment they are attempting to affect” (Thompson, Lobb, Elling, Herman, Jurkiewicz, & Hulleza, 1997, p. 100). Within family–professional collaboration it is essential that families have a sense of empowerment to ensure they are confident, and have the information and problem-solving skills necessary to deal with challenging situations. Thompson et al. (1997) have defined a number of factors that predict empowerment among families within a program structure. Through the development of the Individual Family Service Plan (IFSP), empowerment begins with the family’s assessment of its own strengths and needs rather than the professionals’ assessment of these skills. The service coordinator can also empower families as together they find and arrange services, communicate preferences to other service providers, share their knowledge of the systems and help translate parent concerns into language that produces

action. It is essential to remember that the quantity of supports may not be as crucial as the relationship between the parent and the source of support. Thompson et al. (1997) found that family-centeredness relates to the degree of support, formal and informal, that a family receives. The more helpful support a family gets, the less stress they will experience. This decreased stress is expected to relate positively to empowerment. A second factor related to family empowerment is the implementation of program components in a family-centered manner. This should facilitate “the families’ ability to cope with the challenges they face, lowering family stress therefore increasing empowerment” (p. 108).

The fundamental nature of family-centered practice calls on practitioners to utilize relationship-based and empowerment practices that promote the family to maintain a quality of life similar to families that do not have children with developmental needs. The individual family service plan offers to bridge the gap from relationship-based, empowerment practice and provides the roadmap for the process.

D. Individualized Family Service Plan (IFSP)

The individualized family service plan (IFSP) demonstrates that early intervention is concerned with the whole family and results from a family-centered process of identifying child and family strengths and needs and deciding on intervention priorities (McWilliam, Ferguson, Harbin, Porter, Munn & Vandiviere 1998; Minke & Scott, 1993). The IFSP is a document developed in partnership with families and practitioners. The quintessential needs of the child and family drive the development of the document. It is understood that the final decisions and approval of the plan rests with the family (Minke

& Scott, 1993). IFSP's can be identified as family-centered for four reasons: (a) families can be more in control if they understand the major document pertaining to their early intervention services and if they sense that they have control over decision making; (b) the IFSP theoretically guides services, so it needs to reflect family priorities; (c) if the IFSP corresponds with actual practice, the former should suggest that recommended practices are being implemented; and (d) if the IFSP does not correspond with actual practice, the importance of improving the document is even more compelling (Farel & Shackelford 1997; McWilliam et al., 1998). The IFSP needs to conform to procedures so that families have documentation about what is happening, all service providers involved know what is happening, and intervention is systematic (McWilliam et al., 1998).

Minke and Scott (1995) investigated the importance and benefit of personal relationships between families and professionals during the process of developing the IFSP. What they discovered was that relationship quality and control issues emerged as significant factors in parent–staff interactions. A characteristic that supports the success of the IFSP process is parent–staff bonding. Parents emphasized the importance of this bonding, perceiving it as emotional support. Practitioners reported “easier joint problem solving, greater acceptance of program limitations, and parent’s increased willingness to try new behaviours” (p. 343) as benefits of close relationships. Practitioners also perceived parents as becoming more assertive in the process. This was based on “parents becoming more experienced in the process thus being familiar with the procedures which increased participation and as the relationships became closer, parents experienced greater comfort in expressing themselves” (p. 344).

The McWilliam et al. (1998) study of 100 IFSP's from a variety of agencies identified a number of findings relevant to current practice in developing IFSP's. These included:

(a) the IFSP Family-Centeredness Rating Scale is sensitive to differences between program types; (b) team integration, as reflected in IFSP's, is greater in inclusive programs than in segregated programs; (c) IFSP cohesion as a whole is weakest in center-based segregated programs; (d) IFSP functionality is weakest in programs providing primarily service coordination; and (e) goals and family concerns are predominantly child related (p. 75).

The decade-old concern of IFSP family goals being predominately child-related as identified by Bailey, Winton, Rouse, and Turnbull (as cited in McWilliam, 1998) remains. Beckman (1991) identified a variety of IFSP concerns: "(a) sensitivity to cultural diversity, (b) family assessment, (c) intrusiveness, and (d) establishing family outcomes" (p. 19). Issues such as these are residual in transforming practice from a child-centered to a family-centered model of practice and present constant challenges to early intervention practitioners. While some attention has been given to identifying and describing family outcomes related to the IFSP process, (Park, Hoffman, Marquis, Turnbull, Poston, Mannan, Wang & Nelson, 2003) the issue remains relatively unexplored.

E. Individual Quality of Life

Quality of life is a trend that has emerged extensively in the last decade. The concept has attracted a large amount of interest, especially in the areas of health, social services, and increasingly in medicine, education, and community living (Quality of Life Research Unit, 2004). Quality of life relates to communities, families, and individuals from a variety of population groups (Hancock, 2000; Quality of life Research Unit, 2004). A number of definitions provide an overall sense of meaning to the term. These definitions include: (a) degree to which a person enjoys the important possibilities of his or her life, (b) products of the interplay among social, health, economic, and environmental conditions which affect human and social development, (c) a feeling of well-being, fulfillment, or satisfaction resulting from factors in the external environments, and (d) a popular expression that connotes an overall sense of well-being when applied to an individual, and a pleasant and supportive environment when applied to a community. Quality of life is a global outcome that is highly valued by all populations (Ontario Social Development Council, 1997; Jacksonville Community Council, 1996; U.S. Department of Health and Human Services, 1998 as cited in Hancock, 2000).

With this amount of interest paid to quality of life, it is critical that we understand the importance behind this interest. As presented by Hancock (2000), the interest in quality of life is reflected in a number of concerns: (a) recognition in the development sector that it is not just economic development but also social and human development that relates to the ability to measure economic activity, (b) recognition as part of the environmental movement – in order to be environmentally sustainable, we must also be

socially sustainable and contribute to an improved quality of life, (c) an interest in the liveability of cities – comparing and measuring the quality of life of cities linked to the impact of urbanization and suburban sprawl on the quality of life of individuals and communities, (d) an understanding that the length or quantity of life is a small factor in comparison to the health of life, including disability-free and life expectancy. These factors denote concern on behalf of the environmental, social, economic, and human development sectors, at all levels of government.

A major study by the Centre for Health Promotion of the University of Toronto, (1997), identified a number of quality of life indicators. The three major categories were identified as “Being,” “Belonging,” and “Becoming.” Each of these three major categories encompasses three sub-categories, physical, psychological, and spiritual being; physical, social, and community belonging; and practical, leisure, and growth becoming (Appendix G).

Similarly, yet formatted differently by a variety of researchers, quality of life includes six domains and associated indicators. These domains and indicators include: (a) physical well-being (health, nutrition, mobility and daily living activities); (b) emotional well-being (happiness, contentment, freedom from stress, self-concept, and religious belief); (c) social well-being (intimacy, friendships, community activities, and social status and roles); (d) productive well-being (personal development in education or job, leisure and hobbies, choice and autonomy, and personal competency); (e) material well-being (ownership, financial security, food and shelter, and socioeconomic status); and (f) civic well-being (privacy, voting, access, civic responsibilities and protection under the law) (Schalock, Brown, Brown, Cummins, Felce, & Matikka , 2002)

(Appendix G). The indicators are not exhaustive and provide an ongoing list that may be added to and refined continuously (Cummins & Baxter, 1997; Felce, 1997; Gardner, Nudler & Chapman 1997; Hughes & Hwang, 1996; Schalock, 1996).

An additional way to perceive self-reported quality of life is provided by Musschenga (1997). These related concepts include satisfaction with life, happiness, and well-being (Appendix G).

As presented above, quality of life can be perceived and identified in broad categories or broken down into smaller indicators of quality of life. The research has been extensive and will continue to develop over years to come. Quality of life research has drawn attention to family quality of life in relation to measurement and service outcomes, which are active areas of research being pursued within the early childhood intervention field (Brown, Anand, Isaacs, Baum & Fung, 2003; Donohue, 2002; Park, Turnbull & Turnbull, 2002; Park et al, 2003; Poston, Turnbull, Park, Mannan, Marquis & Wang, 2003).

F. Family Quality of Life

Family quality of life is at the beginning stages of conceptualization (Poston & Turnbull, 2004) and is a natural extension to the past three decades of research and international consensus of individual quality of life (Cummins, 1997; Felce, 1997; Schalock et al., 2002). Similarly, the notion of family quality of life has recently begun to receive attention and is dependent on the literature about individual quality of life (ACSPD, 1995; Bailey, McWilliam, Darkes, Hebbeler, Simeonsson, Spiker & Wagner,

1998; Park et al. 2002; Turnbull, Turnbull, Poston, Beegle, Blu-Banning, Diehl, Frankland, Lord, Marquis, Park, Matt & Summers, 2000).

Family quality of life encompasses conditions where the family's needs are met, family members enjoy their life together, and family members have the chance to do things that are important to them. In comparing family quality of life to individual quality of life, it considers all family members in terms of what it takes for them to have a good life, therefore achieving an aggregated perspective (Poston et al, 2003; Poston & Turnbull, 2004).

Brown and Brown (2003) have defined four core principles related to family quality of life that are consistent with the findings of international research teams. These core principles include: (a) family quality of life changes as each family and its members experience life; (b) family members influence each other; (c) domains impact each other; (d) there is not a standard family quality of life—the family decides what “quality” means to them.

As with individual quality of life, there are a number of ways of developing and perceiving the domains and indicators of family quality of life. Poston et al. (2003) suggest ten individual domains which are: family interaction, daily life, parenting, financial well-being, emotional well-being, health, physical environment, productivity, social well-being, and advocacy (Appendix H). Turnbull et al., (2000) utilize these same ten family quality of life domains, yet categorize these domains into those that affect the family as a whole and those that differentially affect only individual members of the family. Domains affecting the family as a whole include daily life, family interaction, financial well-being, and parenting. The indicators impacting the individual family

members include health, emotional well-being, physical environment, social well-being, health, productivity, and advocacy (Appendix H).

An international study by Canada, Australia, and Israel utilized nine domains and associated indicators that the researchers developed to collect data around a conceptual framework of family quality of life. The domains included health, financial well-being, family relationships, support from other people, support from disability-related services, spiritual and cultural beliefs, careers and preparing for careers, leisure and enjoyment of life, and community and civic involvement (Brown et al., 2003). In general, results indicate that careers, spiritual and cultural beliefs, and family relationships were rated highly, while support from others and support from disability-related services were rated quite low.

As with individual quality of life, there is importance behind establishing indicators, measurement tools, and research for family quality of life. A number of these reasons have been identified by researchers and include:

- Efforts to address the individual's quality of life must also consider the quality of life of those around them (Bailey et al., 1998; Dennis, Williams, Giangreco & Cloniger, 1993).
- Quality of life for families with children with disabilities has emerged as a useful indicator of outcomes for policy initiatives (Bailey et al., 1998).
- Growing recognition of the importance of family-centered service delivery utilizing family-choice, family-strengths, and the family as a unit of support (Allen & Petr, 1996; Bailey & McWilliam, 1993; Dunst, Johnson, Trivette, & Hamby, 1991).
- Need for developing a psychometrically sound scale for measuring family quality of life. Measurement could have powerful social policy implications in addition to effecting philosophical and legal principles (Park et al., 2003; Poston et al., 2003).

- The development of a family quality of life survey that can be used in agencies, with individual families, at the program evaluation level and create innovations in staff training and personnel preparation (Park et al., 2003; Poston et al., 2003).
- Providing a conceptual framework that will guide the evolution of research and family support could produce significant and sustainable enhancements in families' outcomes. This can be instrumental in guiding policy that influences resource allocation decisions (Park et al., 2003; Poston et al., 2003).

As highlighted in Park et al. 2003, the uniqueness of each individual is important in the evaluation of family quality of life. It is a prominent consideration, whether or not the person has a disability. Schalock (1996) argues that quality of life for people without disabilities encompasses the same domains as it does for those with disabilities. Hatton (1998) asserts that the experiences of people with disabilities can be restricted because of the limits imposed by disability conditions, and in turn, these limited experiences may result in different indicators of quality of life. "All nine domains of quality of life are relevant for all families, the tenth one, advocacy, is especially relevant for families who have a member with a disability" (Park et al., 2003, p. 368).

G. Family Quality of Life with a Child with a Disability

The importance of understanding family quality of life for families with children with developmental needs is timely and essential. "Increasingly governments and other funding sources in developed countries are turning to families to provide the principal care to both children and adults of all ages with disability" (Brown et al., 2003, p. 208). Families that have children with disabilities are often left with little choice but to accept an increasing amount of responsibility related to the care and well-being of their children (Brown, 1999; Renwick, Brown, & Raphael, 1997).

A qualitative inquiry on family quality of life by Poston et al., 2003, found that the concerns of parents of children with disabilities were more intense and generally more frequent than the concerns expressed by parents of children without disabilities. The focus groups and interviews produced extensive information about families related to the ten domains of family quality of life: advocacy, health, productivity, emotional well-being, physical environment, social well-being, daily family life, family interaction, financial well-being, and parenting.

Park et al. (2002) investigated the impacts of poverty on quality of life in families of children with disabilities. This research focused on five of the ten quality of life domains (health, productivity, physical environment, emotional well-being, and family interaction). Results indicate that generally “households with a family member with a disability have significantly lower income and greater dependence on means-tested income support, which indicates that poor families of children with a disability will be affected by poverty more severely than either poor families of nondisabled children or affluent families of children with a disability” (p. 159). As mentioned previously, Canadian results from an international study on family quality of life (Brown et al., 2003) where quantitative and qualitative data was collected for four concepts (opportunities available, initiative to access opportunities, attainment, and satisfaction) within each of the nine key areas of family quality of life indicate that careers, spiritual and cultural beliefs, and family relationships were rated highly, while support from others and support from disability-related services were rated quite low. The results of these studies led to many implications for policy, research, and practice.

H. Spirituality and Religion

Spirituality in the lives of individuals is an essential attribute of being human. It is a basic aspect of human experience, development and experience, common to all people, cultures, and religions. It is essential that we know and understand spirituality as being separate from, yet entwined with religious dogma.

Spirituality is a broad, encompassing, and complicated phenomenon that is distinct to each individual. It involves the phenomena of being concerned with the spirit, religion, the divine, or being inspired. It is viewed as something warm, associated with love, inspiration, wholeness, depth, mystery, and personal devotions like prayer and meditation. The term spiritual is used in relation to persons who demonstrate refined aesthetic awareness of poetry, music, the arts, or are sensitive to the needs of other people (Canda, 1999; Fitchette, 1993; Gaventa, 2001; Hay & Nye 1998; Oxford Dictionary).

Inherent in the many definitions of spirituality is the need to find meaning in existence, for fulfilling relationships between oneself and others, the universe, and reality as one views and understands it; as well as the way one responds to the sacred. The underlying common ground has three connotations; religious devotion; being fully aware of one's species being; being aesthetically or ethically aware—all refer to a heightening of awareness or attentiveness (Canda, 1999; Fitchette, 1993; Gaventa, 2001; Hay & Nye, 1998; Oxford Dictionary).

Religion is associated with a belief in a superhuman controlling power, especially in a personal God or Gods entitled to obedience and worship, and with a particular system of faith and worship, a thing that one is devoted to, or life under monastic vows. Religion tends to be identified with what is publicly available: churches,

mosques, bibles, prayer books, religious officials, weddings, and funerals. It is an institutionalized and organized pattern of beliefs, morals, rituals, and social structures that people create to help fulfill their spiritual quest (Canda, 1999; Fitzgerald, 1997; Hay & Nye, 1998; Oxford Dictionary).

Spirituality is expressed through religion and religious practices, but it can also be experienced through nonreligious and non-sectarian forms. Spirituality is personal but can also be shared in communities and religious organizations (Canda, 1999).

Bergin and Jensen (as cited in Butter & Pargament, 2003) reported that religion and spirituality have historically been overlooked based on the alienation between religion and psychology. Miller and Thoresen (2003) noted that since 20th century behavioural and health sciences were dominated by positivistic and naturalistic viewpoints, the spiritual side of human nature was often considered to be immaterial and improper to scientific investigation. Opposition to the scientific study of spirituality claimed that spirituality is immaterial and beyond the senses, science offers inappropriate ways to understand spirituality, and it is a philosophical rather than science-based position. The general negative stance on religion and spirituality is evident in psychological literature's tendency to overemphasize pathology and dysfunction, which minimizes the roles of adjustment and well-being (Brawer, Handal, Fabricatore, Roberts, Wajda-Johnston, 2002).

It is important to note that spirituality and religion are prevalent. Recent American statistics show that about 95% of Americans profess a belief in God or a higher power, nine out of ten people pray (67%-75% daily), 69% reported they were members of a church or synagogue, 82% acknowledged a personal need for spiritual growth—a figure

up 24% from the previous four years (Gallup & Lindsay, 1999 as cited in Miller, 2003; Hathaway et al., 2004).

Miller and Thoresen (2003) argue that there is a need to study spirituality and religion with the provision of sound operational definitions, sound criteria to judge the levels of evidence supporting specific hypotheses, and methodological approaches that provide statistical control.

Based on a societal interest in and a need to study spirituality and religion, it is important to note that compassionate help is a natural way of life imbedded in spirituality and religion. Compassionate help is the source of all genuine helping whether informal or professional. Imbedded in understanding spirituality and religion is the interconnectedness of people, and that compassionate concern rises from this awareness and interconnectedness. Compassion and concern are innate in many cultures, and spirituality and religion are ways of life to find meaning, provide moral guidance, and form proper relationships between individuals (Canda, 1999). Therefore, spirituality and religion are concerns to all helping professions and this establishes a strong impetus to begin exploring spirituality and religion in relation to early childhood intervention practice.

It becomes apparent that spirituality is inextricably entwined within our social constructs of society. Whether we define spirituality in terms of taught or known religions or from what we gather from our own personal and philosophical ponderings, it is a multi-dimensional phenomenon—a result of the complex interactions between culture, family, personality, developmental stages, life events, neighbourhoods, and friends influences (Elkins & Cavendish, 2004; Nierenberg, 2001).

i. Spirituality and religion and healing.

