

**Family Centred Practices in Early Intervention in Nova Scotia:
Quality of Life Issues for Families.**

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requirement for the degree of Master of Arts (Child and Youth Study)

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Dedication

To my parents, Warren and Anne, and my brother, Joseph.

Any achievement of mine is always in tandem with your unconditional support and love.

In my moments of doubt you always insisted that I would be able to persevere.

Abstract

Family-centred practice is comprised of three main components: family choice, working from a strengths perspective, and acknowledging and embracing the family as a unit, as opposed to merely the child or mother-child dyad (Allen & Petr, 1996). Within family centred practice, the Individualized Family Service Plan (IFSP) is used to outline the family's goals and hopes for the future for their family (Garguilo & Kilgo, 2000). Developing IFSPs can be challenging (Jung & Baird, 2003; Jung & McWilliam, 2005; Mahoney & Bella, 1998) as service providers often lack training around family centred practices. Resulting IFSPs become documents created by professionals for the families with goals that are child focused, often ignoring quality of life issues for the family (Katz & Scarpati, 1995). The aim of this research was to gain deeper insight into family centred practices in Nova Scotia. Specifically, issues related to family centred practice such as the IFSP, quality of life issues for families, and formal and informal supports were examined from the perspective of parents and early interventionists.

A qualitative research design was used to gather families and early interventionists perspectives and experiences in early intervention in Nova Scotia. Families (N= 8) and early interventionists (N= 3) from three rural early intervention programs were individually interviewed. Participants eagerly shared their experiences, frustrations and joys with early intervention. Results demonstrated that while early interventionists had a basic understanding of family centred theory, service delivery and IFSP development, practice and knowledge did not always blend. Of note was the disconnect between the knowledge of early interventionists and the experiences of families. Early interventionists discussed the pressures of meeting imposed deadlines for IFSP development while families lamented that goals were too child focused or not always in line with how the family functioned. Further, family quality of life issues did not

appear to be formally addressed and there was some debate regarding the appropriateness and fit of these issues within the early intervention construct.

The need for continued training and entry level qualifications to be an early interventionist in Nova Scotia was evident from the data. Early interventionists in NS need a means to share information and engage in ongoing professional development to ensure that new techniques and philosophies become part of their practice. This can only lead to more family focused practice and family led IFSPs. Continued in-depth training on the underlying philosophy of family centred practice and collective empowerment will help the early intervention community to truly understand and appreciate the notion of empowering each other and result in early intervention programs that truly reflect best practices.

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Chapter 1

Introduction

Background

Family centred practices in early intervention have been evolving for the last forty years. During this time, programs for families and young children with developmental needs have changed from centre-based programs that focused on the child to home-based collaborative programs, which focus on the entire family (Mahoney & Bella, 1998). The evolution, which programs and researchers went through, speaks to the tireless efforts of parents to advocate for families combined with a number of important historical and cultural changes.

Many definitions exist for family centred practices. Allen and Petr (1996) summarized other definitions and added their own perspective. Family-centred practice is comprised of three main components: family choice, working from a strengths perspective, and acknowledging and embracing the family as a unit, as opposed to merely the child or mother-child dyad. Within family centred practice, the tools that service providers use to track development and programming evolved as well. The Individualized Education Plan (IEP) used in the school system evolved into the Individualized Family Service Plan (IFSP) for families with children under school age (Garguilo & Kilgo, 2000). The IFSP outlines the family's goals and hopes for the future for their family.

Developing family-centred IFSPs is not without its challenges (Jung & Baird, 2003; Jung & McWilliam, 2005; Mahoney & Bella, 1998). Major challenges include service providers' lack of training around family centred practices and IFSPs becoming documents created by 'professionals' for the families. Often goals are child focused or not included because it does not

fit within the family goals. Research has demonstrated that service providers work toward goals that are not included in the IFSP (Katz & Scarpati, 1995).

Research has recently begun to extend family centred practice into a new construct, one that examines the family quality of life and collective empowerment. Under the new framework, the service providers work collaboratively together to collectively empower each other and move forward to enhance the family's quality of life.

Personal Reflection

I remember clearly my first few months as an Early Interventionist; I was fresh, invigorated and ready to change the world. I had just graduated from my undergraduate degree where I had completed an extended research project on early intervention. While my degree was not in early childhood education, this project had provided me with a great deal of information and theory surrounding our practices. It was because of this that I was in disbelief when I entered the field and found such discrepancies between research and practice. I quickly learned that I work with a group of intelligent and caring women who are attempting to serve a population with little formal training and support, or at least little formal training in what the research told me to expect. Formalized Individual Family Service Plans were relatively new to many people, and each person was doing them quite differently.

Six years later, many of us are still struggling to evolve our practice according to the research. It remains that the research that we reflect upon is typically from a country with different laws governing EI services. It has been my hope since starting the degree that I would be able to provide a Nova Scotian perspective and create research that speaks to what we do.

Purpose and Aim

The purpose of this study was to explore family and service providers' perceptions of early intervention services. Parents and service providers were asked to discuss their perceptions of EI as it related to their impressions of family centred practice, individualized family service plans, and quality of life.

This research offers meaningful insights into Nova Scotian parent and service provider perceptions of EI service. Currently, much of the literature on EI is grounded in an American perspective. This research provides insight into EI in Canada specifically NS. The information gained can inform parents and service providers of family-centred practices that are effective and areas that still need to be addressed. Parents and service providers can use this knowledge to dialogue and collaboratively plan to ensure that EI services in NS are family centred and enhance the family's quality of life. Early Intervention services are unique in their delivery; families allow service providers into their homes on a regular basis to discuss some of the most intimate details of their lives. This research allows service providers to reflect further on their practice to improve their relationships with families.

Definitions

Family Centred Practice

Family-centred service delivery, across disciplines and settings, recognizes the centrality of the family in the lives of individuals. It is guided by fully informed choices made by the family and focuses upon the strengths and capabilities of these families (Allen & Petr, 1996, p. 68).

Individual Family Service Plan (IFSP)

The IFSP is the guiding document in early intervention services. It is the tool which service providers and families use collaboratively to identify what services will target and how. The IFSP provides accountability to the family for the services requested and provides a timeline in which objectives will be met. The process in which the IFSP is produced is as important as the final document. True family participation is expected through all stages of the IFSP (Bruder, 2000; Garguilo & Kilgo, 2000).

Collective empowerment

A new paradigm to guide interactions between families and service providers. Collective empowerment acknowledges that service providers do not always have the necessary skills or tools that a family might need. This model examines how all team members involved can increase their capacities. Team members achieve capacity building through a process that maintains an equal balance in the power relationship. Within this model, 'problems' are not viewed within the parent-child relationship; rather they are part of the entire community or ecology (Turnbull, Turbiville, & Turnbull, 2000).

Chapter 2

Literature Review

Early Intervention programs are grounded in research that reflects the importance of the early years for a child's development and in the strength of the family as a unit for supporting itself. Brynelsen and Cummings (1991) note that Early Intervention in Canada is:

based on one or more of the following assumptions: 1) infancy is an important period of life; and delays in development during this period may have long-term cumulative effects on the patterns of development of any child, as well as the patterns of interaction between the child and his or her family; 2) intervention for children with developmental problems may be most effective if begun as early in the child's life as possible; and 3) the family unit is the most crucial source of learning, developmental encouragement, and emotional support available to the child (p. 138-9).

Historical Overview

In order to appreciate the points raised by Brynelsen and Cummings (1991), a discussion of the significant theories of child development, special education, and psychology must be presented. For newer or younger service providers of today, the above-mentioned points seem evident, as they are ingrained into daily practice. However, after reviewing the historical trends and theories, specifically of the past 60 years, the effort and advocacy of educators and families is apparent.