Several studies in the fields of health, mental health, and social work point to the contribution of religious and spiritual beliefs and practices to resilience in people who experience illness or disabilities (Canda, 1999). As reported by Miller and Thoresen, (2003) spirituality has been found to be an important and unique component in patients' ability to cope with serious and chronic illnesses (Brady, Peterman, Fitchett, Mo, & Cella, 1999; Ehman, Ott, Short, Ciampa, & Hansen-Flaschen, 1999; Roberts, Brown, Elkins, & Larson, 1997), between religious and spiritual functioning and achieving a sense of meaning in life (Clark, 1958), maintaining a sense of hope and optimism (Myers, 1992; Sethi & Seligman, 1983), mediating substance use and suicide and compliance with a dietary regimen (Martin, 2000; Miller & Thoresen, 2003; Richards & Bergin, 1997; Spilka, Hood, Hunsberger, & Gorsuch, 2003, as cited in Hathaway, 2004). There is increasing evidence to suggest that it is a person's inner world of values, beliefs, and inspiration that helps determine the process of coping (DoRozario, 1997; Kelly, 2004).

More recently, research has focused on a multitude of constructs that address spirituality and religion. For example, Ellis and Campbell (2004) explored ten patients' views about discussing spiritual issues with primary care physicians. Results revealed that patients' willingness to discuss spiritual issues is dependent on their sense of the physician's respect for their spiritual views, attitude about spiritual health, and qualities of openness and approachability.

Kliewer (2004) reviewed numerous studies regarding spirituality and illness and concluded that spirituality can be integrated into the healing process. Kliewer suggested that spirituality significantly influences the process of healing either positively or

negatively and recommended that physicians address issues of spirituality with patients in the context of medical care. Patients' spiritual concerns could be addressed through active listening, identification of spiritual and emotional issues, effective referrals to spiritual advisors, and ongoing communication about this aspect of the healing process. The final recommendation defined the issue of spirituality as entirely about the patient's spirituality and not the caregiver's, and talked about supporting the patient's spiritual beliefs.

Additionally, a similar study was done to determine when patients feel that it is necessary for a physician to inquire about spirituality or religious beliefs. Completed questionnaires by 921 patients indicated that respondents wanted to discuss spiritual beliefs in some circumstances. The circumstances were deemed acceptable when the patient had a life threatening illness, serious medical condition, or experienced the loss of a loved one. The most important reason stated by participants was a desire for physician-patient understanding. They believed that information concerning their spiritual beliefs would impact the physicians' ability to encourage realistic hope, give medical advice, and change medical treatment. The implications of this study indicate that medical care should center on understanding, compassion, and hope. Physicians should be able to identify and have referral sources readily available to patients (McCord, Gilchrist, Grossman, King, McCormick, Oprandi, Schrop, Selius, Smucker, Weldy, Amorn, Carter, Deak, Hefzy, Srivastava, 2004).

These examples provide increasing evidence of the burgeoning and diverse research examining spirituality- and religion-associated life factors and conditions. The expanding research in health, mental health, and social service fields provides

foundational information and progressive implications that can be applied, adjusted, and expanded within early intervention practice.

ii. Assessing spirituality and religion.

Just as it is important for early interventionists to understand recent research on spirituality and religion it is also necessary to examine current assessments and conceptual models that have been developed in order to support families of children with special needs. An awareness of assessments and conceptual models provides early intervention practitioners with information that can be borrowed from other professions and adapted to provide ways of thinking about, assessing, and supporting families.

The development of valid measures of spirituality has not gone unnoticed in research and development. For practitioners in the health, mental health, and social services, an awareness and understanding of ways to conceptualize and measure spirituality and religion as they are linked to specific health and social service issues is necessary to begin to understand the encompassing factors that provide uniqueness, individuality, and supports for an individual or family.

The “Miller Measure of Spirituality” (MMS) is an empirically sound 31-item scale that includes two factors that are related to prosocial beliefs and attitudes about a higher being. This measure provides researchers with a clearer understanding of what is meant by spirituality and how to measure it, which has implications for academic and practical applications, particularly in measuring psychosocial functioning (Miller, 2004).

An additional group of researchers has developed a 29-item survey that comprehensively assesses a patient’s spiritual needs. The tool is designed to be inclusive

of traditional religion as well as non-institutional-based spirituality. This tool provides a working framework for the exploration of a patient's spiritual needs. The tool addresses emerging themes of belonging, meaning, hope, the sacred, morality, beauty, resolution, and a deeper acceptance of dying (Galek, Flannelly, Vane, Galek, 2005). A third example of a developed instrument that measures spirituality is the "Spirituality Index of Well-Being" (SIWB). The instrument was designed to measure the effect of spirituality on subjective well-being. The SIWB has been determined a valid and reliable instrument that can be used in health-related quality of life studies (Daaleman & Frey, 2004).

The "Process Evaluation Model of Religious Coping" as developed by Pargament (1997) provides a preliminary, empirically valid process model of religious coping. The model is useful as a clinical device because it allows for an exchange between lay mental health practitioners and clergy regarding the psychological adjustment of religious copers. The model provides a needed framework for evaluating religion in times of stress and personal crises and allows helping professionals to assess and communicate about impaired religious functioning in a meaningful way (Butter & Pargament, 1997).

An additional conceptual framework for understanding the nature and role of spirituality in relation to coping and health organizes and integrates diverse findings and concepts in the spirituality and religion literature (Gall, Charbonneau, Clarke, Grant, Joseph, Shouldice, 2005). This framework proposes a way to approach, organize, and understand the diverse literature on spirituality, coping, and health. The model illuminates key spiritual constructs that play a role in coping, such as personal factors (beliefs, religious orientation, problem solving style, and hope), primary and secondary appraisals (cause of stress, spiritual evaluation of harm and loss, availability and

effectiveness of coping methods), coping behaviours (religious organizational support, private or non-traditional), coping resources (nature, others, or transcendent), and meaning-making (life purpose, transformation or growth) which all contribute to personal well-being.

iii. Spirituality and religion. The child and family.

The family environment plays a large role in both spiritual and religious development. Negative life events such as abuse, bereavement, illness, and disability also have an impact on spiritual development. These negative life events can act as a catalyst to explore spirituality at a different level than an individual may have previously thought possible (Bibby, 2001; Bourdeau & George, 1997).

DoRozari (1997), in the study of spirituality in the lives of people with disability and chronic illness, confirmed earlier findings of Learner (as cited in DoRozario, 1997), Gignac (as cited in DoRozario, 1997) and Burns (as cited in DoRozario, 1997) that “critical life experiences such as disabilities can enable people to develop personal resources to grow” (p. 432). Specifically, five factors that facilitate coping and adaptation are identified as spiritual transformation, hope, personal control, positive social supports, and meaningful engagement in life, which enable individuals to empower themselves and come to terms with their respective conditions.

Dollahite (1998) presented an overview of findings of social science literature on fathering and religion. He discussed ways in which religion encourages and supports responsible, involved fathering, and addressed other concerns expressed about religion and fathering. Dollahite discussed the role of participating in religious practices like

prayer, attending church, and scripture reading, which have an impact on family life.

Dollahite concludes that religious faith can provide fathers and family members with a sense of identity, purpose, structure, set of moral guidelines, social support, and spiritual resources for personal and relational transformation. Dollahite considers fathering a spiritual process in which fathers work out beliefs, relationships, morals, and the spiritual connection with the child.

Dollahite, Marks, and Olson (1998) investigated the role of fathering, spirituality, religion, and children with special needs. Results indicated six themes that emerged from fathers' narrative accounts. One theme was the fathers' choice to care based on their belief and ability to choose their attitude and actions, which led to feelings of empowerment and decreased feelings of victimization. Another was the way fathers dealt with challenges daily rather than taking a lifelong perspective which minimized feelings of frustration and overwhelmedness. Third was the importance of building love through play. Fourth was the way that having faith in God's purposes provided a sense of peace and strength in relation to having a child with special needs. Fifth was the perceived importance of priesthood-blessing. A priesthood blessing is based on the idea of lay priesthood in which fathers are generally priesthood-holders who administer to their own families. Fathers described the provision of priesthood-blessings as a transcendent act of paternal devotion. Lastly, the acceptance of help from the church was perceived as providing moral, spiritual, social, and tangible support. By maintaining these meaningful connections with a supportive community, the child and family receive many benefits.

Spiritual concerns of the child have not been lost in the literature. Coles (1990) speaks to the innate intrinsic spiritual essence every child is born with, which can be

enhanced. Fulton and Murphy-Moore (1995) and Scott (2003), highlight in their research findings that the evolution of children's spirituality parallels cognitive development, is developmentally sequenced, and involves making meaning out of life. Elkins and Cavendish (2004) call for "the need to develop a plan of care than addresses a child's (1) spirituality, religion, and culture; (2) developmental stage; (3) specific physical care; as well as (4) the needs of the family" (p. 179). They point out that,

spiritual distress may occur when a child experiences a change in health status, or when an illness becomes chronic or the child is dying. The rationale for the occurrence of spiritual distress is the association between the child's developmental needs and spiritual care. Without spiritual care, the child cannot make meaning out of the experience, may have feelings of anger, and demonstrate poor coping behaviours (p. 180).

Dyson (1997) and Kalyn (2003) point out that spirituality helps the child and family feel they are not alone. When spirituality is linked to a specific religious group, religious practices may be used to express one's spirituality. Support from a belief system and connection with a religious community creates a sense of being loved and nurtured by a higher power.

iv. Education and training issues in spirituality and religion.

With burgeoning interest, research, and literature about spirituality and religion, it is necessary to provide foundational as well as advanced training to practitioners to ensure competencies of practice when working with the facets of spirituality and religion in their client populations. Training issues are well represented in the literature with

identification of personal awareness and knowledge of religion and spirituality appearing as consistent factors.

Researchers have investigated the effects of spiritual care training for professionals in palliative medicine. Sixty-three participants participated in a three-and-a-half-day course on “Wisdom and Compassion in Care for the Dying”. They were asked to complete three questionnaires before, immediately after, and six months after the training. Results suggested that spiritual care training had a positive influence on the spiritual well-being and attitudes of the participating palliative care professionals and was preserved over a six-month period (Wasner, Logaker, Fegg, & Borasio, 2005).

Hall, Dixon and Mauzey (2004), after summarizing Miller and Thoresen’s (2003) overview of the field of research dealing with spirituality, religion, and health, examined the roles for spirituality and religion in counsellor education and school counselling. Findings revealed a number of implications for counsellors, including but not limited to: limited awareness of and a need to examine their own spiritual or religious values, the importance of training in spiritual and religious issues, the ability to discuss the role of religion and spirituality when the discussion takes place in the context of multicultural values, and mental health professionals’ acknowledgement of the need for competency regarding religion and spirituality issues in the counselling field.

A competency model for the assessment and delivery of spiritual care developed for health care professionals uses and develops their natural instincts and experience in discerning, identifying, and responding to spiritual need. Competencies are a viable and crucial first step in spiritual care in practice. A four-level competency framework based on knowledge, skills, and actions was developed in order to specify levels of spiritual and

religious care that could be understood and achieved by all staff and volunteers with patient contact. The model seeks to integrate spiritual care into all care rather than assess it as an individual element of care (Gordon & Mitchell, 2004).

Training and education in religion and spirituality within accredited clinical psychology programs is being covered to some degree in most accredited clinical programs. The approach in these programs appears to lack a systematic organization. A number of recommendations have been provided to clinical program trainers in order to foster a training environment in which faculty can enhance students' understanding of religion and spirituality. The recommendations include increased sensitivity and awareness to issues of religion and spirituality, integrating the concepts into existing courses, conducting and funding research, provision of trainers knowledgeable in religious systems, traditions, language, culture and assessment measures, faculty members who can fulfill the mentoring role, use of guest lecturers, familiarization with relevant research, provision of books dealing with the integration of religion and therapy, and finally the provision of and attendance at conferences and seminars at the national, regional and local level that examine issues of spirituality and religion (Brawer et al., 2002).

I. Summary

Spirituality is a complex phenomenon comprised of several facets, including, but not limited to matters of the spirit, divine, love, inspiration, wholeness, depth, mystery, personal devotions, and religion. Similarly, family-centered practice and use of the individualized family service plan present an ongoing dynamic of collaboration,

empowerment, family-driven outcome measures, and relationship-based services that are culturally and spiritually sensitive. Early childhood intervention practitioners are expected to engage with families in a collaborative, relationship-based approach in order to provide supportive, effective, and efficient services. The paradigm shift from child-centered to family-centered services has been problematic and presents an ongoing challenge to the field of early intervention practice. As practitioners and researchers it is an essential component of professionalism to continue the pursuit of practice-enhancing knowledge in order to deal with the everyday complexities encountered in working with families. The blending of informal and formal support systems in the development of the IFSP and practice competencies is an essential attribute to the paradigm shift. As eloquently stated by Marfo (2004), “if family-centered intervention brings about fundamental changes in practice that are consistent with the newer images of family involvement conjured in the emerging literature, it would have been elevated to the status of a true paradigm shift” (p. 1).

Therefore, based on essential contributions from individuals involved in the everyday fundamentals of early intervention services, and from parents and practitioners, their viewpoints concerning spirituality in family-centered practice is a necessary component to continue to move forward in family-centered practice. With an interest in spirituality within other fields, my personal interest in spirituality, and a professional drive to support families and practitioners in family-centered practice, I engaged in this line of research.

CHAPTER III

Method

A. Framework

Qualitative research provided the framework for this inquiry—it provided the researcher an opportunity to collect and interpret nonnumerical data. Present in qualitative research is the underlying belief that meaning is situated in a particular perspective or context, and, since different people and groups have different perspectives and contexts, there are different meanings in the world, none of which is more valid or true than another (Gay & Airasian, 1996).

Qualitative research provided an opportunity to explore participants' understanding of the topic, allowing for the capture of every day life and a deep understanding (Chapell, n.d.). Inherent in the rich description of individuals' experiences is the understanding that the qualitative researcher inductively analyzes the data and interprets participants' understanding, not simply reflects on them (Chapelle, n.d.; Guba & Lincoln, 1994).

This study utilized a qualitative constructivist (previously named “natural inquiry” Lincoln & Guba, 1985) paradigm to guide the inquiry and collection of data. Through the use of focus groups, interviews, and a background questionnaire, the inquiry aimed for understanding. Individuals' responses were a reconstruction of their knowledge with an understanding that there are a number of realities and that these constructs may be altered as an individual becomes more informed. Knowledge was also created in interaction between the investigator and the participants (Guba & Lincoln, 1994). An additional consideration with this qualitative study was the issue of

trustworthiness. To establish credibility, triangulation of data, sources, and theoretical schemes were integrated into the research (Lather, 1986). Data was acquired using three methods of inquiry: interviews, focus groups, and background questionnaires. Two theoretical constructs were integrated within the research framework: family systems theory and ecological theory, both of which are embedded in family-centered practice. The additional constructivist paradigm was utilized to guide the active, collaborative process of data collection and analysis.

Accordingly, as the guiding methodology, the qualitative constructivist paradigm provided for a deeper understanding of the role of spirituality within the framework of family-centered practice for parents and practitioners.

The constructivist paradigm emphasized the dialogic nature of the interview and the understanding of the interview as a process, and the researcher sought to create a meaning-making experience. A ladder question technique of research interviewing was utilized. “Ladder questions are a technique for selecting the most appropriate level of question or researcher response to respondent dialogue, based on the premise that we share a common notion of what is likely to seem most intrusive during discourse” (Price, 2002 p. 4). The purpose of using ladder questions was to allow the participant to ease into the interview process by responding to beginning questions that set the scene, collecting contextual information, and by being provided with assurance that the researcher was interested. Answering knowledge questions was the second stage—these were used when the participant had showed signs of relaxing. The last section of the ladder question technique included questions of beliefs, values, and feelings; a level of questioning that produced extensive rich data (Price, 2002).

The knowledge was acquired through a process of active collaboration between the interviewer and participant. Embedded within this paradigm was the understanding that class, race, gender, and the need to situate self in the research structure the researcher. The audiotaped interviews and focus groups became meaning-making processes that involved all individuals (Guba & Lincoln, 1994).

Focus groups are informal, in-depth, open-ended group discussions of one to two hours duration, guided by a professional monitor who explores a specific set of issues on a pre-defined and limited topic (Robinson, 1999; Lucasey, 2000). Focus groups provided a greater probing of the subject matter through interactions among members (Schilder, Tomov, Mladenova, Mayeya, Jenkins, Gulbinat, Manderscheid, Baingana, Whiteford, Khandelval, Minoletti, Mubbashar, Murthy, Deva, Baba, Townsend, & Sakuta, 2004). The focus groups utilized a semi-structured group interview in which four to six participants discussed the research topic in their own words (Lucasey, 2000).

It is imperative to understand that the interviews and focus groups were weighted in favour of hearing the individuals, though the interviewer controlled the direction of the process. This was done with a clearly stated purpose and the need to hear the participant on a stated topic. Through informed consent the participant understood that she was the informant to the research (Hiller & DiLuzio, 2004).

The third form of data was gathered utilizing participant background questionnaires that collected general information. Participants were asked to complete a background questionnaire to assist in the data management system and to provide a small amount of quantitative data and supplemental qualitative data.

B. Measures

A series of questions for focus groups and individual interviews were developed to ascertain participants' perceptions of the concept of spirituality in relation to family-centered practice. These questions evolved from a careful review of the literature and from the researcher's fifteen years of experience working with families.

i. Focus group questions.

Appendix E contains sample focus group questions. These questions dealt with participants' general perceptions of spirituality and religion. The intent was to determine parents' and practitioners' perceptions in relation to each other within the context of family-centered practice.

ii. Interview questions.

Interview questions delved into more personal perceptions of spirituality within the context of family-centered intervention. Examples of interview questions are contained in Appendix D. These questions focused on issues such as personal spiritual practices, individuals' perceptions of spiritual support, and opinions of discussing spirituality within the context of family-centered practice.

iii. Background questionnaires.

Participants were asked to provide general information such as age range, gender, education, number of children, and to complete a few open-ended questions on spirituality (See Appendix F).

C. Data Collection

The sources of data for this research study came from an early intervention program in the Halifax Regional Municipality, Nova Scotia. The program provides service to children from birth to six years of age who have a developmental delay and their families. The first group of participants consisted of parents of the children with developmental delays, and the second group consisted of early intervention practitioners who work within the program. Two focus groups were conducted—one focus group for parents and one for practitioners were facilitated. The focus groups utilized a semi-structured group interview with four to five participants.

Second, four interviews were conducted using participants from the early intervention program. These interviews included two parent interviews and two practitioner interviews.

The third source of data was background questionnaires that all focus group and interview participants were requested to complete.

D. Participants

This research was undertaken with six parents and seven practitioners who were involved with one early childhood intervention program, met the criteria for participation by utilizing the Individual Family Service Plan (IFSP), and volunteered to be part of the study. Convenience sampling (time available to participate and “first come first serve” allocation) was utilized.

E. Procedure

i. Approvals.

After securing approval from the Mount Saint Vincent University Research Ethics Board, permission to pursue this research was sought by letter (Appendix A) from the Executive Directors of the two early intervention programs in the Halifax Regional Municipality.

Once approval was obtained from the two programs, the researcher arranged to contact the participants. For parents, this was achieved by sending packages to the families via the programs who affixed mailing labels to each package, which contained a letter of invitation (Appendix B), letter of informed consent (Appendix C), background questionnaire (Appendix F), and stamped, addressed, return envelope. Each early intervention practitioner in the programs received a letter of invitation (Appendix B), letter of informed consent (Appendix C), and background questionnaire (Appendix F). As more participants returned the completed consent forms and questionnaires than were required, a convenience sample was utilized.

Once participants had responded, the researcher contacted each person by telephone. Based on consensus, a time, date, and location were arranged for focus groups and interviews to occur. At the outset of the focus groups and interviews, the purpose and aims of the study were reviewed, confidentiality guidelines were addressed, and informed consents were reviewed. The sessions were audiotaped.

The researcher ensured that participants' comfort level and environment were conducive to conversation. The researcher facilitated the focus group utilizing guided questions (Appendix E) and gentle probes (tell me more....) to facilitate rich discussion.

Near the completion of the focus group, the researcher asked the participants if they wished to contribute any other information they felt was important, and reminded them of their option to view the transcript. Participants were formally thanked for their participation.

In the individual interview, as with the focus groups, the researcher ensured that individual participant's comfort level and environment was conducive to conversation. The ladder technique of interview questions (Appendix D) and non-directive prompting to clarify points were utilized. Near the completion of the interview, the researcher "checked-in" with the participant to ensure they were comfortable with the information they had shared and if they had any more thoughts to contribute. The interview participant was formally thanked and reminded of the option to review their transcript.

F. Data Analysis

The collected audiotape data was transcribed verbatim, participant-coded, and organized in a data management system. An in-depth analysis using a modified "grounded theory" approach (Glaser & Strauss, 1967) was utilized. Grounded theory is based on making comparisons and on conceptualizing and categorizing data. The data was broken down into bibbits (bits of data) and organized based on properties (themes or identifiers), categories (groups of bibbits that have common properties), then into substantive themes developed from the categorized data that helped to describe and explain the research focus (Kirby & McKenna, 1989). The main purpose of this analysis was concerned with properties, categories, and links between categories.

Data was also coded by a second reviewer and comparisons were made with the first reviewer checking for consistency. Inter-rater reliability was greater than 90%.

G. Ethical Considerations

i. Informed consent.

Participants were informed that they had the right of voluntary withdrawal from the study at any time without consequence. They were assured that results reported from the focus groups were identified as group data in the final summary of the research and where direct quotes were used, no identifying information was included. Direct quotes utilized in the final summary of the research provided in the interviews did not contain any identifying information. Additionally, procedures for the storage and disposal of tapes and transcripts were carried out in accordance with University policy.

ii. Confidentiality and anonymity.

Measures to protect the confidentiality of all participants were strictly employed. Packages including a letter outlining the nature of the research and the informed consent were distributed through the early intervention programs in the Halifax region. Those willing to participate contacted the researcher, who connected with the participant to organize focus groups and interview dates.

Informed consent was explained in a letter to participants and again prior to commencing the interview or focus group. It was explained to participants that they could discontinue their participation at any time and may request the audiotape be turned off without consequence. Furthermore, focus group participants were requested to keep all co-participant identity and shared information confidential.

Confidentiality in reporting data was employed. Interview and focus group data was reported in group formation. Individual quotations did not utilize identifying information. Participants were not identified by name, nor was there any identifying information about individuals released in the research.

iii. Voluntary participation.

Participation in this study was voluntary. Parents and early intervention practitioners were contacted by the researcher through a third party, and only those wishing to participate in the focus groups or interviews were contacted by the researcher. There were no costs incurred by the participants. Participants were assured that their participation would enhance future early intervention services.

iv. Issues of harm.

Adults who participated in this study had no pressure placed on them to participate. Participants shared information at their level of comfort and were in command of the interview process, or could leave the focus group process. The possibility of harm in this study was deemed to be low. Yet, due to the nature of the topic, an element of risk did exist. There was a chance that the interview or focus group questions and probes would bring participants' thoughts to a time or incident, which in the participants' experiences may have been emotional. The researcher was very attentive to the participants, watching for issues of emotionality. The researcher did have telephone numbers and location of support services available to the participants.

H. Limitations

1. Directors of Early Intervention centres in the Halifax Regional Municipality, Nova Scotia were contacted by telephone and agreed to assist with the distribution of packages to parents and practitioners. A total of 165 packages were sent to centres for distribution: 153 to parents and 12 to practitioners. A total of 19 informed consents and demographic questionnaires were returned: 11 from parents and 8 from practitioners, all of whom were female. Since packages were sent out to potential participants directly by personnel at the Early Intervention Centres to maintain the confidentiality of participants, the researcher cannot be certain that all 165 were distributed. However, a greater response had been anticipated. The lower-than-expected response might also be due to the time of the year that the packages were distributed. Packages were mailed during the month of June, which is an unusually hectic time for families who are typically making summer plans, and for early childhood intervention practitioners who are responding to preschool and school transitions and the summer decrease of services. A greater response may be obtained during other times of the year. Additionally, the families and staff involved with the two early intervention programs within the Halifax Regional Municipality are in demand as research participants from a number of closely located University and educational institutions.
2. A further limitation for this study is the inherent nature of qualitative research. The limited number of participants in the interview and focus group format indicates that the results are likely to be valid for that particular person or focus group and not

necessarily sufficient to make generalizations about the larger population. (Chappell, n.d.). However, the 13 participants did present views regarding spirituality in family-centered practice, and future quantitative or qualitative research can verify these results.

3. The topic of spirituality posed a limitation by the very nature of the topic itself. The structure and beliefs of Canadian society present families that have varying views on discussing this sensitive topic which will be disseminated in the form of research for public viewing.
4. Spirituality has many diverse meanings for individuals, therefore participation in this research produced narrow results dependent on the beliefs and feelings of the participants. Parent participants who designated themselves as part of a religious community were Christian. Therefore, this study did not encompass beliefs and philosophies from other mainstream religions. Practitioners did not designate themselves as regular attendees of religious institutions, therefore the variance in thoughts and beliefs may not be present in this research.
5. The chosen method of audiotaping of the focus groups and interviews may have caused participants discomfort and limited their responses and participation. All participants were made to feel as comfortable as possible prior to commencing the interviews, but the possibility that interviewees did not always reveal their true perceptions must also be considered.

6. Participants who have a high level of comfort and understanding of spirituality may have been more likely to participate in the research. Therefore, the possibility that interview and focus group data may not accurately represent the variety of families and practitioners who are involved in early intervention services must be considered.

7. The active use of the “Individual Family Service Plan” as the guiding document for families and practitioners may have presented a limitation within itself. The document may not be as widely used as the researcher perceived. This perception was validated during the research, as the parent participants who were asked about the document were unsure about the document or process. This again may have placed a limitation on the number of participants.

CHAPTER IV

Results

A. Introduction

The data for this study on parents' and practitioners' views of spirituality in family-centered practice was obtained through focus groups and individual interviews. The transcripts from the focus groups and interviews were coded using a modified grounded theory methodology, and themes and patterns were identified. To identify meanings from the data, it was read initially as a whole, and then several more times in greater detail. Coding followed, using the qualitative analysis technique described by Kirby and McKenna (1989). During the readings, major themes began to emerge that reflected participants' thinking and views on spirituality within the model of family-centered practice. Further detailed reading revealed consistently expressed views within these major categories, as well as ideas that were significant but expressed less frequently.

This chapter will summarize the major emergent themes from the data, providing illustrative examples from the focus group and interview transcripts in order to highlight the meaning to the participants.

B. Summary of Demographic Information

This research was undertaken with six parents and seven practitioners who were involved with early childhood intervention services, met the criteria for participation by utilizing the Individual Family Service Plan (IFSP), and who volunteered to be part of the study. All respondents were female and within the age range of 20 and 50 years. Parents

ranged in educational level from high school completion to university completion. All practitioners had university degrees.

Participants were requested to identify whether they were religious or spiritual. Parents identified themselves in equal portions as being attendees and non-attendees of religious institutions, whereas practitioners identified themselves as non-attendees of religious institutions. In order to conceptualize participants' perceptions of the constructs of spirituality and religion, participants were asked to indicate whether they viewed spirituality and religion as being the same, distinct, or interrelated. Parents chose equally among the three categories, whereas practitioners conceptualized the constructs as being either distinct or interrelated. The majority of the parents had not discussed spirituality or religion within family-centered practice, whereas the majority of practitioners had at some point engaged in discussions on this topic with parents. (See Table 4.1)

Participant families presented with diverse family demographics. The number of children in families ranged from one child to six children whose ages ranged from two to 19 years. The children with special needs (two with developmental delay, two with autism spectrum disorder, and two with Down Syndrome) in these families were all five years old or younger. The majority of parents stated that they had been concerned with their child's development before the child reached 18 months of age, with the exception of one parent who knew about developmental concerns prenatally. Diagnosis of the child's special need occurred within the range of birth to three years of age.

Practitioners' experience as early interventionists ranged from between two to 25 years. In addition, practitioners had varying degrees of experience (one to 20 years)

related to other family/child professional roles such as child life, speech and language pathology, education, and early childhood education.

Table 4.1

Summary of Background Information on Participants

	Parent	Practitioner
Gender		
Female	6	7
Age		
20	1	1
30	2	2
40	3	3
50		1
Education		
High school	3	
College	1	
University	2	7
Frequent Religious Institution Attendee		
No	3	7
Yes	3	
Spirituality and Religion		
Same	2	
Distinct	3	2
Interrelated	1	5
Discussed Spirituality in Family-centered Practice		
Yes	1	5
No	5	2

C. Research Question 1:

What levels of support/services for families involved in early intervention were identified by participants?

Formal supports.

Parents who were interviewed were asked the aforementioned question and easily and succinctly identified the number of formal supports that were involved with their families. These encompassed medical supports such as but not limited to, paediatricians, physiotherapy, speech and language therapy, ophthalmology, and occupational therapy, as well as other social service supports such as early intervention, childcare, financial support, and respite care.

“I have early intervention...day care... ..we see physio ... speech... and occupational therapy ... we have our Paediatrician. also sees ENT, ear, nose, throat specialist...then we have a heart specialist. If we need one we do have a dietician... an one-on-one support person in her classroom... ..social assistance... and respite...child tax.... Every three months you get GST.”

Informal supports.

Parental identification of informal supports required longer contemplation and lists that were not as extensive. The common threads for informal supports included family, extended family, church, or friends.

“Yeah, and I got my friend... And my Uncle ... He’s ah, I guess he’s one of the good supports. He’s around whenever I need him.”

“Usually churches are great...having people there... people prayed for us and care...so it was comforting...I think it is very important for people to have that connection with a group, whether it’s a church is very important...good family that connects is really important.”

However, parents identified family, early intervention, and childcare as being the most important supports to their family and child.

“I’d have to say that day care has been most beneficial to me, and it’s been good fortoo. But I mean early intervention was there from the start.”

Formal and informal supports within the Individual Family Service Plan.

Practitioners were not asked to identify formal and informal services utilized by families. However, during the interviews, practitioners were asked to comment on the use of the Individual Family Service Plan (IFSP) as it relates to identifying formal and informal support systems for families.

In the interviews, practitioners emphasized that the conversations held with the family when preparing for the completion of the IFSP document were extremely beneficial, as they allowed for further understanding of families and helped define informal supports. Practitioners consistently noted that the document was not balanced between formal and informal supports, as paid formal supports were cited more often and appeared more highly valued by families than informal supports.

One practitioner suggested that practitioners may not be as effective in defining or seeking informal supports for families. This practitioner explained that it was often easier to identify and access formal paid services, an idea also stated by some parents.

This practitioner continued to clarify and expressed a level of uncertainty about how to build informal supports for families.

“I get stuck at sections like the informal support. You know, if they say they have nobody, I just say OK...”

Both practitioners and parents stated that families can get so busy with service provision and appointments that they have limited time or energy to build or maintain informal supports.

One practitioner expressed the importance of working with families to ensure that formal and informal supports were balanced and defined equally in the IFSP. Discussions with parents include clarifying supports, exploring how supports feel, and defining whether supports are beneficial or not to the family. This practitioner discussed the importance of informing parents of their rights regarding supports, means of acquiring supports, ways to limit supports, and how to turn down formal supports when, at times, there can be an overabundance of services.

“I make sure of that (*formal and informal supports are balanced*). It’s one of the things that we talk about, when we first get together is, the neighbours, you know the family supports, the friends, the grandparents, you know. We talk about that and it’s a big part of how I want the families to feel, because I’m not their friend...I want them to have some sort of social network... We also talk about; yes the Mom lives next door, but is that really, like what is a support. Like, not only that someone comes over every day. Someone might come once a week and be more of a support than someone who’s there twice a day in your home. So we talk about what kind of support that you need. What kind of support benefits you and

where you can get that support and more isn't better...and sometimes realizing you know, they can say no.”

During the interviews, parents and practitioners were asked to comment on their level of involvement with the IFSP. The IFSP is both a process and a document that is used to guide early intervention services. The document is developed in partnership with families and practitioners. The needs of the child and family drive the development of the document, which defines formal and informal family support systems. The IFSP needs to conform to procedures so that families and service providers have documentation about what is happening, and intervention is systematic. For parent participants, there appeared to be some uncertainty as to whether the IFSP document was in place or not. Responses from parents were brief and not expanded upon.

“I think I have seen the plan... I believe I would have to say yes. If I think I know what you are talking about. Is it on paper work?...What the husband can do...what the kids can do.”

Conversely, interviewed practitioners expressed intense, reflective, and conflicting views when discussing the IFSP. Both practitioners expressed a clear understanding that the IFSP document is a formal document required by the agency to reflect best practice. They also highlighted families' reactions to being involved with the IFSP process, which ranged from reticence to excitement. Both practitioners also described the IFSP as a “living process” which involves ongoing collaborative engagement with families that addresses needs and concerns as they are presented. Documentation is anecdotal and ongoing within the family file. A formal document is

not always created and shared with the multidisciplinary team. The “living IFSP” addresses process but is not necessarily a formal document.

One practitioner expressed uncertainty about whether the actual document was family-centered, stating that the document often ended up being child-centered.

I’m struggling with it (*IFSP*). It’s not a useful document. I’m trying to make it useful. Right now, it’s a paper, it’s a piece of paper that we have to do...and it’s something that, has to get into my files so that there’s an IFSP in my file... the IFSP for me right now is typically a child-centred document.”

Family-centered practice.

In pursuing the topic of the IFSP, a natural extension of the dialogue evolved to practitioners’ perceptions of family-centered practice. Practitioner participants acknowledged the importance of engaging in family-centered practice yet, expressed that the nature of the practice with families was very complex. These practitioners reported that some families have clear expectations for child-centered services. Families view this model as a priority and see it as highly beneficial for their children and, therefore, the families. Both practitioners also felt they were constantly involved in educating and supporting families concerning the importance and effectiveness of family-centered practice.

One practitioner described a gentle process of moving from child-centered practice to a more family-centered model:

“You have to prove yourself...and see you be really child-centered and you show them how good you are at that. You get them to trust you that way...You know you make small chat about things they weren’t even sure that you were going to talk about...You talk about the weather, you talk about the house, you talk about their parents. And maybe that’s what starts the trust...”

Overall, the interview participants verified the complex and ongoing process of understanding and reflecting on services with which families are engaged, whether formal or informal, the IFSP, or family-centered practice.

D. Research Question 2:

How did participants conceptualize religion and spirituality?

i. Religion.

Participants’ conceptions of religion fell under three main themes: a) a group that maintains common beliefs, b) the presence of a Higher Being, and c) rituals or formality.

Group that maintains common beliefs.

All participants reported that they perceived religion as being group-oriented. In general, both parents and practitioners noted examples of a group process and mentality being involved with religion.

One parent defined religion as a group or following that encompassed additional components. This parent said that an essential component of religion was being active in the group; this was defined as being a servant or a leader within the organization. An additional component of religion included being faithful to the church, which involved

attendance at church services and functions. During the interview, this parent also mentioned the component of rules. These were articulated as man-made rules, which governed and formed the beliefs of the church or religion. Another parent simply defined and understood religion as living and going by the Bible and following God's way.