As the second war ended, many social programs and societal standards had changed from the beginning of the century. The war itself had produced a need for early childhood programs to care for children while mothers went to work. Further, as the 50s

began, countries were prospering and research was flourishing. It was in this period that many of the debates around child development (nature versus nurture) were evolving and attempts were being made to negotiate a common understanding between the two theories. It was an exciting time, researchers were devoting their time to individuals who less than fifty years before died young or were institutionalized. The ‘nurture’ side of the debate took strength from the work of John Watson, who spoke to the environmental affect on children’s development (Garguilo & Kilgo, 2000; Meisels & Shonkoff, 2000). This was a new view that opposed a simplistic biological determinism, which concludes that all aspects of children’s development were a result of their genes and not their environment. While a middle ground between these two extremes is now perceived as common sense, one must note that at the time this research was published, it was viewed as exciting and correct. Further, with each new theory or claim came new programs (Allen & Petr, 1996; Turnbull & Turnbull, 2002).

Jean Piaget appeared to take the middle ground as he described intelligence and its acquisition as the product of both biological and environmental factors (Garguilo & Kilgo, 2000). The way in which a child acquired his intelligence was of far more importance to Piaget than the level of intelligence. As the “rapprochement between the polarities” (Meisels & Shonkoff, 2000, p. 11) of nature versus nurture began, new work evolved around the relationship of mother and child.

The importance of the early relationships between child and (typically) mother were articulated by John Bowlby. In his work studying deprived children, he examined the long-term socio-emotional effects on deprived children when early relationships are not formed (Osofsky & Thompson, 2000; Emde & Robinson, 2000). These early theories

would provide the foundation for the educational and family programs that would follow in the 60s and 70s.

The 1960s were a period of political and social change, including issues around the rights and education of children with disabilities (Meisels & Shonkoff, 2000). It was, in part, due to the growing civil rights movements that addressed inequality for racial differences that led to the awareness of rights for all minorities in society. The United States enacted monumental legislation that provided educational programs for children with special needs. Further, in response to the growing awareness of children living in poverty, the United States policy makers created the Head Start program to respond to the needs of families with young children at risk (Garguilo & Kilgo, 2000; Meisels & Shonkoff, 2000). Head Start programs were early childhood programs, which focused on preparing children for success in school, which might have been hindered due to their social situations.

The connection between the early theories to these programs is evident. The interactive nature of biology with environment challenged policy makers to create programs to target the most at-risk populations. Head Start was an attempt to address many of the early risk factors that existed within many families that was affecting later intelligence and coping skills of the children (Mahoney & Bella, 1998; Shonkoff & Meisels, 2000). It was also in the 60s that the United States enacted legislation around education for children with special needs (PL 89-750: Education for Handicapped Children) (Garguilo & Kilgo, 2000).

While the US was enacting legislation, Canadian educators and families were gathering in Ottawa to discuss the needs of those with disabilities. In 1964, the Canadian

Federal / Provincial Conference on Mental Retardation was held (Brynelson & Cummings, 1991). As one of the first gatherings of this type in Canada, it allowed provincial and federal government representatives to discuss the programs for this population. Similar timely responses to the programs in the US were not found in Canada, but as Brynelson and Cummings note “by the mid-1970s parents and professionals in every Canadian province were discussing, planning, or implementing programs for infants and preschoolers with developmental problems” (p. 137).

The Civil Rights movement continued into the 70s as society began to re-examine institutions and demand rights for its members with special needs (Fewster & Garfat, 1991; Nova Scotia Department of Community Services, 1998). It was during this era that three main theories developed which served as the impetus for early intervention services. The movements associated with normalization, ecological theory, and the family systems theory, while revolutionary at the time, are regarded as best practice in today’s services. These theories and movements form the history from the 70s forward and lead into the modern day EI programs.

Normalization

Wolf Wolfensberger articulated the theory of normalization as it is known in North America (Brown, 1991; Fewster & Garfat, 1991). Wolfensberger drew attention to the idea that society was treating persons with special needs as deviant members and was segregating them from the rest of the world. He advocated for the most typical treatment of these individuals as possible, more specifically: “utilization of means which are culturally normative as possible, in order to establish and / or maintain personal behaviours and characteristics which are as culturally normative as possible” (Wolfensberger, 1972, p.28).

Originally discussed in the Scandinavian countries in the 60s, Wolfensberger brought it to the forefront in the 70s. Institutions were being reviewed, governments were analyzing the costs spent on institutions, and thus conversations were beginning around the placements for individuals with special needs (Brown, 1991).

Interestingly, these theories asserted for culturally relevant / appropriate inclusive treatment for all members. There are similarities between these early concepts and today's inclusive society values. It was the beliefs associated with the principles of Normalization that continued the evolution of the present day Community Living agencies in Canada (formerly Canadian Association for the Mentally Retarded) (CACL website, n.d.). Within Canada, it was the concept of normalization that had many families keeping their children at home and advocating for community based services. These advocacy groups laid the foundation for early government sponsored programs for young children with special needs (Brynelson & Cummings, 1991).

As conversations and debates were had surrounding the concept of normalization, practices did begin to change. Institutions were closing, children were at home, and instruction was given to children in their home. With the new advances came new discussions around the functions of a family and its interactions.

Ecological Theory

As the 70s ended, numerous important legislations had been enacted in the United States. In 1974, the American government enacted Public Law 94-142, the Education for All Handicapped Children Act (Meisels & Shonkoff, 2000). Free and appropriate education was guaranteed to all school-age children with special needs. Individual programming (via Individual Educational Plans) and parent involvement were included and mandated as part of this

law. Families were to be part of their children's education. Further, the federal government provided incentives to states who served children as young as three years of age. This legislation created an environment organized for change as family involvement was guaranteed and preschool services were gradually created.

Debates and discussions around the dynamics of families began to enter the realm of special education. As the entire family was becoming the focus of intervention, it became apparent that the effects of these services on the family must be recognized. Urie Bronfenbrenner challenged service providers to consider the ecology of the family, more specifically "the interrelationships and interactions of individuals within the environment" (Garguilo & Kilgo, 2000, p. 51). The family is in the middle of a series of layers of involvement, commonly presented in today's practice as a bull's-eye diagram. The child's development, according to Bronfenbrenner (1979), was not a simple trajectory; rather it was dependent on the various environmental influences that were present (or not present).

While previously stated, it is important to note the shift that this required for many of the service providers of the time. The child could no longer be the sole focus of any intervention. Bronfenbrenner challenged society to consider other relationships that might affect a basic mother-child interaction: "the capacity ... to function effectively as a context of the development depends on the existence and nature of other... relationships with third parties" (Bronfenbrenner, 1979, p. 77). As were many others of this time, Bronfenbrenner also spoke out against institutionalization of individuals with special needs. In the context of relationships with others in the environment, institutions limited a person's ability to interact with challenging / stimulating individuals and objects.

Family Systems Theory

Discussions surrounding children being in their “normal” communities combined with the theories regarding the ecologies of families shaped many new ways of working with families within the early intervention community. Linking much of the two previous theories together, Turnbull and Turnbull (1986) brought the sociology research on Family Systems into this domain. There are four main parts to their model: family resources, family interactions, family functions, and family life cycle (Turnbull & Turnbull, 1986). Each of these components provides insight into the unique characteristics of each family.

Family resources entail the descriptive factors that create the family. These characteristics allow each family to be independent from another (cultural background, family size, socioeconomic status, and location). Further, resources include the individual characteristics of each member (health, coping style). Focusing on family interactions leads to examination of the interactions amongst the family subsystems, therefore studying parents, siblings, and parent –child, as well as extended family interactions. Further, Turnbull and Turnbull (1986) elaborate on the way in which each family member interacts, specifically the cohesion and the adaptability of the family members. Family functions include the “interrelated activities that are necessary to fulfill the individual and collective need of the family” (Garguilo & Kilgo, 2000, p. 69). The interrelated activities are affection, self-esteem, economics, daily care, socialization, recreation, and education. The final component of the family systems theory is the family life cycle. Within a family, change is certain, it is guaranteed that children will grow older and mature, and thus the family will experience transitions. Further, other changes are unexpected: the diagnosis of a special need, a divorce, or sudden death. The family’s response to each of these changes is of importance to the service providers.

Specifically, this new framework challenged service providers to view each family independent of other families. Service providers were not to assume that all parents wanted to be their child's advocate, nor did they all want the same thing. Rather, each family member has their own set of needs, which affect all other members' individual needs to form the needs of the family (Garguilo & Kilgo, 2000). When a service provider examined the Family Systems theory related to the individual families they are working with new practices became obvious. Not all families could be assigned 'homework' in the same fashion. Acknowledgement of individual family systems would demand the service provider respect the eccentricities of the family and work within those limits. The underlying feature, according to Turnbull and Turnbull (1986) is "[an] individualizing parent-professional relationship for the benefit of all concerned – the child, parents, other family members, and professionals" (p. 21).

While these frameworks led us to the family centred, home based early intervention that we are familiar with today, such intervention has not been delivered in a consistent fashion. As society deliberated on the various theories of development and on frameworks to address them, early intervention service providers conducted similar debates, which led to an evolution in their practice.

Family Centred Practice

One can examine Early Intervention from its early roots in 1968 when Public Law 90-538, the Handicapped Children's Early Education Assistance Act created the first demonstration programs for infants and young children with special needs. These early programs were centre based and child focused (Mahoney & Bella, 1998). If any focus was placed on parents (typically the mother), it was in teaching parents to teach their child. Given new information concerning the environmental effects on development, service providers believed that by "fixing" the

parents' styles of interaction, the developmental challenges would be ameliorated (Allen & Petr, 1996; Tunbull, Turbiville, & Turnbull, 2000; Turnbull & Turnbull, 2002).

Furthermore, in these early days, it was assumed that teaching the parents would lessen the need for institutional care (Bailey et al., 1998). As the practices progressed, there were events that affected the ways in which service was provided. While it is difficult to determine whether parental/community advocacy spurred the research on or the reverse, it is obvious those two factors advanced the field. The new theories, mentioned above challenged service providers to view their service within the family, as well as, within a normal societal viewpoint. Parent involvement became mandated for school age children in 1975, but as many point out this was purely in the form of parents being part of programming meetings in the beginning. As McWilliam, Tocci and Harbin (1996) stated, "parents should participate in the activities that professionals deemed important" (p. 206). Further in 1975 more laws were enacted which required all community mental health centres to have a centre-based children's program (Allen & Petr, 1996). Despite these numerous advances in the 1970s, many would articulate that true family centred practice did not evolve until the 1980s (Allen & Petr, 1996, Dunst, Boyd, Trivette, & Hamby, 2002; Turnbull & Turnbull, 2002).

Definitions of family centred practice are abundant. Each author, researcher, or service provider defines the term with subtle differences. In pursuit of a central definition, Allen and Petr (1996) reviewed more than 100 definitions of family centred practice. These results coupled with their own theoretical viewpoints resulted in the following definition:

Family-centred service delivery, across disciplines and settings, recognizes the centrality of the family in the lives of individuals. It is guided by fully informed

choices made by the family and focuses upon the strengths and capabilities of these families (Allen & Petr, 1996, p. 68).

There are three main points to this definition that are collectively agreed upon in the research: family choice, family strengths, and family as a unit of support (Allen & Petr, 1996; Turnbull & Turnbull, 2002; Bailey et al., 1998).

Respecting and encouraging families to make choices regarding the services they would like is an overriding feature to family centered practice. Allen and Petr (1996) provide a sample of areas that should be included when considering the families choices: who is considered their family, who makes decisions regarding services, the extent of the relationships of those providing the services, the quantity and method of information sharing amongst team members, and the identification of goals. Having families participate actively in the programming is a significant shift over the past decades. In the past service providers told families what to work on, and how to work on it.

It is difficult to determine how these principles should be reflected in practice. McWilliam, Tocci, and Harbin (1998) studied the characteristics of service providers who aligned closely with the best practices definitions of family centred practice. Participants, in their study described their philosophies and practices. Underlying components of their philosophies included: a primary concern with the family, and “a philosophy of positiveness... [which] included a belief in parents’ abilities, a non-judgemental mindset, and optimistic view of children’s development, and an enthusiasm for working with families” (McWilliam, Tocci, & Harbin, 1998, p. 7). Additionally, these service providers were sensitive, attempted to understand parents’ needs, responsive to parent needs, and friendly. They found that good

service providers needed both good inter-personal skills in dealing with families as well as knowledge of child development and available community resources.

Turnbull and Turnbull (2002, 1986), along with their colleagues at the University of Kansas have been examining family centred practice for over 20 years and have been synthesizing the research into a model. The evolution of practice from the early child centred programs can be described as the move from the old paradigm into the new paradigm. According to Turnbull and Turnbull, the early models before family centred practice were the old paradigm: psychotherapy (fixing the child), parent training (teaching the parent to fix the child), and parent involved (at meetings only). Each of these models is described using a power relationship between service provider and family member. The early models of the Old Paradigm fell within a “power over” relationship, whereby the service provider (i.e. expert) had the power over the parent. Characterized by a “power with” relationship, family centred practice was the bridge into the New Paradigm (Turnbull & Turnbull, 2002; Turnbull, Turbiville, & Turnbull, 2000). While many service providers of today would believe that they have achieved success with family centred practice, this framework challenges the community to a next level. According to Turnbull and Turnbull, families and service providers together should be striving for a “power through” relationship, whereby the emphasis is on “empowerment as the process and family quality of life as the outcome of research and professional services” (p.91). Rather than the former approaches, which attempted to “fix” a child, the new community based approach examines the various environments and settings of a family in order to alter (“fix”) them to accommodate the families’ needs. Collective empowerment acknowledges that service providers do not always have the necessary skills or tools that a family might need. It would be extremely difficult to empower a family, as was previously termed, if the provider did not have

the necessary tools. Collective empowerment models examine how all team members involved can increase their capacities. Team members achieve capacity building through a process that maintains an equal balance in the power relationship. Within this model, 'problems' are not viewed within the parent-child relationship; rather they are part of the entire community or ecology (Turnbull, Turbiville, & Turnbull, 2000).

A central feature to this model directly related to practice is the acknowledgement of a family's quality of life. As Brown (2003) summarizes, his colleagues have researched individual quality of life extensively. It has only been in the last ten years that researchers shifted into examining the quality of life for the entire family unit (Bailey et al, 1998; Park et al., 2003). Returning to the original tenets of family centred practice of choice, strength, and family as a unit, the quality of life model takes all of the key factors into account. Following a family's choice, working from their strengths, and interfacing with the entire family will only enhance the quality of interactions amongst all members.