The discussion of religion in the parent focus group was extensive, with each participant expressing their personal views of religion. All articulated their beliefs, feelings, and affiliation or nonaffiliation with religion in addition to providing a standard definition. Mentioned a number of times within this discussion was the structured nature of religion. This structure was defined by two participants as "being taught to be good people" or "religion provides guidelines to live your life in order to be a good person." One parent participant discussed "original teachings" of religion as being caring, loving, and giving. As with the interview parent, two focus group parents highlighted the component of rules within religion. One parent expressed rules as "straight and narrow guidelines" the other as "religion providing a guided path."

"...for me, religion, sort of, it means a set of principles and views that are common to a group of people."

"The original teaching is to be caring and loving and giving and so somehow we need to teach that and I think that that's where religion gives you a basis for it all."

"I need to be set on the straight and narrow. I need to know the guidelines. I need to know how I'm going to get from here to there and what's going to help me get there."

The discussion of religion was shorter for practitioners, yet a number of them did express their personal experiences with religion as this provided the base for their conceptualization of religion. One practitioner defined religion as being “group-oriented with a common philosophy.” This participant also perceived religion as providing a belief in a greater world order. Within the focus group, practitioners also saw the concept of religion as being group-oriented. One expressed religion as “a set of principles and views common to a group of people.” Another participant described religion as being dogmatic and having circumscribed principles.

“Like I find it more, when you hear religion you kind of think it’s more structured. They have their dogma. Each religion has its own dogma.”

“...religion is more circumscribed than spirituality...need to shorten the word from formal to form. ...it’s sort of like the form that is superimposed on a belief system...”

As mentioned previously, parent respondents spoke extensively on the topic of religion and used a number of emotional descriptors and qualifiers to conceptualize religion. A number of parents articulated common beliefs, which included love, care, giving, or guidelines, which were defined as the capacity to teach people to act as moral individuals. In contrast, practitioners used descriptive terminology such as common philosophy, circumscribed, and dogmatic principles to describe their conceptualization of religion.

Presence of a higher being.

The second theme identified by participants was the presence of a higher being as an important component of religion. The higher being was expressed in a number of ways including: Buddha, Krishna, Jesus, God, or the Ultimate.

One parent participant succinctly described the presence of a higher being by defining religion as “God’s way.” Another parent acknowledged a higher being by expressing that “I think God cares more who we are.” Additionally, one parent mentioned the historical and conflicting issues entrenched in religion and the frustration this causes society since it all comes down to humans being formed in an image of an higher being.

“ ‘cause we’re all made in His image, even though His image might be Buddha, or it might be Krishna, or it might be Jesus, or...there’s so much overlapping that it doesn’t make a difference.”

Entrenched in the discussion of religion was the need to be reliant on something larger than the self.

“I can’t do it by myself. I’m just a stupid weak human being. Yeah, that’s the way I see it. I mean God is the centre of all things and I couldn’t walk without Him.”

Practitioners rarely noted the component of a higher being in conceptualizing religion. However, one practitioner did state that religion was associated with “belief in God of some form.”

Rituals or formality.

Finally, parents and practitioners shared their thoughts about religion by describing the external trappings associated with the rituals and formal activities of a religion. These descriptions included previously mentioned concepts such as living and following the Bible, circumscribed beliefs, doctrines, or a vehicle to sustain spirituality. Additionally, the importance of ceremonies, rituals, and activities was also highlighted.

Prayer was mentioned by a number of the participants as being a ritual of religion. One parent commented on the importance of prayer for her family, noting that this included praying together, saying grace together, and praying for other people's needs. Part of this ritual of prayer included giving thanks to God, and articulating what one is thankful for. Another parent mentioned that she prayed regularly for her children. Additional religious rituals noted by parents included doing for others and attending church faithfully.

Practitioners did not specifically elaborate on rituals, yet one practitioner did note that some of the "hallmarks of traditions and rituals and doctrines are part of a religious group." Another practitioner appeared to view lack of religious affiliation as a loss, noting it led to a lack of traditions and beliefs associated with religious institutions. A third offered that by following the rules of religion, individuals "actually get into their concept of heaven." These comments reflect the third theme of rituals and formality that participants felt conceptualized religion.

An important finding worth mentioning, while not directly related to the noted themes, is the powerful emotional charge surrounding the concept of religion. These feelings were reflected when participants shared their experiences and beliefs. At one point during the focus group, one parent clearly articulated her religious affiliation as the

group discussed their beliefs, criticisms, and feelings surrounding a particular religion of which she was a member. Once the religious affiliation was articulated by the parent, there was a subtle change of tone within the focus group and this parent became more engaged as the nature of the conversation gently shifted.

One parent passionately named the characteristics of love and decency as being the basis of religion while at the same time she commented on how complex religion had become throughout the world:

“Those are all just being a decent giving, loving person, like to care for people and so I think that over hundreds and hundreds of years religion has become very complicated and, you know, everybody’s fighting amongst each other which is really rather silly, when you think that it’s all about love.”

Another parent felt that participants in her religion were judgmental rather than supportive after the birth of her child with special needs:

“At one point, you know after I had ... God or praying was pretty much the last thing I wanted to do... I think too, partially, my church expressed a view point, where this was not something from the Lord. So, when you had something like that expressed either through the pastor or somebody else in leadership... some people don’t understand and have different points of view or different understanding of what God has to offer ... I don’t believe that we’re under a curse. I don’t think ... was a curse. I think... was a gift I have I always thought that.”

A practitioner vividly defined fears regarding religion. The practitioner had previously articulated having little formal knowledge of religion and very few

experiences with religious organizations. The practitioner's perceptions of religion had been formed "from the outside looking in" at religion. This practitioner stated that at one point in her career, a previous early interventionist had shared insights into a family with whom she was beginning work, noting that the family was very devout and religious and prayed before home visits. The interviewed practitioner expressed "like I got that pit in my stomach, nervousness" and further articulated not wanting to pray with the family, or make a "farce" out of her religion and further expressed:

"This is why I don't go there (*religion*). Because I'm scared. So if we went there I'd be more scared. I'd be nervous, anxiety, all that kind of thing."

The practitioner clarified that the reason for the feelings was that the practitioner was still in the process of trying to understand religion herself.

ii. Spirituality.

Participants' conceptualization of spirituality could generally be organized under three broad themes: a) tradition, b) personal beliefs, and c) spiritual essence.

Tradition.

Parents and practitioners provided conceptualizations of spirituality that were entwined with cultural and traditional language and beliefs. When describing spirituality some parents used terms that are familiar within the dominant Judeo-Christian, North American culture. In order to articulate spirituality, terms such as God-conscious, believe in but not live by the bible, knowledge of heaven and hell, belief in God, or prayer were utilized. These terms are entrenched in North American culture and thus help

us conceptualize spirituality. One parent was able to articulate the difference between spirituality and religion using traditional language in the following way:

“I am not real religious, because I don’t go to church, I don’t follow the Bible. But I do have some beliefs in me. Right. I know that there is a difference between heaven and hell and I know all that, but...I’m spiritual.”

Similarly, another parent conceptualized spirituality using North American cultural and traditional terminology:

“...Just God conscience... conscience of caring about others...sensitive to other people. Trying to help them, I guess.”

Similarly, but not as frequently, practitioners described spirituality utilizing traditional or cultural terminology. One practitioner spoke of spirituality as a belief in a higher being, rather than God, which has become a politically acceptable term in North America. Another practitioner highlighted ancient traditional religions as a way to conceptualize spirituality:

“...even other types of forces that are considered heresy, in that kind of religious sense. Very old religion types or concepts even, you know like spirits, Celtic types of beliefs.”

Practitioners linked spirituality with traditional values. One practitioner noted that the values connected with people were part of spirituality and interconnected with these values was one’s lifestyle. Within the focus group, a number of practitioners spoke of a

sense of values as being part of spirituality. These values would guide how one interacts with people, how one lives life, and how one reacts to people and situations.

An additional way to conceptualize spirituality in a traditional form was noted by practitioners in the focus group. Some appeared to connect spirituality with external worldly experiences or beings. When commenting on spirituality, respondents noted connection with environmental forces such as nature or the cosmos.

“I agree with everything that has been said and pick up on the point in talking about connection...And not just connection with people but also I view it more as a connection to the cosmos or whatever you want to call that...nature...environmental... Those types of things I think or the concept of cosmos ...”

Personal beliefs.

Whereas religion was conceptualized as group doctrine, spirituality was articulated as intrinsically personal. The personal nature of spirituality was expressed by both groups of respondents, yet the conceptualizations were as unique as each individual participant.

As defined by one parent, spirituality is an innately personal concept that can be manifested in interactions with others and as a way of conducting oneself. Another parent simply stated that spirituality is caring about and being sensitive to others. Within the parent focus group, a parent spoke about spirituality as being personal and a combination of experiences and beliefs that may reflect organized religion. Additionally, one parent spoke of personal spirituality in terms of hope and observing what other parents go through with their special needs child and described this as inspiration.

Practitioners were much more reflective when discussing the personal nature of spirituality compared to the discussion of religion. One practitioner articulated that spirituality provided her sense of identity, who she was, what was the very core of her being. Similarly, other practitioners conceptualized spirituality as being a big part of who they were, how they conducted themselves, how they viewed the world, or a personal “Zen-like” feeling that gave one a sense of peace, contentment, and being fine with the world and oneself. Within the focus group, the first practitioner to comment conceptualized spirituality as:

“I think of it (*spirituality*) as sort of a belief system that perhaps it is some sort of destiny or some sort of higher being. Belief in something along this line there is a reason... I think of it as a lifestyle a way one lives by, a sense of values, beliefs in terms of how you practice your, how you interact with people and how you live. That doesn't necessarily mean to be one particular God or particular way of looking at God. ...Almost like there is a guiding feature to our life. And that helps us live and decide how we live, and how we react to people. Perhaps the pathways we choose in our lives.”

As previously noted, participants articulated how innately personal spirituality is for each of them and this was reflected in the uniqueness of their descriptions of spirituality.

Spiritual essence.

The third theme dealt with the conceptualization of spirituality as spiritual essence, or human beings as spirit. During the parent focus group one parent dramatically lifted her skin from her arm and stated:

“I think we are spiritual beings and the flesh stuff is really just something that just has to have a spirit for a certain amount of time...whether we know it or not, we are spirit.”

Another parent respondent articulated a similar thought, describing people as spiritual beings. A number of the parent participants spoke about the spirit within and connected this with strength and resiliency.

Under this theme, spirituality was seen as being a growth experience, providing resiliency and strength. A number of parents clarified the strength and resiliency aspect of spirituality by describing spirituality as something that sees them through or as a resource within themselves to help them face things that come their way. Another parent simply described spirituality as something that “sees us through difficulty.”

As with parents, practitioners also mentioned the strength-giving nature of spirituality. One defined spirituality as providing a way to keep going. Another described spirituality as finding a way to come to a level of acceptance.

Aspects of spiritual essence were also described by one practitioner as something unexplainable in an intellectual fashion, as if spirituality was a facet unto itself.

“I think of spirituality as something that almost, it has to be discerned in a spiritual way. It has to be experienced in a spiritual way. And therefore it doesn't necessarily lend itself to a conceptualization and form and, an agreement, or a least an agreement in what you know, intellectual kind of way. So I mean there has to be a form, but in a way spirituality is, is only personal to me.”

Additionally, one practitioner was able to conceptualize spirituality and religion in a succinct way. For this person the concepts were intertwined, yet spirituality was still seen as something that flows from a person:

“So it’s almost like religion is coming inward to you and then perhaps your spirituality is based on what you believe and develops on an outward fashion.”

As a way to further understand participants’ discussions and explanations of the constructs of religion and spirituality, they were asked to articulate their manifestation of these constructs. Both parents and practitioners tended to be consistent in their comments on spirituality. However, as a number of parents are regular attendees at or are familiar with religious institutions, they could speak to their manifestations of the religious constructs.

Parents said that the practices of religion were manifested by attending church, being active in church leadership and activities, calling on God, reading the Bible, praying, others praying for them, church family connections, and doing for others.

They felt spirituality was manifested in varied modes: talking to oneself or relatives who have died, subconsciously figuring things out, questioning, examining, being introspective, finding one’s path, special places to think, being by oneself, crying, and accepting others.

Participants clearly articulated their thoughts about the constructs of religion and spirituality. Both groups of participants reflected similar perceptions of spirituality, noting that it was unique, spiritual within itself, and reflective in nature whereas religion

was presented as being reflective, and grounded in a particular philosophy with the added component of social connectedness within a group.

E. Research Question 3:

Is spirituality and religion a valid concept to be integrated within early intervention?

Participants' responses fell into three definitive themes when considering integrating the constructs of spirituality and religion within family-centered practice. Participants perceived these constructs as being either appropriate and comfortable within early intervention or noted that it was inappropriate to integrate religion and spirituality within the early intervention process as it created personal discomfort. There was equal representation of these two divergent views by participants, yet the rationale from the parent and practitioner groups were distinct. The third theme that emerged was the necessity of making spirituality and religion an overt concept within family-centered practice.

Religion and spirituality being appropriate within family-centered practice.

When asked about integrating these constructs into family-centered practice, a group of parents acknowledged being comfortable with the integration of spiritual and religious discussions within early intervention while delineating the need for clear parameters. Parents clearly defined the boundaries, emphasizing that families were not expecting practitioners to be their spiritual guides or counsellors. However, they felt that early interventionists needed to understand the families' beliefs, feelings, and supports

surrounding spirituality and religion. Parents stated that discussions of the constructs of spirituality and religion should center on family's needs, journeys, and beliefs, not those of practitioners. Discussions should emerge naturally and be culturally significant. Parents expressed the intrinsic nature of care within early intervention, which they considered spiritual within itself. Parents believed that religion, spiritual beliefs, and practices would emerge naturally based on the relationship-focused orientation of early intervention services. It was noted that parents should not push their beliefs on others, yet it was helpful to understand the practitioner's beliefs and philosophy surrounding the constructs of spirituality and religion.

“I think it, might be discussed, even though the question ‘what religion are you?’ is not asked... I don't think you can avoid having discussions that actually reflect your spirituality and to some degree your religious beliefs because how can you actually have a relationship with somebody from the time your child comes here till the time when we send our children off to school and in that number of years you've been involved and whether it (*spirituality and religion*) is addressed point blank or in conversations ... (*practitioner*) would have an idea of what is in me from just being near us and my kids, it's there without being there, not necessarily overt.”

Another parent stated:

“I've just been thinking. The child is not going nowhere without the strength of the parent and family support and for the worker to have an idea of how you muster up the strength and how you know... where she finds her strength. I think that's important because they can help the mother feed that strength to keep on going.”

Continuing with the first theme, about the appropriateness and comfort of integrating spirituality and religion into family-centered practice, some practitioners' and parents' views were congruent. A number of practitioners emphasized the need for parameters when discussing religion and spirituality. A predominant theme expressed by practitioners was the necessity of parents being the ones to initiate the topic.

“If they bring it up, I am very comfortable in listening to it. Their connection is, where their supports are, you know, their get-togethers, but I don't bring it up.”

Practitioners explicitly explained that the essence of family-centered practice is utilizing competencies that follow the parents' cues and needs. Discussing spirituality and religion within the IFSP process or in family-centered practice is a natural extension to identifying informal supports for parents. Spiritual and religious discussions also provide insight for practitioners by suggesting ways to support parents. Some practitioners found it beneficial to have spiritual and religious discussions with parents as it gave practitioners a clearer understanding of who the families were, their beliefs about accepting and raising a child with special needs, and their personal and family journeys.

Practitioners also noted that discussions of spirituality and religion were appropriate within family-centered practice if the topic was brought up by the family or they were requesting ideas, strategies, or problem solving methods in order for the family and child to attend a religious or spiritual gathering. Practitioners expressed that this type of discussion clearly fell within the realm of family-centered practice as it was seen

as engaging and supporting families. Practitioners spoke of feeling safe when engaging in discussion on spirituality and religion in a problem-solving mode.

“I know of another family who’s been really struggling, trying to get their little ... to church. They really want to get him to church. ... But I can talk about that, cause that’s something I can problem solve. I don’t have to know that it’s a church. I just have to problem solve getting him there.”

During focus groups and interviews with parents and practitioners it was interesting to note that practitioners needed clear parameters in order to engage in the discussion of spirituality and religion. Practitioners appeared to be less inclined to open up the discussion, even if they felt it was appropriate or necessary. Additionally, practitioners presented as less flexible than parents to engage in the discussion on spirituality and religion unless it was specifically listed as an informal support or as a problem-solving issue. A number of parents expressed their willingness to engage in discussions of spirituality and religion in family-centered practice, as they perceived these constructs to be a significant part of their lives.

Spirituality and religion not appropriate within family-centered practice.

However, not all parents and practitioners were comfortable with discussions of spirituality and religion in family-centered practice. Two parents felt that it would take time away from the child’s goals.

“Well, it’s about the child, about how to get this child through this period of time. And if you’re religious then that will blend in there and if not

religious—it's a moot point. It is all about where your family is going with the child, which direction you are taking ...”

Another parent felt that spiritual and religious conversations could impact their relationship with the early interventionist if they had differing beliefs.

“I think it does because everybody has different beliefs and once you share yours, maybe my specific interventionist wouldn't have a problem with it but I've had friends that once you share your beliefs there's a line drawn because if it differs from what they believe.”

One parent emphasized a conservative, yet common North American cultural belief that one never talks about religion.

“No, I was brought up; you never talk about religion, politics or sex, that's what you don't talk about.”

However, some practitioners commented that it is easier to discuss spirituality and religion with families of a different ethnicity due to the perceived understanding that it is suitable to explore another's culture within family-centered practice. In such situations, spirituality and religion are seen as an essential component impacting the families' interactions and participation in early intervention.

“The other thing I have found that has been interesting over the years, is when you meet families of different religious backgrounds or different cultures that come from a different framework that have been brought up in North America and how happy and proud they are to share their background and what they do as part of their rituals and so on, and if you ask they seem to really like to invite you into their world for lack of better

terms so you can understand that better. That's a nice rapport building, too, in some ways. Not that it means you are practicing it, but it is a sharing. So it is important to understand why, you know, exactly."

Conversely, practitioners explained that they did not feel comfortable discussing religion with families from the dominant culture.