In accordance with the evolving beliefs around quality of life, the outcomes for early intervention should reflect this focus. Evaluating whether a family feels their quality of life has increased can require greater sensitivity and reflection than whether the child's development was enhanced because of early intervention. While the new paradigm may require more effort, the value is far greater. Researchers and service providers, through formal evaluations and anecdotal stories, are realizing that early intervention, while full of good intentions, may not be decreasing the need for support or additional teaching later in life for the child with special needs (Bailey, Aytch, Odom, Symons, & Wolery, 1999). Therefore, a new set of outcomes, along with appropriate measures, is needed. Poston, Turnbull, Park, Mannan, Marqus, and Wang (2003) investigated this construct and identified ten domains within the family quality of life framework:

advocacy, health, productivity, emotional well-being, physical environment, social well-being, daily family life, family interaction, financial well-being, and parenting.

In order for service providers to be accountable for their services and to engage in family-centred practices, appropriate documents must exist to facilitate this. The Individual Family Service Plan has evolved as the process and document that assists service providers in their work.

The Individualized Family Service Plan

The Individualized Family Service Plan (IFSP) guides early intervention services (Bruder, 2000). The IFSP should discuss the child and family's status, and identify areas for goals, which the family has indicated they would like to target (Perry, Greer, Goldhammer, & Mackey-Andrews, 2001; Boone, Moore, & Coulter, 1995).

IFSPs evolved from the Individual Education Plans (IEP) of the school system (Gallagher & Desimone, 1995). As programs for children with special needs were made available to children at a younger age, appropriate documentation was needed. The IEP was naturally used for the younger children as it had been used for the school age children. However, the IEP was not a good fit with the evolving family centred nature of early intervention services.

IFSPs are the vehicle to ensure that service providers are following the principles of family centred service delivery (McWilliam et al., 1998). Research has demonstrated that more change can occur in a family when the family feels that they are, not only part of the process, but a leading factor in it (Jung & McWilliam, 2005). Service providers must always remember that families are with their children for a lifetime while various service providers have sporadic contact throughout their children's life. It is the families who need to feel they can make the needed changes on their own, and feel confident in this. The IFSP is a family centred document based on four assumptions:

The IFSP should be a document for the family as well as for the professionals; the IFSP should reflect what the family wants; the IFSP should reflect recommended practices (anything less is unfair to families); the IFSP should be functional (i.e. useful to families and service providers) (McWilliam, et al., 1998, p. 2)

IFSPs must be family centred as it guides and outlines services. Family wishes and priorities are the cornerstone of this document, ensuring that family goals are guiding services (Jung & McWilliam, 2005; Perry et al., 2001; Boone et al., 1995). Further, families have asserted experiencing more family centredness in their program when an IFSP was in place (Harrison, Dannhardt, & Roush, 1996). The IFSP is a process that allows for enhanced service delivery, by enhancing communication and service coordination (Farel & Shackelford, 1997).

In addition, as parental control and full understanding are key goals for most early intervention services, the IFSP guarantees these goals using plain, non-technical, language. Technical terms and government labels are not welcome in an IFSP. Further, the IFSP is written in positive, active verb, strength based language (Jung & McWilliam, 2005). To ensure that the four assumptions underlying the IFSP process are practices, researchers and service providers have outlined the basic components that should be included in an IFSP. While the basic components (listed below) to be included in an IFSP are legislated in the United States, Canada does not have similar provisions or laws. According to Bruder (2000), the IFSP should contain the following eight core components:

1. Present level of development

The IFSP should always contain information regarding the child's present level of development across domains. Often, the IFSP is written following assessment of all areas of development. This information will provide accurate and up to date information for the IFSP.

Domains to consider would include physical, cognitive, social / emotional, communication, and adaptive.

2. Information related to the family

Personal concerns for the family or child, their resources, and their most important priorities should be included in the IFSP. This section is the crux of the family centred nature of early intervention. Families must have the opportunity to express their dreams and wishes for their family and child. Further, they can identify what it is they would like to target in order to achieve their dreams for the future.

Identifying these areas can be a challenge for some families as they are focused purely on the needs of their child. Perhaps, in the past service providers led them to focus on the needs of their child. Service providers must ensure the family's wishes guide the IFSP process and document. A variety of surveys and questionnaires exist to assist parents in identifying their needs. These can be part of the preparation for the IFSP.

3. Outcome statements

Outcome statements are the family's goals. They are the outcomes that the team will work toward with the family. Outcome statements flow naturally from the family identified wishes and concerns. Outcomes should be measurable and specific. Within each outcome statement, it must be easily apparent what the criterion is for success of the goal (i.e.: how many times must the child do a new activity, or what does the family want to learn from engaging in a new process). Specificity allows for measurable goals. The service provider's role is to help the family refine their broad wishes or concerns into achievable, measurable and specific outcomes. This allows the family to experience success early in the process.

4. Specific services needed

All IFSPs should clearly articulate the type(s) of service(s) needed to achieve and support the outcomes. It is the IFSP that guides services, therefore it must be indicated how each service will be of use. For legal and billing purposes in the United States, this section must also contain the intensity and duration of services. In many states, service providers bill for services through the IFSP, making appropriate indications of service a necessity.

5. Environments for service

Families and children learn and function best in their own environment. As early intervention services evolved, so to have the delivery of the services. In the past, services were centre based and did not fit with the daily experiences of families. An increased awareness of family centred services has led to services being offered in natural environments. This change has necessitated this section on the IFSP to ensure these natural environments are being utilized. Natural environments can vary for each family. It is important to identify these preferred environments early in the IFSP process. Various parent needs surveys also assist families in identifying the areas of their day and routine they would like to focus on.

6. Timeline

All IFSPs must include reference to when outcomes are anticipated to be achieved, and reviewed. Dates make IFSPs functional and ensure accountability. Anticipated review dates or completion dates also ensure continued focus on goals and outcomes.

7. Main contact

Each IFSP team will establish a service coordinator.

8. Transition

The IFSP will identify any forthcoming transitions. Transitions may include commencing a new preschool-type program or leaving the early intervention program. Reasons for leaving

the early intervention program may include, but are not limited to preparing for entry to public school, services are no longer needed, and parents choose to discontinue services. The necessary steps to secure a seamless transition for child and family should be outlined within the IFSP. Some IFSPs may include transitioning as an outcome.

While the IFSP is a legislated document in the United States, there is no such legislation in Canada. Melanson (2005), in reviewing IFSPs from across Canada found extreme variation in the style and presentation of the IFSP. Of the seven documents reviewed against the above-mentioned features of an IFSP, only one section (outcome statements) was in every IFSP. No other section was in every IFSP. Further, not one IFSP included any information regarding the environments to be served in (Melanson, 2005).

It is important to note, that while this information is useful for that state of IFSPs in Canada, it is in no way a full indication of the service delivered. Due to the general nature of this project, it is impossible to ascertain whether the IFSP process was truly family centred (Melanson, 2005).

Other core components of the IFSP process include the recognition of the IFSP as a fluid process which is constantly changing as children and families do. Traditional IEPs tended to be written and forgotten. Recognizing the fluidity within a family, the IFSP process is perceived as ongoing. As families meet goals and outcomes, new ones are written. Outcomes are revised as priorities change within a family. These factors ensure the functionality of the IFSP. In examining the information on IFSPs, Melanson (2005) demonstrated that some of the provincial documentation did allude to these functional pieces of the IFSP.