"...to me the thing about ethnic and minorities is that religion and ethnicity are, are interconnected... There's so much cultural awareness... they brow beat it into you, as it should be... so it's easier for me... And I would never go there with a white family, with a classic kind of middle-class family. You just don't go there. You don't, you don't have anything to be culturally aware of."

A few practitioners stated that it was inappropriate or uncomfortable to discuss spirituality and religion when they did not have a good understanding of a number of spiritual and religious philosophies and beliefs. One expressed sentiment addressed the need for practitioners to be acutely aware of their personal beliefs.

"I don't know what I believe in this world so I'm not for... when you're the service provider, the paid professional, you need to know what you're talking about."

Spirituality and religion overt and separate constructs within family-centered practice.

The third theme to emerge related to making the concepts of spirituality and religion overt and separate constructs within family-centered practice. Parents from the focus group had clearly articulated their thoughts surrounding spirituality and religion. There are fundamental differences between religion and spirituality. However, while at times the concepts appear entwined, parents argued that the constructs should be clearly

separated. One parent mentioned that they would feel comfortable discussing spirituality but not necessarily religion. Whereas, another parent noted that religion was a major component of their life and the discussion of religion could easily become part of family-centered practice. Likewise, another parent presented a similar view and spoke about spirituality being a part of “our everyday world,” therefore requiring acknowledgment in family-centered practice.

“And also I think it’s got to be, because there’s people out there who are not religious but very spiritual as we’ve all discussed and I think it would be important to not have it, spirituality and religion or religion and spiritual beliefs. Because that makes spiritual sound very religious. So therefore, there should be a question about religious beliefs, yes, no, don’t want to talk about it and spiritual beliefs, yes, no, don’t want to talk about it.”

One parent articulated the need for flexibility when discussing spirituality and religion with families. For her family, spirituality and religion would not have to be components of their early intervention service. However, for other families it may be essential components.

“So, had the question been on your forms or initiated by the worker then you would simply...it could be a check box. And if it said are you willing to discuss spiritual or religious beliefs I would check no. But I wouldn’t want to take that away from someone else who is willing to discuss that or has/wants that type of relationship, personally I don’t so I would have a check box.”

Participants suggested overtly introducing spirituality and religion as formal components of the early intervention intake process. This could be realized in a number of ways, through the use of forms in either a check box fashion or a brief anecdotal comment. As a parent stated:

“When you ask for supports...you haven’t discussed it formally but it’s there...when you ask who you have for supports—Do you have a church, church group, a this/that so it is formal any questions should be asked...in the beginning.”

Moreover, comments suggested spiritual and religious discussions could be positive, providing parents and practitioners with a means to explore spirituality and religion and how it is manifested in their everyday lives. For example, one parent acknowledged:

“I also think it makes people stop to think, like about their, if nothing else it would make somebody think about their spirituality. Which is not a bad thing to think about every once in a while... You know, separate from, not that they shouldn’t also be thinking about their religion. People take it for granted. They move through life and they never really stop to contemplate...”

Likewise, a practitioner stated:

“I think as practitioners it’s important to always kind of reflect. I think you can get lost to what’s important to families...It’s just interesting to hear each person’s opinion. This experience (*focus group*) is helpful.”

An interesting sidebar pursued during the practitioner focus group characterized the presence of spirituality and religion as an overt construct for families, yet a covert topic within family-centered practice. Practitioners discussed the type of nuances that were presented by families and observed by practitioners in order to provide them with a sense of the family's beliefs surrounding the constructs of religion and spirituality. Comments and ideas incorporated numerous realizations such as families talking about going to church, child christenings or baptisms, spiritual or religious symbols on the child's body or in the home, a sense of calmness and peace in the home, music, families talking about hope and strength, or subtle questions to practitioners. The topic precipitated reflective remarks from the practitioner participants.

“I recently had a visit with a family, it was a very interesting experience. Very, very soft Christian music being played in the background of their home when I arrived and there was just a sense of calmness and peace when you went into the home...So you pick up on these nuances ... sometimes when you go into baby's rooms, you see little things that are conducive to knowing that there is some sort of faith or religion that the families are practicing because they are put into place to safeguard the little one or to help them out...Sometimes the parents will say things. A lot of little things, and sometimes they are testing like asking ‘do you go to church?’ or ‘you involved in anything?’ you know, and ‘what do you believe in?’”

As one practitioner noted:

“I begin to wonder why I haven't picked up on.... because I see myself as part of a secular agency.”

Another practitioner also reflected upon nuances stating:

“I agree with you, I mean I am sitting here thinking have I shut people down when they wanted to open up this conversation just because I have not viewed this necessarily as a time for it. But it is something I am going to have pay attention to because I don’t know if I do or not.”

From the focus groups and interviews it became apparent that divergent views were presented regarding the integration of religion and spirituality into family-centered practice. What did emerge was the importance of acknowledging the constructs within family-centered practice and providing a number of ways that make the constructs overt and separate. This in turn invites families and practitioners to enter into discussions based on their needs, beliefs, and feelings.

F. Research Question 4:

What competencies do early intervention practitioners need to integrate spirituality and religion in family-centered practice?

Parents and practitioners articulated a variety of competencies required for early interventionists to have in order to incorporate the sensitive constructs of spirituality and religion into family-centered practice. Three themes encompassed the competencies and qualities of early intervention practitioners relative to spirituality and religion in family-centered practice: professional qualities; personal qualities; and relational intuitiveness.

Professional qualities.

Parents and practitioners differed in the type of competencies presented. Some parents pointed out the need for practitioners to be professional in practice, which for them encompassed generic principles such as seriousness about work, being resourceful, and utilizing assessment capabilities. One parent expressed that the early interventionist was professional in that she shared a little bit about her belief system, but not too much. Professionalism was also exuded in the practitioner's approach to the "task at hand" and the way the practitioner was not casual about the situation. A number of parents and practitioners spoke to the importance of the early interventionist being a resource. This included providing information that the family requested, such as typical developmental and behavioural information, in addition to understanding and knowing the community resources very well.

Parents also spoke to the topic of assessment. This subject was described in a number of ways by parents. One parent discussed assessment as the early interventionist "having a sense in what direction the family needs to go." Another parent identified assessment as:

"They're professionals, they would walk into a situation and know something was going on here...they may change the frequency of visits, 'cause they would know this child would suffer, because there is not enough inner strength here to get this child to go."

During the interviews and focus groups, a number of parents expanded on practitioner professional competencies and expressed the importance of practitioners

being non-judgmental, providing judicious disbursement of advice, and having boundaries.

One parent stated:

“She’s listening and not judging and when I ask for advice she will advise. She doesn’t overrun me, like people who give you advice even when you’re not asking for it. I think that’s why I wouldn’t want somebody as my EI giving me advice and I not looking for it.”

A number of parents identified the importance of practitioners listening as a professional quality. This was described as a listening ear, a person to vent to, and being open to parents’ views.

Practitioners also defined a number of necessary professional competencies needed to integrate spirituality and religion into family-centered practice. These included having or being able to define spirituality, ensuring that spirituality and religion are overt constructs within family-centered practice, and increased formal knowledge of religious and spiritual philosophies.

“Like I need a lot... cause I don’t think you can have one definition of spirituality, ...it’s going to be different for everybody. So I need lots of different people to tell me their definition of spirituality so that I start to get to that point.”

Some participants expressed the need for formal knowledge, which included formal courses and in-services about spirituality, religion, and philosophy.

“... I need a university course in religion...that encompasses philosophy and spirituality. I think you have to challenge us to go to that next level. ...Like I need to talk to families who can tell me.”

One practitioner also suggested the need for ongoing professional experiences, especially mentoring, to develop the knowledge base and confidence to address spirituality and religion. The mentoring could take the form of shadowing coworkers or staff sharing how spirituality and religion can be manifested in family-centered practice.

“I think as practitioners it’s important to always kind of reflect ... I think you can get lost ... I think that (*mentoring*) would be something that’s important. It’s just interesting to hear this (*focus group*) experience is helpful.”

Personal qualities.

The second theme that emerged for competencies of early interventionists dealt with personal qualities. A number of parents suggested that early interventionists need to be caring. This encompassed caring for the child in addition to caring about the parent. Being humble was mentioned by one parent. This humility was described by one parent as the practitioner being available and never having a feeling of being superior to the parent. One parent expressed that it was important that the early interventionist had a family of her own, as the parent believed this contributed to a similar value base of the importance of family. Three parents mentioned the importance of the practitioner sharing a small amount about themselves, including values and beliefs. One parent highlighted that it was “nice” to know a bit about the practitioner in order to have a shared sense of familiarity, yet not too much to change the professional relationship.

One parent stated:

“...I liked the fact that she had a family of her own...and seemed to be oriented in that way. ... And caring, humble, those are the things that count, right off.”

Another parent shared:

“She really didn’t share too much about herself which is also good, because when you do, when you do a job, we’re often used to people sharing too much of themselves.”

Practitioners also defined personal qualities as being important in order to discuss spirituality and religion with families. Their perceptions of necessary personal qualities were different from parents. Practitioners articulated the importance of understanding their own internal and personal beliefs of religion and spirituality. One practitioner expressed the personal need to be safe when discussing the topic with coworkers or families. For this practitioner it was essential that the environment in which one was discussing spirituality and religion was safe, as the topic can be emotional and personal. This practitioner expressed the importance of being able to explore spirituality and religion in a trusting venue, as not to feel ridiculed or pressured.

“You know, and I mean, even when I look at my professionals, I don’t know if they’ll all go there. Like I’m scared of it, but I’ll go there. As long as you make me feel safe and as long as you let me know that it’s OK that I’m scared ...”

As with parents, practitioners also highlighted the need to be sensitive when engaging in these discussions with families. All participants expressed the importance of being sensitive and non-judgmental.

Relational intuitiveness.

The final theme that emerged for qualities and competencies of early intervention practitioners is defined by the author as relational intuitiveness. Parents articulated this elusive competency in several ways and at different times during the interviews and focus groups. Parents did not use the term *relational intuitiveness*, yet described this competency in a number of ways. One parent described the early intervention practitioner as having a “sixth sense.” Another expressed this knowing and understanding as something similar to “woman’s intuition.” A third parent discussed relational intuitiveness as a “knowing” and stated:

“... heard things I didn’t say, she could read between the lines with some of the feelings, either you are going to click with the person or not. Not all personalities get along ... quite frankly, from the very beginning a different worker should be assigned and not because you can’t talk about your inner feelings with this person, but if you are not comfortable, it will affect everything.”

An essential component of relational intuitiveness appeared to be a compatible relationship between the practitioner and parent. A number of parents expressed having an immediate liking or compatibility with the early interventionist.

Similarly, practitioners did not utilize the term *relational intuitiveness*. Like the parents, they discussed this competency in many ways throughout the interviews and focus groups. During an interview, one practitioner described relational intuitiveness as an understanding of “when to go there” with the parent. Whether it was through body posturing, a change in the tone of the conversation, or other subtle indications. Another practitioner describes relational intuitiveness as:

“Well, I know this is kind of silly but part of it is, you got it or you don’t. In terms of that timing that understanding. Like we all go to school to get our child development degree or whatever, but it’s so much more than that ... they need to, have that belief that families are doing the best that they can...”

For this practitioner, the sense of timing and understanding that is integrated into family-centered practice adds to the essence of relational intuitiveness, which is perceived as an important early intervention competency.

As noted there are many competencies that are required by early interventionists in order to be competent with family-centered practice. Parents and practitioners differentiated a number of competencies required by early interventionist that were perceived as beneficial to integrating spirituality and religion into family-centered practice.

Overall, participants in this study willingly shared their perceptions on a number of issues related to family-centered practice and spirituality and religion. Parents and practitioners were generally consistent in their views on religion, spirituality, relational intuitiveness, and overtly introducing spirituality and religion into family-centered

practice. Participants' views became varied when discussing the need to integrate the constructs in family-centered practice. Participants also differed in the specific types of professional and personal competencies required by early intervention practitioners in order to integrate spirituality and religion in family-centered practice. However, it was evident that participants shared a number of common beliefs, laying the foundation for future collaboration as they move toward family-centered early intervention.

CHAPTER V

Discussion and Recommendations

A. Introduction

This qualitative study explored parents' and practitioners' views of spirituality within family-centered practice. While a considerable amount of research examining spirituality as a family quality of life indicator exists within other professions, little research has addressed the role of spirituality in the early intervention field within the model of family-centered practice.

A constructivist paradigm guided the inquiry and data was collected from focus groups, interviews, and demographic questionnaires. Through the use of focus groups and interviews, participants provided reconstructions of their knowledge. In using this interactive approach, knowledge was created between the investigator and participants.

Parents and practitioners have a unique perspective that provides a rich, concerned, and stakeholder depth to research. Therefore, the present research provided an avenue for open dialogue with parents and practitioners in which their perceptions were explored, and feedback was obtained regarding their opinions and insights into the topic of spirituality within family-centered practice. Such information can be used to extend our knowledge in the area of spirituality and religion and to enhance current practice within early intervention family-centered services.

In the following discussion section the results summarized are examined and explored in relation to topics presented.

B. Discussion

i. Current level of formal and informal early intervention supports.

Families and practitioners participating in this study provided insight into their perceptions and level of involvement with informal and formal supports. Informal supports encompass unpaid and natural resources within the community, whereas formal supports are paid services. As the data unfolded it became apparent that parents easily identified and categorized formal or paid services that their child and family utilized as those within the medical and social service systems. A number of supports were identified, such as speech therapy, occupational therapy, physiotherapy, medical practitioners, early intervention, daycare, and respite care services. Informal systems were identified, but were considered as a lower level of support. Informal systems included family, extended family, friends, and, less frequently, religious institutions.

The complexity of formal/informal services for families has been explored in the literature as highlighted by Dunst (2000), who defined early intervention as “ the provision of support to families of infants and young children from members of informal and formal social support networks that impact both directly and indirectly upon parent, family, and child functioning” (p. 96). The radical feature of the definition is that interventions should emphasize mobilization of supports from informal network members rather than relying solely or primarily on formal supports from professionals and professional help-giving agencies. It became apparent from data collected that families and practitioners are proficient at acquiring formal supports, but less so with informal supports. As one practitioner articulated, they were not very good at organizing, supporting, and exploring informal support systems with families.

The findings of this study may speak to the historical complexity of early intervention services. Historically, trained professionals provided services to the child utilizing a formal structure of instruction strategies derived from developmental theory to facilitate behaviour change in the child with parents being concerned bystanders (Bricker & Veltman, 1990). Several participants did emphasize that parents often look to professionals to provide services for the child in order for the child's developmental outcomes to be optimized.

Practitioners also expressed the complexity of formal and informal supports. One practitioner articulated that if the first identified service provided to the family was within the medical, social, or early intervention service, families would alter their perceptions of their needs and request levels of support based on their initial support service involvement. For example, if a child was born medically fragile and the primary levels of support were within the medical services, families would come to perceive the need for continued medical services as especially important. Once the child stabilized, parents would continue to seek services within the medical field, such as speech therapy, physiotherapy, or occupational therapy, even though such services may not be appropriate or needed by the family and child, just perceived to be necessary. Whereas, if the initial help-giving agency highlighted and helped coordinate informal supports, the family could perceive informal supports such as parent/tot groups, child play dates, and time with extended family as a priority for their child and begin to understand that child developmental outcomes are achieved within informal social networks. Parents' energy and perceptions in maintaining informal supports could be increased.

Practitioners also noted the importance of encouraging and maintaining informal supports within the family unit. Practitioners identified the importance of integrating informal supports with formal supports and engaging with families to maintain an understanding of the necessity of informal supports within their families. Brown et al. (2003) noted that governments and other funding sources are turning to families to provide the principal care to children with disabilities. This trend is evident as parents and practitioners often report extensive waitlists for services. It is often the case that families are faced with waitlists up to a year for early intervention, supported childcare, or speech services. This does not even begin to illustrate the often lengthy waitlists for assessment and diagnostic services.

Currently, within medical and social service agencies, practitioners and agencies are continually in the process of advocating for further funding in order to ameliorate the waitlists. Often, agencies begin to increase practitioner caseloads, create resource caseloads, and adjust service provision (e.g. including parent training) in order to address waitlists. The hope is that family capacity will increase while waiting for service, and agencies can maintain a level of consistent and best practice service to families on current caseloads. It becomes essential for families and practitioners to understand the importance of informal support systems for the child and family as informal supports can meet some family support needs and begin to address the child's developmental outcomes.

The results of this study and supporting literature underline the critical need for parents and practitioners to continue working toward creating a balance of formal and informal supports for families in order to equalize the types of supports individuals

within the family require. It is essential for parents and professionals to understand the effectiveness of informal supports and how the child's and family's needs can be met by informal supports working in collaboration with formal supports.

ii. Family-centered practice and the Individual Family Service Plan.

Minke and Scott (1993) describe the IFSP as a document developed in partnership with families and practitioners. The quintessential needs of the child and family drive the development of the document. Results from this study indicate parental confusion regarding the development and use of the IFSP to guide services within family-centered practice. Confusion was manifested by parental responses such as "I don't know," or "I think I have seen the plan." During the interviews, the researcher had to describe the IFSP process and document in order to clarify for parents what the question was asking. The quasi-confusion presented by parents regarding the IFSP document may be reflective of the document being completed, but not necessarily family-centered. A number of explanations for such a perception were noted by Minke and Scott (1993), including: the family not having control over the decision making process, the document not reflecting family priorities, or the document not corresponding with the recommended practices being implemented.

In contrast, practitioners understood the role of the IFSP within early intervention practice, though models and utilization varied. They identified the IFSP as either a formal, static document that was developed and written in conjunction with families and interdisciplinary team members, or as a "living" IFSP—a formal or informal document that was part of the ongoing interaction with families with needs being presented and

addressed in a continual collaborative fashion. Practitioners considered the IFSP document to be a plan that drives family-centered practice.

Conversely, practitioners also reported intense frustration with the actualizing of the IFSP. The IFSP document is often child-centered rather than family-centered. The description of the child's needs and strengths become the dominant focus while family needs and strengths receive minimal attention. Practitioners reported this was often the case with multidisciplinary involvement, especially when medical, child-focused, practitioners partnered in the development of the document, or parents' focus identified children's needs as a higher priority than family needs.

There appears to be reticence within the practice of early intervention to shift from a child-centered approach to a family-centered approach. Beckman (1991) presents a number of issues that block the IFSPs from transforming child-centered practice to family-centered practice. The first IFSP concern is sensitivity to cultural diversity. It appears that early interventionists direct little attention to cultural diversity when developing IFSPs, as programs usually represent views of the English, Anglo-Saxon, and middle class. This leads to incorrect assumptions about the reaction of families to a child's disability and family outcomes, and may limit the effectiveness of the interventions. Second, family assessment may not address the families' needs, yet rather may be formal assessments of the child's development which results in child goals and outcomes. Third, family assessment and in-depth conversations around families' needs are often perceived as being intrusive. Intrusiveness is alleviated if concerns addressed are presented by the family, services are relevant to the family, and the purpose of the interventionist is clearly identified. Fourth, establishing family outcomes has been

difficult. Outcomes need to be written in the form of suggestions rather than definitive objectives as developed for the child, and formed around what the family can expect of professionals rather than imposing professional expectations on the family.

Practitioners concerns appear to be consistent with those presented by Beckman (1991). In this study, practitioners were concerned that they may be too intrusive, and consistently emphasized the importance of following the parents' lead. At the same time, practitioners worried about missing covert cues presented by the family and making assumptions regarding families' needs at specific times. One practitioner expressed having limited conversations with families regarding spirituality and religion due to her own perception of the constructs "not being necessary at this time." Additionally, other practitioners noted the significance of spirituality in relation to cultural diversity, reflecting comfort when discussing spirituality and religion with culturally diverse families, yet not with families from the dominant culture. Likewise, family-friendly assessment tools to determine family strengths and needs to develop family outcomes are not typically utilized in practice. In order for child-centered practice to move toward family-centered practice, the assessment or interview tools that guide practice need to reflect both family quality of life and family outcomes. Additionally, practitioners need to be supported to shift from a professional expert model of practice to a collaborative model of practice that includes training in the development of the IFSP. A quality IFSP would include clear, simple, concise language, an active voice, be positive, and emphasize family strengths, include non-judgmental statements, include family-centered functional goals, utilize specific outcomes that result in an action being achieved and can be incorporated into everyday routines, relate methods and outcomes, provide services

that are in inclusive natural environments, set one to three month target dates for short-term goals, collaboration of professionals, and include the family by stating how they are involved (Bruder, 2000; McWilliam et al., 1998). As posited by Bailey, Winton, Rouse, and Turnbull (as cited in McWilliam, 1998), the decade old concern of the IFSP family goals being predominantly child-related remains. As a practitioner it is difficult to reframe initial education and training while also embracing the constantly evolving changes in early intervention. Systematic support and training take financial investment, time, and an ever-important attitude that will readily grasp and change to meet the continual evolution of early intervention practice. This evolution is slow in occurring, early interventionists need to actively embrace family-centered practice and begin to mentor families and colleagues in the essence of family-centered practice.

The apparent confusion and reticence by parents and practitioners regarding the use and understanding of the IFSP is inextricably intertwined with the model of family-centered practice. It is difficult to analyze the use of the IFSP without examining the overall model of family-centered practice.

The nature of early intervention services, whether they are child-centered or family-centered, raises perplexing issues. Early intervention is a relatively new profession, being approximately 40 years old. The metamorphosis of the profession has been continuous and rapid. Models of practice and professionals have been integrated and borrowed from within the medical, social, and educational fields, and have vacillated from child-focused, parent-focused, and to the now-recommended family focused model (Shonkoff & Phillips, 2000). Within the early intervention field, models and philosophies have continually evolved and been driven by research, whereas policies and

practices have moved at a relatively slower pace. In 2004, Marfo reflected on the possibility of family-centered intervention bringing about a fundamental change in practice that was consistent with the newer images of family involvement conjured in the literature. If practice does change significantly, it would be elevated to the status of a true paradigm shift.

This paradigm shift from research to practice is multifaceted and slow in occurring. Early interventionists are professionally trained and come from multiple backgrounds including nursing, speech therapy, psychology, occupational therapy, education, and child and family care and development. At this point in time, some post-secondary education programs that prepare them for a career in early intervention do not provide foundational knowledge of family-centered practice, the use of the IFSP, or family quality of life (Park et al., 2003; Poston et al., 2003; Bruder, 2000; McWilliam et al., 1998).

During this study, the focus group parents debated the critical role of the early interventionist in providing child and/or family related services. Some parents articulated that family issues and concerns could detract from focusing on child directed goals. For example, parents stated they were hesitant to enter into discussions that would reflect their spiritual or religious views, as they perceived this as detracting from the child-focussed outcomes. It was an interesting perspective, and the researcher felt that these parents had a more child-centered rather than family-centered view of early intervention. Interestingly, the children of parents expressing this view have a similar diagnosis, and recommended practice for children with this diagnosis emphasizes specific training for the child for a certain number of hours each week to meet optimal child

outcomes. When working with families it is evident that they want the absolute best for their child. This process may take on different forms, which may include the parent working intensely and directly with the child, acquiring financial resources to pay for additional supports for their child, or seeking alternative avenues of care and therapy hoping to effect change in the child. As uniqueness continues to be present in every family and with every model of intervention that researchers develop, how and what intervention a family chooses for their child with special needs will remain unique.

In contrast, some families appeared to grasp the nature of family-centered practice and expressed high levels of comfort in discussing relevant issues with the early intervention practitioner. Parents stated they were comfortable having discussions with early interventionists that reflected personal spiritual and religious beliefs. They also noted that practitioners need to understand where parents find the internal strength to continue facing the challenges presented within their families.

It is clear from the findings that confusion remains regarding the practice of early intervention. Should it be professionally-centered, child-centered, family-centered, or a combination of the three? There is a need for early intervention to clarify its values of the means to implement early intervention. Empirical evidence supports treating families with dignity and respect, being culturally and socioeconomically sensitive, providing choices based on families' concerns and priorities, fully disclosing information to families to make decisions, utilizing a range of informal, community resources and family supports, and employing help giving practices that are empowering and competency-enhancing (Bruder, 2000). Essential to family-centered early intervention practice is the utilization and implementation of quality research available. It is necessary

to close the gap that exists between the literature and everyday practice. Additionally, the attitudes of families and practitioners need to encapsulate the philosophy of family-centered practice and work together to create momentum.

A side-note worthy of mention is a concern related to family-centered practice and inadvertently the IFSP. Canada does not have legislation or consistent policies that provide coherent leadership and guidance throughout the country. Therefore, each province and community remains eclectic in its approach to early intervention.

While the essence of family-centered practice may be practitioners utilizing relational and participatory practices that meet families' needs (Dunst, 2002), the reality is that various models of early intervention will remain as long as families and early interventionists have eclectic needs, beliefs, and practices.

iii. Participants' conceptualization of religion and spirituality.

Given the complex nature of spirituality and religion, it was important to gauge participants' understanding of these constructs prior to exploring their perceptions of their role within family-centered practice. Participants' perceptions of religion and spirituality were similar to those expressed by participants in other studies (e.g. Canda, 1999; Fitchette, 1993; Gaventa, 2001; and Hay & Nye, 1998). These authors noted that spirituality is a broad, encompassing, and complicated phenomenon that is distinct for each individual. They further noted that spirituality encompasses the phenomenon of being concerned with the spiritual, religious, divine, or being inspired. It is viewed as something warm, associated with love, inspiration, wholeness, depth mystery, and personal devotions like prayer and meditation.

In the present study, parents and practitioners used broad terms and ideas to express the significance, conceptualization, and enactment of spirituality. Similar with the researchers, parents, and practitioners discussed spirituality in terms of connecting with nature, finding solitude, and finding opportunities to meditate in and become inspired by these environments.

Parents discussed the individuality of their spirituality, some expressing the idea of the self as spirit. Other parents spoke about the spiritual being within as it created a wholeness to their lives, and they often called upon their inner spirit to find their strength and resiliency. Parents expressed that by looking inward they gained internal strength to continue facing family or personal needs. One parent defined spirituality as “where with all.”

Additional conceptualizations of parent participants included God-conscious, which related to spirituality being connected to the religious or divine. One practitioner saw the essence of spirituality as being interconnected with older Celtic religions.

As reflected in the research, some parent participants described spirituality as being sensitive and caring to others, relating to warmth and love. Another parent discussed the importance of prayer or meditation, spending time with God each day, relating to personal devotions like prayer and meditation.

Throughout the interviews and focus groups it became evident that all participants did not reflect or understand their personal spirituality at the same level. These distinct differences were especially noticeable when comparing responses from some of the younger participants with those of the older participants. Younger parent and practitioner responses included “don’t go there,” or “I’m scared to go there,” whereas, older

participants expressed comments such as “this is who I am,” or “I cannot separate myself from my spirituality.” This is reflective of the many facets of spirituality and religion as presented in literature: the personal nature of spirituality encompasses the interactions of culture, family, personality, developmental stage, life events, neighbourhood and friends’ influences (Elkins & Cavendish 2004; Nierenberg, 2001). Comfort in understanding and reflecting one’s own spirituality definitely had an impact on whether participants chose to discuss spirituality in family-centered practice.

Religion was seen by participants as being connected to a higher being or associated with a system of faith, vows, rituals, and group orientation. Such findings are similar to results obtained in research conducted by Canda (1999), Fitzgerald (1997), and Hay and Nye (1998). Some parent’s conceptualized religion as a way to provide parameters in order to express and practice their intense beliefs. Similarly, Poston and Turnbull (2004) found that participants in their study turned to their spirituality and faith to find meaning and purpose in life and that they joined religious communities as a way to share and develop their spirituality with others. In this study, one parent shared that she did not currently attend a religious institution as it does not meet her entire family’s spiritual needs, but expressed the desire to find a church that they can attend together as a family with the children receiving spiritual nurturing and education as well as the parents worshipping in church together.

An interesting finding in this research was that a number of practitioners defined themselves as non-attendees of religious institutions whereas, half of the parents attended a religious institution. This may be reflective of findings by Bibby (2001), which suggest that individuals attend religious institutions when their individual and family needs can

be met and they receive a high level of enjoyment from the religious environment. Additionally, families that experience the birth of a child with special needs may be in a process of examining their religiosity (Dollahite, 2003; Do Rozario, 1997). Reasoning for practitioners may be related to research that indicates lower levels of religiosity among mental health professionals than in the general population (Bergin & Jensen, 1990; Shafranske & Maloney, 1990, as cited in Hathaway et al., 2004), or similarities to the bulk of the American Psychological Association membership who describe themselves as agnostic or atheistic (Plant, 1999, as cited in Brawer et al., 2002). Practitioners reported that they are seeking spirituality in different modes than through organized religion.

The awe and sagacity of spirituality and religion was especially significant for participants. The concepts were richly shared, listened to, debated, and reflected upon during the interviews and focus groups. Parents expressed bipolar views (e.g. the thought of religion making one parent cringe whereas another parent felt religion was the center of all things). Parents shared different philosophies about religion including Catholicism and Protestantism and conversion to and from religious groups.

Similarly, practitioners became inherently reflective when asked how spiritual or religious nuances are manifested in their daily practice with families. Some practitioners easily identified these nuances from family visits, which ranged from environmental cues, parents' comments, music, or items on the child's body. Others expressed the need to contemplate and think about nuances, as they did not recall any being obvious or presented by families.

Throughout the interviews and focus groups, the importance of spirituality and religion to participants was evident. Parents clearly expressed the need for something

outside of themselves from which to draw strength. Often the drawing of personal strength was fed by their spiritual or religious beliefs and manifested in their interactions with their families. A parent shared an especially emotional story during one of the focus groups. She discussed how a practitioner had made a comment about babies with a certain condition– the practitioner expressed that these children were “specially blessed.” The parent said that she did not know if it was true or not, yet during every subsequent surgery and hurdle her child encountered, she reflected on that comment and it helped her conjure up the strength to proceed forward and to have a level of peace and acceptance concerning the safety of her child. Poston and Turnbull (2004) also noted the importance of having faith or believing in something greater than oneself. Participants in their study noted that their faith gave them strength and helped them make sense of the events in their lives.

iv. Role of spirituality and religion within early childhood intervention.

One of the main goals of this research was to determine parents’ and practitioners’ views of discussing spirituality within family-centered practice. During the interviews and focus groups mixed views were expressed.

Both practitioners and parents stated that spirituality and religion were not appropriate topics to discuss within family-centered practice. However, parents and practitioners offered different reasons for why they considered these topics inappropriate. Some parents noted that discussing spiritual and religious issues could take time away from focusing on child outcomes. Again, this speaks to the adherence to the traditional belief that early intervention is child-centered. Additionally, a parent expressed that

within her family, specific topics were considered inappropriate to discuss, including sex, religion, or politics. For her, this encompassed spiritual beliefs as well. This explanation says much regarding the family's inherent belief system and of dominant North American cultural values. As previously highlighted, cultural beliefs and spiritual and religious beliefs are often interrelated (Elkins & Cavendish, 2004).

Some practitioners expressed the idea that these constructs may not be appropriate in family-centered practice as the administering agency is secular. This reasoning may be plausible and explained by a number of provisions as expressed by Beckman (1991), such as the intrusiveness and personal nature of spirituality, and the habit of practitioners not using family assessments that highlight these constructs which can then be developed into family outcomes.

Additionally, some practitioners expressed concerns about their own personal understanding and formal knowledge of spirituality and religion. Due to these perceived limitations, they mentioned being uncomfortable discussing the topic with families. Reflected in this comment was the need for practitioners to have education and mentoring that would allow for increased competencies and knowledge. Results from research by Hall, Dixon, and Mauzey (2004) demonstrated that this point of view was shared by others, and they suggested that training was needed in the area of religion and spirituality within family-centered practice. Issues such as personal awareness of one's own spiritual and religious values, training on spiritual and religious topics, and the ability to discuss the role of religion and spirituality with professional peers need to be addressed.

One parent expressed reluctance in discussing religion and spirituality within family centered practice, stating that depending on the practitioner, the parent-practitioner

relationship might be compromised if parties have opposing or different views. This parent noted that beliefs and judgments were directed toward their family upon the arrival of their child with special needs. She clearly articulated that the church's position regarding the birth of their child differed from the family's beliefs. She mentioned that the family was no longer actively involved with their faith community because the church was not meeting the dynamic needs of their family. Poston and Turnbull (2004) found that families in their research study were looking for three things from their religious communities: acceptance of their child, spiritual and emotional support for themselves, and supports for their child during services so that both they and their child could participate meaningfully in religious activities. It becomes apparent from this expressed view that integrating spiritual and religious constructs into family-centered practice is a complex component of a collaborative relationship that needs to be carefully articulated, defined, and implemented based on families needs and desires.

The diverse views presented by parents and practitioners reflected the necessity of integrating the constructs of spirituality and religion within family-centered practice.

Some parents stated that the constructs are inherent in how their families function and thus need to be acknowledged and understood by the practitioner. For families who are especially devout and involved in religion, it is hard to separate religion and spirituality from family-centered practice. For them, it was important to be able to express their beliefs and to receive non-judgmental acceptance of this concept in their family's lives. As reported by Dollahite (2003), results from the limited number of studies dealing with religion and spirituality and families with children with special needs indicate that religious beliefs and supportive religious communities tend to be perceived

by parents as coping resources in their initial acceptance of both the child with a disability and the challenges of raising a child with special needs.

Parents who expressed the necessity of spirituality being integrated into family-centered practice believed that due to the strength-giving nature of religion and spirituality it was necessary for the practitioner to have a sense and understanding of this source. Once parents felt the practitioner understood their spiritual source, they felt the practitioner could provide comprehensive family-centered supports. Practitioner understanding was manifested through listening to the parent, understanding where their resiliency was drawn from, or ensuring that informal supports from the spiritual and religious networks were acknowledged and drawn upon in the IFSP process. Similarly, Poston and Turnbull's (2004) research participants spoke very passionately about their spiritual beliefs as a contributor to their emotional and overall family quality of life.

Parents expressed particularly well the importance and need for spirituality and religion to be overtly integrated into early intervention. Parents' reflections were similar to those of Poston and Turnbull (2004), who found that spirituality can be encompassed into the family quality of life indicator "emotional well-being." The presence of and specific form of spiritual and religious beliefs of a family should be private. Therefore family quality of life models should recognize spirituality and provide spiritually appropriate supports without getting into specific belief systems. It is important to highlight the need for spirituality and religion to be generalized in order to avoid the feelings of judgment and fear previously noted. Within the same theme, a practitioner also suggested encompassing spirituality within the family quality of life indicator "emotional well-being." The rationale for its inclusion is that it may lessen the feeling of

anxiety that is sometimes present in conversations on the value-laden construct of spirituality and religion.

Practitioners clearly expressed the appropriateness of spirituality and religion being incorporated into family-centered practice if the parents initiated the topic. This may reflect practitioners' initial willingness to embrace the philosophy of family-centered practice and follow the parent's lead in a collaborative fashion. Additionally, if the family's need was clearly defined, for example, if the family desired the child to attend a religious or spiritual activity, practitioners were comfortable discussing and engaging in the relational and participatory practices of family-centered practice to meet this family's need.

A number of practitioners mentioned that if the family was of a different ethnicity than the dominant white, Anglo, Judeo-Christian culture, they were much more comfortable engaging in and continuing discussions of spirituality and religion. They reasoned that they had the professional training and competencies to accept others' cultural beliefs and values. Alternately, practitioners felt discussing these issues could become a means to engage and understand families better due to their own limited understanding of the particular culture. These perceptions reflect typical social norms, as seeking information is acceptable whereas queries on mainstream religion could be viewed as intrusive.