Challenges with the IFSP process and document

The IFSP is not without its challenges. Despite the increasing amount of research on IFSPs and their content, there are still many service providers writing IFSPs that do not fit with best practices (Jung & Baird, 2003). As previously discussed, an IFSP is meant to guide all services for a child and family. Despite this, research has demonstrated that service providers are not following the IFSP for their delivery. Katz and Scarpati (1995) found that because of the family focus of the plans, service providers did not always have their goals on the plan. This was part of their role as a professional to censor the goals if they felt the family was not ready to discuss a particular topic. These service providers lacked a core understanding of family centred service delivery.

Other challenges associated with IFSPs revolved around the nature of the goals. Despite the move to a family focused approach, research has demonstrated that IFSPs predominantly contain child centred goals (Harbin et al., 2004; Katz & Scarpati, 1995). More so, it has been proven that, while intervention settings are now more natural (as suggested); service providers are providing interventions that do not fit within the daily routines of the home or family life (Jung & McWilliam, 2005; Jung & Baird, 2003). Limited or outdated training in the field has also contributed to the challenges associated with the IFSP. Jung and Baird (2003) reported that with increased experience IFSP quality decreased (Jung & Baird, 2003). Due to an attitudinal shift in the field, related to families, those with more experience had more difficulty with family centred IFSPs. On going, family centred, in-service training is obviously needed.

Early Intervention in Nova Scotia

There are currently sixteen Early Intervention programs in Nova Scotia, providing full provincial access to early intervention for families with infants and young children with special

needs (NS Department of Community Services, 2001). Full provincial coverage was not available until 2001 when the Nova Scotia government expanded the existing budget to cover the remaining areas of the province. Early Intervention in Nova Scotia has existed since the early 80s when parent groups in local communities advocated for and organized services for their children with special needs (Irwin, 1995). As programs developed, they would access funding from a variety of sources including the Federal Government's Canada Assistance Plan (Brynnelsen & Cummings, 1991). The provincial government began funding early intervention programs in 1987 providing 75% of the program funding, expecting the program to fundraise the remaining needed funds (Irwin, 1995). In addition, each program had to ensure that a sub-group of the families was below a specific income level (via income testing) through the Canada Assistance Plan.

Volunteer Boards of Directors (NS Department of Community Services, 2004) run early Intervention programs in the province. As noted, programs receive funding from the Department of Community Services, and are responsible for fundraising the remaining funds needed to sustain the program. A provincial manager within the Department of Community Services oversees the programs. A Standards and Guidelines manual exists with minimal standards for the Early Intervention programs (NS Department of Community Services, 2004), however there are no laws or regulations governing early intervention programs and practice.

Chapter 3

Methods

Framework

The proposed research is situated within a qualitative framework. Langenbach, Vaughn and Aagaard (1994) state that qualitative researchers “are interested in an extensive understanding of their participants’ or informants’ world...” (p. 92). Qualitative research focuses on emergent themes in the data; theory will develop out of a grounded theory, as opposed to proving or disproving a pre-existing theory in quantitative research (Wiersma & Jurs, 2005). In the realm of studies on those with disabilities and other marginalized groups, qualitative research provides an opportunity for the researchers to hear the personal needs and events in the form of storytelling (Pugach, 2004). Further, according to Pugach, qualitative research emphasizes, “understanding the complexity of a situation and enabling a fuller consideration of the phenomenon under study” (p. 440).

Following a constructivist approach, this research was relative in ontology (nature of reality), interactive and inter-subjective in epistemology (relationship between research and participant), and dialectic in methodology (Guba & Lincoln, 1994; Guba, 1990). More simply articulated, a constructivist approach acknowledges and encourages the relationship between the researcher and participant, the conversation had between the two is reciprocal and evolves with a common understanding. Constructivist research does not attempt to prove or disprove a-priori theories or notions, rather its “aim is to distill a consensus construction that is more informed and sophisticated than any of the predecessor constructions” (Lincoln & Guba, 1994, p. 111). In the constructivist research, theories typically arise through a grounded theory approach.

In accordance with this approach, the researcher utilized interviews to gather information. Qualitative interviews allow the researcher to gain insight into a person's experiences and the full, rich details of the meanings of their experiences (Seidman, 1991; Rubin & Rubin, 1995). The interviews were semi-structured; which allowed the researcher to present main topics and guide the participant through a series of questions. In the interviews, the participants were treated as conversational partners and the questions flowed from the previous answers. While a list of questions was created to guide the researcher, they were asked when they fit into the conversation or they were not asked (Rubin & Rubin).

Rubin and Rubin (1996) describe this design as “flexible, iterative, and continuous” (p. 43). Flexibility permits the researcher to respond to the nuances of the participants. As participants present new ideas, the researcher will want to adjust subsequent interviews to reflect the new ideas. There is a cyclical nature to the interviewing process, which is the iterative part of the design. With each interview the researcher is gathering, analyzing, and forming smaller units of meaning. Finally, the design is continuous as the researcher is continually redesigning based on the previous two principles.

Participants

Eight parents currently receiving early intervention services from one of three local early intervention programs in NS and three early interventionists employed by these programs were the participants.

Measures

Demographic Questionnaire

All participants completed a demographic questionnaire (Appendix A) containing questions related to participants' gender, age, and education. While the participant pool was

small, this information assisted the researcher to situate the data and compare the responses within and between groups based on the specific demographics.

Interview Schedule

The researcher developed a series of questions to discern participants' perceptions surrounding family centred practices, individualized family service plans and family quality of life. These questions evolved from a careful review of the literature, the researchers five years of experience in EI, and through dialogue with relevant service providers. Questions covered such topics as participants' perceptions of early intervention services, family centred practices, and outcomes of early intervention and family quality of life (see Appendix B).

Procedure

After securing ethics approval from the Mount Saint Vincent University Research Ethics Board, contact was made with the Executive Directors of the three local early intervention programs to obtain their permission to conduct the study at their centres. During this phone call, the nature of the research was discussed as well as the roles and the responsibilities of the researcher and the participants. Any questions and /or concerns were addressed with the director during this call. Follow up letters were sent to the Executive Directors of the early intervention programs (Appendix C).

Executive Directors affixed labels to the family packages for mailing, and provided each of their staff with a package. This method of distribution was utilized because the programs are home based and the researcher has no access to this confidential information. There were two separate packages, one for service providers and one for families. Each package was clearly marked on the outside of the envelope. Package contents included: 1) a letter inviting families / service providers to participate in the research, noting the purpose of the research and outlining

the responsibilities of participant and researcher as well as participant rights (Appendix D); 2) an informed consent form (Appendix E); 4) a demographic survey (Appendix A); and 5) a stamped, self-addressed return envelope.

Of the three programs contacted, there was only one program with more responses than necessary. To select the three families for participation, stratified random sampling was utilized to ensure that there were representatives from each of the three early intervention programs (three stratum) (Wiersma & Jurs, 2005). Those not selected were contacted and thanked for their willingness to participate. All selected participants were contacted and a mutually convenient time and place for the interview was arranged.

Prior to commencing the interviews, participants were reminded of their rights as well as the purpose and aims of the research. The researcher signed the consent form in front of the participant. As the interview began, the researcher strived to maintain the participant's comfort level, and ensure a positive environment that fostered conversation. During the interview, the researcher only used non-directive prompts such as "tell me more" to encourage the conversation. At the conclusion of the interview, participants were formally thanked, and reminded that they would be contacted and given the opportunity to review his or her transcripts. All interviews were audiotaped and professionally transcribed. Numerical codes were given to each audiotape to ensure participant anonymity. The same code was used on the researcher's field notes to further ensure anonymity and to connect the two sources of data. Tapes will be destroyed after they are transcribed.

Trustworthiness, credibility and preventing contamination of data were of foremost concern during the interviews and the subsequent analysis (Langenbach, Vaughn, & Aagaard, 1994; Weirisma & Jurs, 2005). Participants were asked to read the transcriptions of their interviews to

ensure that they felt confident that their ideas and thoughts were heard correctly. Credibility for the final research was established by the researcher's continual demonstration of comfort and knowledge with the topics based on experience and a thorough literature review. Finally, the integrity of the data (thus preventing contamination) was ensured by the researcher's continual self-reflection of any existing biases. Awareness of these biases prevented the researcher from imposing judgment during the interview or in analysis. Further, a second coder was utilized to ensure the consensual validation of the data (Eisner, 1991).

Data Analysis

Rubin and Rubin (1986) present an approach to analyzing data that involves three main steps: coding the data, grouping it into categories, and finally grouping the information into themes.

In order to begin the coding process, the researcher read every interview transcript very closely examining for "core ideas and concepts, recognize emotive stories, and [to] find themes" (Rubin & Rubin, p. 229). Within each question, unique words associated with the field, repeated words or phrases, or examining for an opposing concept were methods used to elicit the early themes for the researcher. Once the early concepts and themes were identified, the researcher began to create codes to group similar items together. Codes were established on a variety of features, including concepts, names, agencies, or steps in a process (Rubin & Rubin). Once all coding was complete, the researcher grouped the information according to the codes (which alluded to the properties and dimensions of the groups). These groupings allowed analysis of the groupings within a category and across categories. Demographic information was summarized. Coupled with the demographics, the researcher was able to discuss the overriding themes that alluded to the underlying properties of the nature of early intervention programs. Three levels of codes were used for each question.

Ethical Issues

1) Informed Consent

Participants received information outlining the purpose, aim and intended outcomes of the study, as well as the expected time commitment and their role. Participants were informed that their participation was voluntary, and that they could withdraw at any time without consequence. Results reported from the interviews analysis were only reported as group data. The report does not include any identifying information when using direct quotes. Further, procedures for the storage and disposal of tapes, documents, and transcripts were carried out in accordance with University procedures. Prior to beginning the interview, the researcher reminded participants of their rights and signed the Informed Consent form.

2) Confidentiality

The confidentiality of the participants was protected through a variety of means. The introductory packages were provided to the early intervention programs to affix the mailing labels. This ensured that the programs did not release any confidential information. Those who did not want to participate did not contact the researcher.

Prior to commencing the interview, the researcher reviewed the information presented in the original package regarding informed consent. Participants were reminded of their right to end the interview at any time and request the taping to cease.

No identifying information was linked to any notes or tapes. Further, during reporting no identifying features were utilized. Participants were reminded that while some direct quotes may be used, their confidentiality would remain of foremost concern. All tapes and notes will be destroyed once the research is finished.

3) Voluntary Participation

Participation in this research study was voluntary. Contact with families and early intervention service providers was through a third party and only those wishing to participate in the interviews contacted the researcher. There were no costs incurred with participation.

4) Issues of Harm

All participants in this study were adults. There was no pressure to participate. Participants shared information at their level of comfort and were in command of the interview process, and could end it at any time. The possibility of harm was deemed low. The researcher, however, was attentive to participants, observing for any indication of discomfort or distress, and had telephone numbers and locations of support services available to the participants.

Limitations

1. Representation in the sample could be limited as individuals more familiar with family centred practice may have been more willing to participate. This may not have provided an accurate description of the larger early intervention programs. It is important to note in this type of research though representation is not expected.
2. The use of audiotapes may have created some discomfort in the participants and led them to be less forthright with their responses. The researcher ensured all attempts at increasing the comfort level of the participants occurred.
3. The small sample size may have been a limitation to this study. Due to the time constraints of the researcher, a small sample size was preferred. A larger size would have allowed for more individual perspectives on the topics. With a limited sample size, there is less chance that the discussion applied to a larger group. It is important to note that the

thoughts and perspectives of the smaller group are still important and offer important points for reflection.

Research Questions

1. How did Early Interventionists describe their profession?
2. Who did participants indicate families rely on for support?
3. What did respondents indicate was their level of knowledge of and prior expectations of Early Intervention prior to their involvement with an early intervention program?
4. How did participants describe a family centred program?
5. How did participants describe their experience with the Individual Family Service Plan (IFSP), as well as their role within it, the process, the decisions that were made and who was involved?
6. How did participants describe families' quality of life and any changes to make?
7. How did participants describe the impact of early intervention on families, the positives and negatives of the program, and whether they would want to change the program?

Chapter 4

Results

Introduction

Participants

There were eleven participants in total, three early interventionists and eight parents. Of the three early interventionists, two were from the same agency. All three had a university degree, two having training specific to the field. The early interventionists had been in the field from one year to over twenty years. Early interventionists ages ranged of 31 to over 45 years of age. One early interventionist had no children of her own, one had two and the other had three; none of their children had identified special needs.

Eight mothers from three different early intervention programs participated in this study. Mothers ranged in age from 26 to over 45. The number of children in families' household ranged from one to seven with most families having one to two children. Families had been involved with early intervention for up to five years with two families receiving services for less than a year. Their children with special needs were between eighteen months and six years of age and had been diagnosed with varying conditions such as Down syndrome, Autistic Spectrum Disorder, Cerebral Palsy, and global delays among others.

Responses to interview questions

Question 1: How did Early Interventionists describe their profession?

When early interventionists were asked to describe their profession, three main themes emerged as descriptors: child / family functioning, programming, and visits. Child and family functioning included working with families because of a specific diagnosis and addressing this

diagnosis via the family and child's strengths and needs. One early interventionist described her profession: "early interventionists work with children from birth to age six who have developmental delays or who are at risk for developmental delay".

Programming is a core component of early intervention. Early interventionists discuss, initiate and model developmentally appropriate activities for the child and family. Further, early intervention was described as being in the home and collaborating with other professionals. Home visits were described as flexible with regard to schedule and focused on both child and family needs. Home visits allowed the early interventionists to see the child and family in their natural routines.

"...we arrive at the home with a bag of developmentally appropriate toys and we play and interact with the child in a developmentally appropriate way. And we get to know the families' strengths and needs and concerns and ways that we can help the family grow and develop, increase knowledge of the child's condition and help incorporate goals and concerns of other professionals into there everyday working life in the home."

Visits are not limited to family's homes, early interventionists also see family's in other situations:

"And we also accompany families on clinic visits and we also do daycare visits as well where we go in and work with the daycare staff to help them, to help the child to be included and to be comfortable so the staff is comfortable as well with the child being in there setting..."

It is important to note that throughout the responses, early interventionists demonstrated and articulated a great respect for the families and children whom they work with. Early interventionists' descriptions of their profession implied a sense of pride and joy in what they do.

Question 2: Who did participants indicate families rely on for support?

Families and early interventionists both agreed that the two main groups families relied on for support are their informal networks and formal networks. Informal networks included immediate family members, neighbors and church groups / clergy, and community supports. Paid service providers would comprise the formal network of support. These paid service providers may include speech –language pathologists, occupational therapists, early childhood educators, physiotherapists, or social workers. It is interesting to note that while both groups identified similar support providers, three of the eight families also noted that they had no support.

“I have absolutely nobody, and this is where I’m from and we got a compassionate posting back here from [another province] because our family is here hoping to get support, and we get absolutely none from anybody.”

Not one early interventionist acknowledged that a family might not have any informal supports. However, early interventionists were able to list a variety of the same support providers that families noted.

“Family, extended family, friends, to some extent they rely on professionals as well, including us, and some families I know certainly rely on support groups and church.”

One of the eight families discussed having a strong support network that included both formal and informal supports.