The constructivist process was evident within the interviews and focus groups as these apparently divergent views merged to a consensus to reflect parents' and practitioners' views of the importance of overtly incorporating the constructs within family-centered practice. Participants articulated this viewpoint with recommendations

being offered to the practice of early childhood intervention. First, it is important that spirituality and religion be presented as overt choices in order for families to decide whether or not they want to engage in discussions on these constructs. Parents suggested the use of clear questions that separate religion from spirituality and provide parents with a place to check a box based on their desire to discuss or not discuss the individual constructs. Second, parents did not expect or desire early interventionists to become their spiritual mentors. Parents stated that they would go to their spiritual community for this support. However, parents stated that expressions of spirituality and religion are an integral part of families; there is the need for the constructs to be acknowledged and appreciated by the interventionist. Third, spiritual and religious beliefs are reflected in the nature of early intervention practice, as it is a service that follows the families' needs and utilizes relational and participatory practices. As noted by Gordon and Mitchell (2004), a competency framework based on knowledge, skills, and actions could be utilized with early intervention practitioners in order to supplement their professional competencies.

A practitioner who is not open and receptive to a parent's beliefs and feelings in regard to their child with special needs could impact the parent-practitioner collaborative relationship. Results from Dollahite's (2003) research reflect the very essence of one parent's feelings. This parent noted that she felt blessed by her child with special needs. Likewise, Dollahite highlighted that until recently, scholars have perceived, studied, and treated families with children with special needs as if there were only negative, burdensome, and painful aspects to this experience. Bennett and colleagues (1995), as cited in Dollahite (2003), suggest that only about one-third of parents with children with

special needs seem to fit this generalization. Most parents actually adapt, grow, and even come to feel gratitude for the privilege or “blessing” it is to parent a child with special needs. In highlighting the importance of the integrating spirituality and religion into family-centered practice, a parent shared this belief about her child:

“Along came... and I was so happy, so thankful, then I found out that... wasn’t just a little (*gender*), ...was a very special little (*gender*), ...is so special, ... can’t walk and can’t talk, but you can’t wipe the smile off ...face every single day. And ...teaches us all something, that we realize that what ... has we want and we need... is such a blessing to our family, we can’t begin to thank God, honestly.”

When working with families, the presence of spirituality is evident, especially in the cues and nuances presented by families. Practitioners need to be cognizant of these clues and be willing and prepared to engage in this topic with families. Practitioners will know when the time is right to open or respond positively to parents’ overtures if they are perceptive to the parents’ expressions of spirituality. Over many years of practice I have encountered spirituality in many forms within families, ranging from adherence to strict doctrine to alternative expression of spirituality. Early interventionists need to be open and prepared to engage with families. It is imperative that practitioners understand this facet of families because at times families end up in crisis, are struggling, and need the extra supports that their spiritual community can provide.

v. Competencies of early intervention practitioners.

An essential component of this research was to identify specific early interventionist competencies that would support encompassing spirituality and religion

into family-centered practice. Participants fluently defined a multitude of qualities needed by early interventionists to incorporate spirituality and religion into family-centered practice. For example, participants noted the importance of early interventionists being professional.

Parents emphasized the importance of professional qualities. One parent articulated the importance of the early interventionist being serious about the work. This parent described the interventionist as being prepared to spend time with the child and the parent. Relating closely to “serious about work” was the concept of resourcefulness. Parents articulated feelings of comfort and assurance when requesting information from the early interventionist, as they knew that the results were going to be appropriate to their outstanding concerns.

Parents also discussed the importance of early interventionists recognizing their boundaries, such as knowing when things were beyond their capabilities, and following the parents’ lead.

One parent eloquently expressed that they appreciated judicious disbursement of advice. At times, it was important to be able to talk and not have ideas, suggestions, or solutions directed their way. Similarly, the early interventionist was perceived as a “pair of ears” that listened empathetically and allowed the parent to vent.

An additional competency discussed by parents during the focus group session emphasized the importance of quality assessment skills in order for the early interventionist to accurately assess the situation and gauge the type and amount of support needed by families to support their child with special needs.

Frequently, research from other professional fields is applicable to early intervention and family-centered practice. For example, Kliewer's (2004) synthesis and review of findings in numerous studies regarding spirituality and illness led to a number of practical recommendations for physicians. Kliewer found that patients wanted physicians to address issues of spirituality in the context of medical care. Patients suggested that appropriate models for addressing their spiritual concerns would require active listening skills, identification of spiritual and emotional issues, effective referrals to spiritual advisors, and ongoing communication about aspects of the healing process. It is important that physicians understand that the issue of spirituality is all about the patient's spirituality, not the caregiver's, and is also about supporting the patient's spiritual beliefs. Early interventionists can utilize this knowledge and begin to apply these practical suggestions in family-centered practice.

Like the parents, practitioners articulated the importance of professional boundaries and following the parent's lead. Practitioners noted the need for early interventionists to have quality relationship-building and communication skills that utilized listening, acceptance, and respect. A number of practitioners also noted the need for adequate training and education regarding spirituality and religion. Following this theme was the need for ongoing mentoring. As suggested by Kliewer (2004), and Gordon and Mitchell (2004), competencies regarding religion and spirituality are necessary for practitioners.

One practitioner noted the importance of consistency as a professional quality, explaining that families should have one consistent practitioner with whom to build a relationship, trust, and be able to support in the service-coordination role with the family.

One plausible explanation for emphasizing consistency is the reality that some families are involved with numerous help-giving agencies and personnel. Families having to disclose, share, and build relationships with numerous practitioners can be especially burdensome for families. The nature of early intervention is relationship-based, with the relationship being developed over a number of years. The consistent home visits provide an atmosphere conducive to developing long-term connection and trust, so it is understandable that this practitioner highlighted the importance of consistency.

The second category of relevant qualities for the early interventionist to possess was identified by parents and practitioners as personal qualities. Parents labelled a number of personal qualities that they appreciated in their early interventionist. These included being caring, humble, family-oriented, and having a family of their own. Parents also expressed the archetypal nature of family-centered practice and the importance of early intervention practitioners' competencies that reflect love, care, and acceptance. Parents defined these competencies as spiritual practice within itself. Dunst (2002) introduced a similar notion when he stated that competencies were reflected as "relational skills" which encompass good clinical skills and professional beliefs about and attitudes toward families.

The personal qualities identified by practitioners had of a different tone than those noted by parents. Practitioners highlighted the need to have their own internal and personal understanding of religion and personality. Similarly, Hall, Dixon, and Mauzey, (2003) address the importance of examining one's personal spiritual and religious values. It is imperative for practitioners to have an understanding of their own personal spiritual and religious beliefs in order to be prepared for and support rather than roadblock

conversations of a spiritual and religious nature. Secondly, practitioners expressed the need for personal safety. This was described as the need to feel safe in the context of peer mentoring when discussing spiritual or religious journeys, as the topic is very personal. The need for safety was also reflected in the practitioners need to feel safe from being indoctrinated or pressured into accepting someone else's beliefs. This explanation may say more about the practitioner's own personal awareness, experiences, developmental stage, and beliefs of spirituality (Elkin & Cavendish, 2004).

During this study it became evident that the parents involved in this research had very positive relationships with their early interventionist. Comments included being excited about and looking forward to visits, being comfortable "telling all" to the practitioner, and feeling the family was being cared for by the early interventionist. One parent discussed this high level of comfort as being reflected in the clothing she chose to wear during an early intervention visit as compared to clothing chosen to wear during another professional's home visit. An obvious explanation incorporates the incomparable relationship being developed in collaboration with parents. At the core of early childhood intervention is the collaborative relationship.

The majority of participants expressed what could be defined as relational intuitiveness. This elusive construct was articulated as a sense of knowing, intuition, connection with each other, reading between the lines, or "someone who can read me."

One parent expressed that at times the early interventionist would say things or understand something before the parent could. Another expressed similar levels of perception by the practitioner, explaining that the practitioner would correctly speak of things in school transition meetings that had never been articulated during their time

spent together. Parents highlighted the importance of immediate connection with the early interventionist, especially the need for extreme comfort with this person due to the personal nature of early intervention. Another parent expressed that if the parent and practitioner did not “click,” the whole essence of early intervention would be lost. This parent also mentioned that families should have the option of selecting a different practitioner if they did not “click” with the original.

Relational intuitiveness was articulated by practitioners as discernment, timing, sensing the family’s needs, and reading cues. One practitioner described this as “intuitive support” based on trust. Another practitioner articulated relational intuitiveness as “telling when they are ready.” This has been referred to as the family-practitioner dance. It is a combination of feelings, skills, knowledge, and awareness interwoven into everyday collaborative practice that occurs in synchronous rhythm.

It was interesting to note that the research process itself caused some practitioners to reflect for the first time on spirituality and religion within family-centered practice. One practitioner stated that she did not believe she had an opinion on spiritual and religious issues in family-centered practice, but at the end of the process she realized that she had a very definite opinion. Second, practitioners stated that the focus group itself was an “eye opening” experience that spoke to the importance of spirituality and religion being actively discussed within the early intervention field.

C. Summary

This research was designed to capture information regarding perceptions by parents and practitioners regarding the constructs of spirituality and religion within

family-centered practice. In order to explore the idea of incorporating spiritual supports and resources into family-centered practice, perceptions of informal and formal supports, the individual family service plan, family-centered practice, spirituality and religion, and practitioners' competencies were examined. Due to the relatively small sample size, it is difficult to establish conclusive outcomes, and the results herein must be interpreted with caution. However, several interesting findings did emerge.

Parents and practitioners demonstrated a good general knowledge of the constructs of spirituality and religion. Overall, participants were able to delineate between formal and informal supports. Both groups of participants agreed that within family-centered practice formal supports were focused on more intently within the individual family service plan. Confusion on parents' behalf and frustration on practitioners' behalf provided support for Dunst's notion that the IFSP and family-centered practice present a significant challenge for early intervention programs. Child-centered practice and family-centered practice create disparities in the field of early intervention as practitioners struggle with which model of practice is best suited for the child and family. Consistent with the research, some families and practitioners appear to be meeting the challenges and are adapting to the changes presented by family-centered practice by using relational and participatory practices (Dunst, 2004) and working in a collaborative fashion (Bruder, 2000).

The results of this study found opposing views regarding the role of spirituality and religion in family-centered practice. Parent and practitioner participants articulated points for integrating and not integrating the concepts into family-centered practice. It became apparent that if spirituality and religion are to be incorporated into family-

centered practice, the concepts need to be discussed overtly and separately. Additionally, it is necessary for practitioners to possess knowledge and competencies that adequately prepare them for engaging in spiritual and religious discussions with families.

To assist early interventionists in engaging with spirituality and religion in family-centered practice, participants recommended a number of competencies and strategies to assist in the process. Included was the need for personal awareness of one's own spiritual and religious values, training in spiritual and religious issues, and an ability to discuss the role of religion spirituality with peers, which are consistent with findings by Hall, Dixon and Mauzey, (2004). Consistent with Kliever's (2004) findings, participants in this study identified the importance of (a) addressing issues of spirituality in the context of family-centered practice, (b) the need for models and boundaries for addressing the families' spiritual concerns, (c) referral to spiritual advisors, (d) supporting the families' spiritual beliefs, and (e) understanding that the topic of spirituality is about the family's spirituality and not the practitioners.

The findings suggest that participants value the role of spirituality in family-centered practice; there is a need for in-service training and formal education to expand and enhance competencies of practitioners. Continued research of the individual family service plan, family-centered practice, and models that incorporate spirituality and religion into family-centered practice are required. The knowledge can be shared with practitioners and parents to utilize a more family-centered approach in early intervention. A good beginning may be closely examining current family quality of life models.

D. Recommendations

An amazing amount of new early childhood intervention research is being carried out in North America. Opportunities arise daily for new issues within practice to be systematically researched. Within Canada, the profession of early intervention is very new in offering systematic and comprehensive early childhood intervention services. There is much grassroots, and less provincial and federal work being done to ensure that Canada will become proficient in providing early intervention services for families with children with special needs. As this research appears to be within the beginning stages of exploring the family quality of life indicator of spirituality and religion within family-centered practice there are many recommendations that naturally arise from this study.

i. Future research.

1. As with many educational theses, this study was hampered by financial restraints. An adequately-funded research study could provide broader depth and breadth to examine spirituality and religion within family-centered practice.
2. This study was carried out with a limited number of participants. A larger number and broader range of diversity among participants may reveal further findings that would be pertinent to family-centered practice.

3. This study occurred in an urban setting. A similar study in a rural setting might uncover additional relevant findings. Social connectedness and formal and informal resources in rural communities are different; therefore parents' and practitioners' utilization of supports may differ.

4. The family-centeredness of the Individual Family Service Plan needs to be researched in detail. As expressed throughout this research, the document presented levels of uncertainty for a number of participants.

5. Family quality of life is an imperative topic to pursue in future research. An exploration of valid and reliable tools that measure family quality of life within research and practice needs to be undertaken. The indicator of spirituality and religion needs to be encompassed as an essential part of family quality of life and guidelines for practitioners to encompass these constructs in family-centered practice are necessary.

ii. Families.

6. For families, it is essential to discover ways they can be enlightened and involved in the IFSP process in order for this guiding document to become pertinent and practical for families and practitioners.

7. The concept of family-centered practice needs to be defined and enhanced for families in order for the paradigm shift to occur in early intervention. It is essential that families understand the focus of family-centered practice while allowing the child-centered goals to naturally occur from the strength and needs of the family being met.

8. As evidenced by parents' responses, spirituality and religion provide families with strength and empowerment. Families who choose to incorporate spirituality and religion into family-centered practice need to be provided with a comfortable, safe environment to discuss this facet of their lives. An honouring, acceptance, and respect of families who overtly or covertly acknowledge this essential strength-giving construct is fundamental.

iii. Practitioners.

9. Constant reflection and critique of practitioners' own practice needs to occur. In order for family-centered practice to become the dominant mode of service provision in early childhood intervention, practitioners need to become experts in practice, thought, and philosophies of family-centered practice.

10. Practitioners need to be provided with safe and supportive venues in order to reflect on their own beliefs, practices, and understanding of the spiritual and religious constructs. They need opportunities to engage with the topic. Safety can be provided through mentorship, peer review, or generative reflection.

11. The IFSP precipitated rich exploration through this research. Practitioners need to continually reflect, engage, and evaluate the use of the IFSP. This includes issues such as the family-centered nature of the document, practical use of, and continual improvement of the process.

12. An additional emergent theme that invites inquiry is the cultural implications of spirituality and religion. As practitioners explained, it is often easier to explore these constructs with families of a different ethnicity rather than the dominant culture.

iv. Supports.

13. The very nature of formal and informal supports for families needs to be explored— an acknowledgement that these supports are essential to all families but need to be presented and available in a balanced and equitable fashion for families that have children with special needs. Families specifically indicated the importance of spiritual and religious supports, so practitioners need to be aware of and encourage families to access these supports.

14. Policy development is needed in Canada to provide support to family-centered early intervention programs. An increased awareness of the nature of early intervention practice, policy, and financial supports needs to be systematically enhanced in order for early intervention programs to function at a best practice level.

v. Professional development.

15. As with all paradigm shifts in best practice, practitioners need to be provided with ongoing, systematic in-services that provide opportunities to reflect on the IFSP, family-centered practice, family quality of life, and the delivery of early intervention services.

16. Mentoring within agencies provides a means for practitioners to safely examine in an ongoing manner their insights, concerns, and experiences concerning integrating the family quality of life indicator spirituality and religion within early intervention.

17. Post-secondary institutions that are serious about early intervention and family-centered practice need to systematically and comprehensively provide early intervention curricula, knowledge, reflection, and education regarding spirituality, religion, family-centered practice, family quality of life, and the development and use of the IFSP.

vi. Policy.

18. Of utmost importance within the field of early intervention services in Canada is the concern of funding. Currently there is no comprehensive systematic way, provincial or federal, to address early childhood intervention funding. Adequate funding policies and finances will provide a partial means to ensure that best practice is offered to all families that have children with developmental needs, nationally.

19. Leadership within early intervention needs to be supported to set best practice guidelines. Practitioners need to explicitly know what is expected of them when they engage with families and offer services. As with any effective delivery of service, comprehensive leadership is crucial. For provinces in Canada that do not have comprehensive leadership, active advocating for non-partisan, non-governmental provincial leadership is essential.

20. At the very least, standards for the practice of early childhood intervention need to be developed in order for families and practitioners to be provided with a comprehensive understanding of what early intervention can offer children with special needs and their families.

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Appendix A
Letters of Permission



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Director, Progress Centre for Early Intervention
3530 Novalea Drive
Halifax, Nova Scotia
B3K 3E8

May 11, 2005

Dear Patricia,

As you know, I am currently enrolled in the Master of Arts (Child and Youth Study) Program at Mount Saint Vincent University. As part of my theses requirements for my degree, I am investigating parents' and practitioners' views of spirituality in family centered practice. The proposed study will involve gathering qualitative data through focus groups and individual interviews with parents and practitioners from the two early intervention programs in the Halifax Regional Municipality. This research endeavours to explore the role of *spirituality* among parents and practitioners within the framework of the Individual Family Service Plan. The aims of the study are to:

- explore parents' and practitioners' perceptions of spirituality within family centered practice;
- identify if this is a concept that is valued within family-centered practice;
- provide practitioners with a beginning reference point to discuss spirituality with parents;
- determine what supports, resources, or competencies are necessary to enhance discussions of spirituality in the context of family-centered practice.

In order to do this research I am asking that you distribute the enclosed packages to your staff and to parents involved in your program. Each package contains a letter outlining the nature of the research, a background survey, and a consent form. Parents and practitioners willing to participate should sign the consent form and indicate whether they want to participate in either the focus group or the individual interview. There will be two focus groups at each centre, one for parents and one for practitioners. Copies of the survey, consent form, and interview and focus group questions have been enclosed for your information.