“For support, we go to a great church, and so there is the church, my extended family as well, my dad and sisters, even though they don’t all live here... before when I was working we had a great babysitter.”

Early interventionists were asked to describe the types of supports that families rely on. Upon reflection, the question may have been rephrased to elicit thoughts and perceptions around whether families had support, as opposed to the types of support.

Question 3: What did respondents indicate was their level of knowledge of and prior expectations of Early Intervention prior to their involvement with an early intervention program?

All of the families interviewed had no prior knowledge of early intervention before referral to the program. Even once referrals were discussed, families were still unsure of the need or purpose of the program.

“I was getting a very vague description from people... we were like, play what is it? What is early intervention, I don’t understand what is it, what they do?

What we are suppose to [know what it is], do we need it?”

Another parent expressed remorse at not knowing about it before she needed it:

“I didn’t know anything about it, shamefully. You know when you get into the program it’s like all this was going on and I knew nothing about it, like shame on you.”

Early interventionists had mixed knowledge of the field prior to becoming involved. One early interventionist was aware of the services in another province, while another had been working in the field since the inception of the program and stated, “I guess I’ve kind of been around from the very beginning.” One of the early interventionists studied the field in her university courses and had worked with children who had an early interventionist while she was in another job.

When asked about their expectations of early intervention, both families and early interventionists identified similar themes. They expected early intervention to provide information and family support, as well as to be child focused. Both families and early interventionists recognized that the need for child-focused intervention was what brought the family to the program. Further, each group expected support for their entire family in addition to the support for their child’s learning.

Early interventionists spoke at length about providing family support and advocating on the family’s behalf. The early interventionists believed that support encompassed all the other expectations they had. They described providing support to the family which allowed the family to better navigate the system.

“...in a word I’d say support... I can easily see how that early interventionist could be lots of things for the family but I think it all boils down to that family feeling supported and that they are not alone...”

“I guess maybe thinking you know that a supportive role, that we would kind of be almost a jack of all trades, kind of filling in the gaps, and also doing what you are expected to do within the parameters of the profession.”

Four families did indicate that they were not sure what to expect. For example, one parent noted:

“I didn’t really have any expectations because she [referral source] didn’t really give me a lot of information about it. She just told me that somebody would come to my home...”

Other families had clearer expectations of the program.

“I thought it would provide me with the professional support, and the ‘how to’ of offering my daughter strategies for learning...”

“Support, more in just appointments, and someone there to explain it a little bit better, someone there to help set things up, tell me things to branch out from there... it would be like my second brain...”

Most families and early interventionists believed that early intervention was meeting their original expectations. Some families responded excitedly to this question and were adamant that early intervention was meeting their needs. One early interventionist, interestingly, responded that her practice was always evolving: “there’s always learning and room for improvement.”

Question 4: How did participants describe a family centred program?

Families and early interventionists had differing views on the nature of a family centred program. Families identified two main themes when describing family centredness: characteristics related to actual service and those related to process. Early interventionists described family centred programs relative to skills and awareness.

Within service characteristics, families identified a family centred program as being in the home, flexible to their schedule and the opportunity for many family members to be involved.

One parent described family centred programs as

“It means that everyone’s involved, mom, dad, and grandparents that want to be involved, anyone in the family that wants to be involved, caregivers of any kind can be involved in anything that’s done... And everybody is learning in the same respect so that everybody can help just as much and be as understanding as one another are to get everything done.”

Further, families identified characteristics as related to process. Many families described family centred programs as following the family’s lead. Following their lead included being concerned about siblings, taking into consideration families needs and wants, and acknowledging how families function as a whole. As well, families identified that everyone learns to understand the needs of the child in this model.

“[Early interventionist] comes into the house, so that’s a bonus. Because that means I don’t have to go out of the house. And that means when she comes here she can involve whoever is here. Because it’s not just sometimes [child] and I here, sometimes it’s my husband here, the other kids are here and the younger kids, she includes them too if they are sitting here...It’s [the teaching] not just something we are going to forget when she leaves.”

Early interventionists noted that those working in family centred programs tend to be collaborative, good listeners, and partner with families. Moreover, there is an awareness of family’s priorities and needs, the importance of connecting families with other families, and the

need to respect the families culture and beliefs. Two of the early interventionists spoke highly of the need to listen to families in order to move forward.

“To me it’s, being a really, really keen listener, and really being aware of what the families priorities are, really finding out what’s important to them as a family. As opposed to going in with your own agenda, and what you think they need to be doing. You know ‘according to my checklist we are supposed to be doing this skill’ when according to the family that’s not important at all.”

“...essentially it’s helping families identify and realize the strengths that they have as a family, and to become a really good listener in what they are identifying as needs or concerns...”

Interestingly, while early interventionists emphasized the importance of listening to families’ identified needs, this was a concern for one family. This parent identified that family centred practice was challenging for her, as she wanted professionals to make the decisions for her.

“Well, they come in and see the way our family works as a whole, and then sort of take their lead from us. Which is, I understand that but I’m more of, not that I wanted to fix things but I wanted to talk more to experts, I want to know, I don’t want to say that I don’t like that but I kind of go to them to like, well “what do you think?” and I get nervous when people say, “well what do you think?”

This parent was the only one of the eight to identify this type of concern with the philosophy of family centred practice.

Question 5: How did participants describe their experience with the Individual Family Service Plan (IFSP), as well as their role within it, the process, the decisions that were made and who was involved?

Most participants were familiar with the Individual Family Service Plan (IFSP) process. Six families and all early interventionists had experience with the IFSP, while one family was unsure, and one family had no knowledge of the IFSP. When asked to describe their experiences with the IFSP process, families responded by describing their feelings regarding the process involved in developing the IFSP and the paper work.

Many families found the IFSP experience to be helpful as it brought many team members together. The IFSP experience was also described within the discussions around IFSPs. Families talked about sharing their own goals for their child and the importance of involving all family members. However, one parent expressed mixed emotions regarding her experience. While it was amazing to the parent that many people came together for her child, this parent expressed concern at her lack of familiarity with the process and with being tied into goals.

“...it was a good experience I mean I kind of sat there and thought “all these people are here because of us?” It was a little bit like “wow”. I wasn’t really that familiar with it when it started and I’m getting more, I kind of understand the process now, but I wasn’t really that familiar with what the whole purpose was. And then kind of like, I don’t want to be bound into something...”

In addition, families described in detail the form that was completed. Families described having the form sent to all service providers as a communication tool to know what is happening with

the child. Families described the form as containing information from all team members, activities the child was involved in, as well as child centred goals.

“I remember filling out goals and information about things that she’s involved in right now, like [Speech Language Pathology]...”

“The goals that we just recently did were getting him ready for school. A lot of it was, school readiness skills, also with his behaviour, we set goals for those.”

Early Interventionists noted their IFSP experiences were generally positive but that they could be restrictive. They noted their IFSP experience was dependent on the individual family and how they perceived the process and document. Early interventionists found the experiences helpful as it provided a guide for their services with families. Families identified their priorities and the early interventionist incorporated them in the IFSP. It was a positive process when the early interventionist listened to the family needs and concerns as well as assisted the family in identifying their strengths.

“I really think it depends on the family and the timing of when you work with them to develop the IFSP, it could either be like goals to them or it could be just something else they have to do. But, I find for me, personally, once the IFSP is developed, I find it really helpful in helping to plan for home visits and to kind of know which direction, developmentally speaking the child will be going. I think it really is different from lots of other assessments, and things like that, in that it really is a snap shot of what the families’ goals are and it gives them a chance to kind of put their own little personal spin on it I guess.”