166 Bedford Hwy Halifax Nova Scotia B3M 2J6 Canada
Tel 902 457 6255 • Fax 902 457 6134
www.msvu.ca


I am further requesting permission to hold two focus groups approximate one and one half hours to two hours in duration, at your centre during evening or weekend hours.

Thank-you for taking the time to consider these requests. Please contact me if you are willing to participate in this study.

If you have any questions, please feel free to contact me, Denise Salanski-Cleveland, at 444-0999 (dsalanski@eastlink.ca) or my thesis supervisor, Dr. Carmel French, at Mount Saint Vincent University, 457-6187 (carmel.french@msvu.ca). If you wish to speak with someone who is not directly involved with this study, you may contact the acting Chair of the UREB, Dr. Anthony Davis at 457-6350 (anthony.davis@msvu.ca).

Respectfully,


Denise Salanski-Cleveland
Graduate Student
Mount Saint Vincent University


Dr. Carmel French
Department Head
Department of Child & Youth Study
Mount Saint Vincent University



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Department of
Child and Youth Study

Caroline Gallop
Director, Sackville-Bedford Early Intervention Program
PO Box 617,
45 Connolly Road
Lower Sackville, Nova Scotia
B4C 3J8

May 11, 2005

Dear Caroline,

My name is Denise Salanski-Cleveland and I am currently enrolled in the Master of Arts (Child and Youth Study) Program at Mount Saint Vincent University. Recently we spoke on the phone regarding my thesis research. As part of my thesis requirements for my degree, I am investigating parents' and practitioners' views of spirituality in family centered practice. The proposed study will involve gathering qualitative data through focus groups and individual interviews with parents and practitioners from the two early intervention programs in the Halifax Regional Municipality. This research endeavours to explore the role of *spirituality* among parents and practitioners within the framework of the Individual Family Service Plan. The aims of the study are to:

- explore parents' and practitioners' perceptions of spirituality within family centered practice;
- identify if this is a concept that is valued within family-centered practice;
- provide practitioners with a beginning reference point to discuss spirituality with parents;
- determine what supports, resources, or competencies are necessary to enhance discussions of spirituality in the context of family-centered practice.

In order to do this research, I am asking that you distribute the enclosed packages to your staff and to parents involved in your program. Each package contains a letter outlining the nature of the research, a background survey, and a consent form. Parents and practitioners willing to participate should sign the consent form and indicate whether they want to participate in either the focus group or the individual interview. There will be two focus groups at each centre, one for parents and one for practitioners. Copies of the survey, consent form, and interview and focus group questions have been enclosed for your information.

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I am further requesting permission to hold two focus groups approximate one and one half hours to two hours in duration, at your centre during evening or weekend hours.

Thank-you for taking the time to consider these requests. Please contact me if you are willing to participate in this study.

If you have any questions, please feel free to contact me, Denise Salanski-Cleveland, at 444-0999 (dsalanski@eastlink.ca) or my thesis supervisor, Dr. Carmel French, at Mount Saint Vincent University, 457-6187 (carmel.french@msvu.ca). If you wish to speak with someone who is not directly involved with this study, you may contact the acting Chair of the UREB, Dr. Anthony Davis at 457-6350 (anthony.davis@msvu.ca).

Respectfully,

Denise Salanski-Cleveland
Graduate Student
Mount Saint Vincent University

Dr. Carmel French
Department Head
Department of Child & Youth Study
Mount Saint Vincent University

Appendix B
Letters of Invitation



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Child and Youth Study

May 11, 2005

Dear Parent or Guardian,

My name is Denise Salanski-Cleveland. I have worked as an Early Intervention practitioner for the past 15 years; I am currently enrolled in the Master of Arts (Child and Youth Study) Program at Mount Saint Vincent University. For my thesis requirement of my degree, I am investigating parents' and practitioners' views of spirituality within family-centered, early intervention programs. This research will provide practitioners with an understanding of the value of spirituality for parents and will aid in determining what supports, resources, or competencies are necessary to enhance discussions of spirituality in the context of family-centered practice. For this research project, *spirituality* is defined broadly to include personal beliefs, opinions, practices, and faiths.

You are invited to participate in either a focus group or an individual interview. Focus groups will consist of four to six parents who will meet with the researcher to discuss the enclosed focus group questions. For the interviews, the researcher will meet with one parent at a convenient time to discuss the attached interview questions. Both the focus group and the interview will be informal conversations lasting approximately one to one and one-half hours. All sessions will be audio-taped and tapes transcribed. There are no right or wrong responses as all thoughts and discussions are pertinent to the research. Once the tapes have been transcribed, they will be destroyed. Participants' identities will be confidential, as only group trends will be reported. Your participation is voluntary and you have the right to withdraw at any time without consequences.

Convenient times and locations of meetings will be arranged once the focus group and interview participants are determined. If you are willing to be a participant in either the focus group or interview, please sign the attached consent form and return it in the enclosed envelope.

166 Bedford Hwy Halifax Nova Scotia B3M 2J6 Canada
Tel 902 457 6255 • Fax 902 457 6134
www.msvu.ca

If you have any questions, please feel free to contact me, Denise Salanski-Cleveland, at 444-0999 (dsalanski@eastlink.ca) or my thesis supervisor, Dr. Carmel French, at Mount Saint Vincent University, 457-6187 (carmel.french@msvu.ca). If you wish to speak with someone who is not directly involved with this study, you may contact the acting Chair of the University Research Ethics Board, Dr. Anthony Davis at 457-6350 (anthony.davis@msvu.ca).

Thank you for taking the time to consider this request.

Respectfully,

Denise Salanski-Cleveland
Graduate Student
Mount Saint Vincent University

Dr. Carmel French
Department Head
Department of Child & Youth Study
Mount Saint Vincent University

Department of
Child and Youth Study

May 11, 2005

Dear Early Intervention Practitioner,

My name is Denise Salanski-Cleveland. I have worked as an Early Intervention practitioner for the past 15 years. I am currently enrolled in the Master of Arts (Child and Youth Study) Program at Mount Saint Vincent University. For my thesis requirement of my degree, I am investigating parents' and practitioners' views of spirituality within family-centered, early intervention programs. This research will provide practitioners with an understanding of the value of spirituality for parents and will aid in determining what supports, resources, or competencies are necessary to enhance discussions of spirituality in the context of family-centered practice. For this research project, *spirituality* is defined broadly to include personal beliefs, opinions, practices, and faiths.

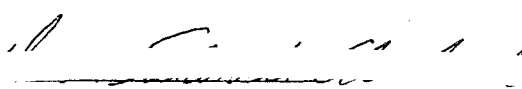
You are invited to participate in either a focus group or an individual interview. Focus groups will consist of four to six practitioners who will meet with the researcher to discuss the enclosed focus group questions. For the interviews, the researcher will meet with a practitioner at a convenient time to discuss the attached interview questions. Both the focus group and the interview will be informal conversations lasting approximately one to one and one-half hours. All sessions will be audio-taped and tapes transcribed. There are no right or wrong responses as all thoughts and discussions are pertinent to the research. Once the tapes have been transcribed, they will be destroyed. Participants' identities will be confidential, as only group trends will be reported. Your participation is voluntary and you have the right to withdraw at any time without consequences.

Convenient times and locations of meetings will be arranged once the focus group and interview participants are determined. If you are willing to be a participant in either the focus group or interview, please sign the attached consent form and return it in the enclosed envelope.

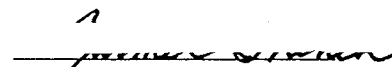
If you have any questions, please feel free to contact me, Denise Salanski-Cleveland, at 444-0999 (dsalanski@eastlink.ca) or my thesis supervisor, Dr. Carmel French, at Mount Saint Vincent University, 457-6187 (carmel.french@msvu.ca). If you wish to speak with someone who is not directly involved with this study, you may contact the acting Chair of the University Research Ethics Board, Dr. Anthony Davis at 457-6350 (anthony.davis@msvu.ca).

Thank you for taking the time to consider this request.

Respectfully,



Denise Salanski-Cleveland
Graduate Student
Mount Saint Vincent University



Dr. Carmel French
Department Head
Department of Child & Youth Study
Mount Saint Vincent University

Appendix C
Letter of Informed Consent



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Informed Consent

Department of
Child and Youth Study

I, _____, am willing to participate in a
(Please print)

small focus group _____ or one-to-one interview _____

(Select only one choice: either the focus group or the interview)

I have been fully informed of the nature of my participation in the study entitled
“Spirituality in Family Centered Practice. Parents’ and Practitioners’ Views” being
conducted by Denise Salanski-Cleveland.

I understand that my participation in this research project will be entirely voluntary and
confidential.

I am aware that I will be participating in an audio-taped, one-on-one interview or an
audio-taped focus group lasting approximately one to one and one-half hours.

I understand that I can choose not to respond to questions during the interview or focus
group or on the Background Questionnaire, especially if the question causes discomfort.

I know that I can review my transcripts and request material be added or deleted.

I understand that quotes from interviews and focus groups will be used to support
findings in the actual thesis document. However, no individuals will be identified, as the
source of the quote is confidential, and the research focuses on emerging group themes.

I also understand that tapes and transcripts will be stored in a locked file cabinet. Tapes
will be destroyed after transcribing, and that transcriptions will be shredded one year after
the defense of this thesis.

Signature: _____

Date: _____

Phone number(s) I may be reached at: _____

Times I may be reached: _____

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If you would like a summary of the findings of this study please include a mailing or e-mail address below.

Name _____

E-Mail Address _____

Mailing Address _____

Researcher's Signature:  _____

Appendix D
Sample Interview Questions

Sample Interview questions –Parents

- Tell me about your family.
- Could you share with me your family's story of the birth/adoption of your child with special needs?
- Tell me about your current level of service and types of services you are being provided with.
- Are you familiar with the IFSP process? Tell me how you are currently involved?
- Based on your experience do you think your IFSP is balanced with formal (paid service provision) and informal (family friends, faith group) supports?
- Would you describe yourself as a spiritual and religious person?
- There are many ways to be involved with religion and spirituality. Tell me about your involvement with spirituality and religion?
- Has your spirituality and religion helped you? In what ways?
- You and your early interventionist talk about many things, how would you feel about talking to your practitioner about your spiritual and religious belief system?
- How could this discussion be valuable or important for you?
- Would the discussions on spirituality and religion offer some support?
- Based on what you have told me, what types of supports or resources would you find useful for facilitating your families' needs in this (participant determined) context
- Is there anything else you would like to tell me in relation to spirituality and family-centered care?

Sample Interview questions - Practitioners

- Tell me how long have you been involved in the early intervention field?
- How would you describe your philosophical/theoretical approach to working with families and children?
- Are you familiar with the IFSP process? What is your current level of useage?
- Do you think the IFSP's developed with families are balanced with formal (paid service provision) and informal (family friends, faith group) supports?
- Would you describe yourself as a spiritual and religious person?
- There are many ways to be involved with spirituality /religion. Tell me about your involvement with spirituality and religion?
- How would you feel about talking to your families about their spiritual and religious belief system?
- What would be the biggest costs or payoffs in discussing spirituality and religion with families?
- Do you believe discussions with your families would be valuable or offer any level of support?
- Based on what you have told me, what types of supports, resources or competencies would you find useful for facilitating your needs in this (participant determined) context
- Have there been any other thoughts or ideas in relation to spirituality and family-centered practice that you would like to tell me?

Appendix E
Sample Focus Group Questions

Sample Focus Group Questions- Parents

- There are many ways to think about spirituality and religion. When you hear the word spirituality what comes to mind?
- When you hear the word religion what comes to mind?
- When things are really hard in your family where/who do you turn to for support?
- What would your religious/spiritual supports look or feel like?
- Tell me your thoughts about discussing your spiritual and religious beliefs and practices with your early intervention practitioner?
- Do you think spirituality/religious beliefs and supports should be discussed in the parent/practitioner relationship?
- Do you believe that integrating your spiritual and religious beliefs into the IFSP process would be beneficial or not?
- What do you think would be the outcomes of opening a discussion about spirituality and religion with your early intervention practitioner?
- As parents, what do you need from your early intervention practitioner in order to comfortably express your spirituality?
- Are there any other thoughts you would like to share in relation to spirituality, family-centered care and the IFSP process?

Sample Focus Group Questions- Practitioners

- There are many ways to think about spirituality and religion. When you hear the word spirituality what comes to mind?
- When you hear the word religion what comes to mind?
- What are your thoughts of discussing spiritual and religious beliefs and practices with your families?
- Do you believe that integrating spiritual and religious beliefs into the IFSP process would be beneficial or not?
- What do you think would be the greatest outcomes/deficits in opening a discussion about spirituality and religion with your families?
- As practitioners, what do you need to feel competent when discussing families' spirituality?
- Are there any other thoughts, ideas, or suggestions you have in relation to spirituality, family-centered care and the IFSP process?

Appendix F
Background Questionnaires

Background Information - Parent

Education: High school _____

Community/Private College _____

University _____

Gender: Male _____ Female _____

Age: 20's _____ 30's _____

40's _____ 50's _____ Older _____

Number of Children in household: _____ Ages: _____

Gender/s: _____

The following questions pertain to the child receiving early intervention services:

Child's Diagnosis: _____

Age of child when you first became concerned about developmental status: _____

Age of Diagnosis: _____

Child's Current Age: _____

The following questions pertain to spirituality and religion. For the purposes of this study spirituality and religion are defined within broad parameters and encompass personal beliefs, philosophies, and organized religions.

Do you consider yourself a regular attendee of a religious institution or group? Yes ____,

No ____. What is your level of involvement?

For you, are spirituality and religion one in the same thing_____, distinct_____, or inter-related_____? Please elaborate.

How would you define spirituality?

Have you ever discussed spirituality and religion with your early intervention practitioner in the context of family-centered practice? Yes_____, No_____. Please elaborate.

Thank-you.

Background Questionnaire - Practitioner

Education: High school _____
 Community/PrivateCollege _____
 University _____

Gender: Male _____ Female _____

Age: 20's _____ 30's _____
 40's _____ 50's _____ Older _____

Position: _____

Number of years practicing in Early Childhood Intervention: _____

Number of years practicing in other relevant work experience: _____

The following questions pertain to spirituality and religion. For the purposes of this study spirituality and religion are defined within broad parameters and encompass personal beliefs, philosophies, and organized religions.

Do you consider yourself a regular attendee of a religious institution or group? What is your level of involvement?

For you, are spirituality and religion one in the same thing _____, distinct _____, or inter-related _____? Please elaborate.

How would you define spirituality?

Have you ever discussed spirituality and religion with families on your caseload in the context of family-centered practice? Yes _____, No _____.

Please elaborate.

Thank-you

Appendix G
Quality of Life Indicators

Quality of Life Indicators

Physical Being	My body and Health	Looking after physical health Eating a balanced diet Hygiene and body care.
Psychological Being	My thoughts and feelings	Self-control Self-concept Freedom from anxiety
Spiritual Being	My beliefs and values	Understanding right and wrong Attaching meaning to life Celebrating life
Physical Belonging	Where I live	Place of residence Space for Privacy Living in a neighbourhood
Social Belonging	The people around me	Having a spouse or special person Family Friends
Community Belonging	My connectedness to the resources in my community	Access to meaningful work Access to community places Access to education
Practical Becoming	My practical daily activities	Work, school, or program Work around the home Looking after people/pets
Leisure Becoming	What I do for fun and enjoyment	Visiting and socializing Casual leisure activities Hobbies
Growth Becoming	What I do to change, grow, and adapt	Learning about new things Attaining new independent living skills. Adjusting to changes in life

Adapted from: Centre for Health Promotion of the University of Toronto, 1997

Synthesis of Quality of Life Domains and Indicators

Physical Well-Being	Health, nutrition, mobility, activities of daily living
Emotional Well-Being	Happiness, contentment, freedom from stress, self-concept and religious beliefs
Social Well-Being	Intimacy, friendships, community activities, and social status and roles.
Productive Well-Being	Personal development in education or job, leisure and hobbies, choice and autonomy, and personal competency.
Material Well-Being	Ownership, financial security, food and shelter, and socio-economic status
Civic Well-Being	Privacy, voting access, civic responsibilities and protection under the law.

Adapted from: Cummins & Baxter, 1997; Felce, 1997; Gardner et al. 1997; Hughes & Hwang, 1996; Schalock, 1996.

Self-Reported Quality of Life

Satisfaction with Life	Welfare, contentment, pleasure, flourishing and excellence.
Happiness	Pleasure (physiological-level), satisfaction (cognitive-level) and a sense of value in and worthiness of one's life.
Well-Being	Life satisfaction or happiness, measured as self-reported/ rated health

Adapted from: Musschenga, A. W. (1997)

Appendix H.

Family Quality of Life Indicators

Family Quality of Life Domains and Indicators

Family Interaction	Relationships among family members and the relational environment in which the family operates.
Daily Life	Daily, recurring activities of life, which help meet individual and collective needs.
Parenting	Activities which adult family members do to help children grow and develop in multiple areas of life
Financial Well-Being	Financial means to pay, for what the family needs, and in some cases, for what it wants.
Emotional Well-Being	Emotional and internal aspects of life.
Health	Physical and mental health aspects of life and access to healthcare.
Physical environment	Physical environment aspects of life. Including safety space, comfort and access.
Productivity	Skills and opportunities to participate and succeed in various activities of life
Social Well-Being	Relationships of family members with people outside the family
Advocacy	Advocacy activities required by one or more family members, which benefit the child with a disability and/or the family.

Adapted from Park et al. (2003). Toward assessing family outcomes of service delivery: validation of a family quality of life survey.

Conceptual Framework of Family Quality of Life

FAMILY AS A WHOLE	
	Daily life
	Family interaction
	Financial Well-Being
	Parenting
IMPACT OF INDIVIDUAL FAMILY MEMBERS	
	Advocacy
	Health
	Productivity
	Emotional Well-being
	Physical environment
	Social Well-being

Adapted from: Park et al. (2002). Impacts of poverty on quality of life in families of children with disabilities.