Early interventionists also spoke of the time restraints and deadlines imposed by their program policies and how they did not always fit with a family's readiness to engage in the IFSP process. For example, early interventionists stated that the IFSP had to be completed within the three to six months of entry into the program. Such time constraints influence early relationships with the family. One early interventionist furthered this discussion when speaking to the timing:

“...because we kind of have the mandate that the IFSP has to be done every so often, and say the IFSP is due to be done in January well they've [the family] got a lot of other things that are on their mind at that time; so for them I think it would be more of a pain to have the IFSP done then. And I think that's where the early interventionist has to be able to say 'is this something that you're wanting to do right now' and not kind of shoving it down their throats.”

Involvement in the IFSP

Both families and early interventionists agreed on who was typically involved in the IFSP process. Most families identified that the IFSP was done with themselves and their early interventionist. A few described having input from other team members. One family described a large team meeting where everyone offered input. Early interventionists described larger meetings with many people present. Further, one early interventionist noted that the family could involve whomever they chose, including any informal supports.

“It depends on the who the child is involved with, the family, and any extended family, if the grandparents want to be involved, if their caregiver is really involved with the family then they are there...”

Families and early interventionists described the roles of those present in the IFSP process to be that of information sharing. Moreover, early interventionists felt that some people who may be

present during the process might be of a supportive role. One early interventionist stated that each therapist brings his / her own perspective to the process: "... so it would really be their role to kind of provide a summary and some future direction of their particular area [developmental domain] of the IFSP." One parent spoke highly of the roles each person play and how it became a true team from their perspective:

"It was me and [early interventionist] pretty much for the early intervention side, but the speech and language therapist was also involved, the occupational therapist and the child psychologist. We would have meetings here at the house, we would have meetings with everyone involved and we would decide what our speech and language therapy goals would be, child psychology everything and then [the early interventionist] would have her opinions. She would roll into it. It was great because everybody, it was a team, and they actually listened if I had something that I wanted to work on."

Interestingly, one early interventionist discussed at the end of the interview the child centred focus of the IFSP. This participant articulated that while there was a lot of interaction between parent and early intervention regarding family support issues these were not included in the IFSP. It was felt that the other service providers who participated would not wish to engage in those conversations surrounding family support: "Sometimes I wonder if it is almost two separate things because we are more on community level and the other professionals in the IFSP are more on a different level".

Families and early interventionists articulated that decisions were made collaboratively regarding what to include in the IFSP. Further, both groups indicated that families made many of the decisions. Early interventionists did indicate that developmental checklists might be a

reference point for what to include. One parent indicated that she had the final say on what was included:

“[Early interventionist] would never write anything down without asking me first. It’s true we would do it together... it was like a brain storm.”

An early interventionist spoke to her reflecting on parent involvement and how it has changed her practice:

“Those would come from discussions between the early interventionist and the family members. It’s been my experience, as well, that you can do up a wonderful [IFSP]; and speaking from someone who’s been doing this for a while, I could do up some really elaborate IFSP years ago but they may have been more ‘mine’ than families goals. I mean they might have been very developmentally appropriate goals but they may have come more from me than the family.”

Comfort with the IFSP

Participants discussed their comfort with the IFSP process in depth. For the families, most were comfortable with the process. Of the six families who had an IFSP, one indicated not being comfortable with the process and wanting to see changes. The parent who spoke to wanting changes was keen to have more of a living document that she felt would reflect her goals for her child. At the end of the interview when asked if she would like changes in her early intervention program her response speaks to her IFSP experience:

“...maybe things like shorter term goals, a better understanding of, yeah maybe shorter term goals like lets say in 3 months, he should be doing this or he should be, we have that a little bit with speech and stuff like that but then early

intervention is sort of a grouping of everything together so that would be hard to do, I would like to see maybe more of it... We have with the plan, we had some goals, like some larger ones but it's not like it's on the kitchen counter and I do it all, I had some things like he has some behavior issues like pushing and things like that in daycare that I wanted to see fixed and toilet training and dressing, these were bigger ones. Maybe some shorter-term things like by the end of March he should be able to put his shirt on. Things like that I guess."

Other families were extremely comfortable with the process and found it helpful:

"Well, I thought it was good because sometimes you've got all these thoughts floating around inside your head, and they don't really mean a whole lot when they are just inside your head, you need to put them on paper. And it kind of gives other people an idea of what they should be doing as well, because if there are no goals then all they are doing is coming to your home and playing. And it's not just playing it's structured playing, which is important for a child like [child] because she has a difficult time sharing and playing with others because she has social issues because of her autism but, I really think it's important to have, everybody needs goals, whether you have developmental issues or not. So I think it's really important."

When asked about whether writing goals down was important; this parent said:

"...but I think it's important to focus on just a little bit at a time, set a goal and get it done in six months, and then six months later set another one, and then six months later set another one, and just do little baby steps, and not try to put too many on a child, right."

All the early interventionists spoke of both being comfortable with some of the process and desiring changes as well. Two of the early interventionists discussed their comfort with the process and resulting document at length. However, when reflecting on the IFSP process, their tension with some aspects was evident. The timing requirements of having an IFSP done regularly were a concern for two of the early interventionists. Families participating because they have to, rather than because they value the process was also a concern for early interventionists.

“I’d kind of like for it to be optional because I think that there are some families that just don’t want to do one. I’ve come across that a couple of times too that I think it’s really important that we have something on record for what we’re doing with families and to show a progression of support that we’ve provided I think that rather than having to have it done every six months or once a year that it could be more up to the parents of when they feel that it’s the right time for them to do something like that.... Most families do want to participate in them and it’s not an issue, but for some it’s just another thing to have to do, and I think for them it should be something that then can choose to do or not choose to do. And that we should be able to have something that says the family declined at this time and we are going to revisit it again in the New Year.”

In addition, another early interventionist described the challenge of following family wishes versus following protocol:

“I guess we always come back to, you follow the needs of the family. And some families will identify ‘I’m not interested in doing this’ or ‘I’m not

interested in...’, and you always go back to that, what the families do and you do the best you can to present the information to inspire the best you can, to ask as many thought provoking questions, to listen as well as you can, but it always falls back on it is the families decision as to what input.”

Family role in the IFSP

The final question within the section on IFSPs was regarding the family’s role in the IFSP process. Families described their role slightly differently than the early interventionists. Families’ responses revolved around their role as part of a team, collaborating and working on goals. Families spoke a great deal about the need to follow through on the agreed upon goals. The need to be honest with the team about whether they would follow through was important to families. Further, the need to utilize the team members to their full potential and to collaborate with them was important.

“Well she can show us what to do. But it’s our role to make sure that we help him, and you know, to gain these skills. Because she only comes once every two weeks so she will show us what to do but we have to keep working on it. Because if we don’t do it then he’s not going to learn it right.”

“For me you have to listen to the interventionist and then you have to follow through... I think as a family when you are dealing with someone like an interventionist you have to be honest and you have to follow through and say okay, this is what she wants me to do for the week... You have to follow through because if you don’t then the interventionist comes back and they

know if you didn't follow through so you to have to kind of, if you are going to get involved with that as a family you have to step up and follow through."

Another parent described her need to form partnerships

"I think it's like a partnership, I think there are a lot of parents out there that know exactly I guess what they are going to do doesn't matter what an expert says to them this is how they are going to proceed, I guess I sort of more, I wanted to tap into the experts and take what they say..."

Early interventionists spoke to parents being proactive in the process and being a participant in the process. Early interventionists wanted families to be proactive in describing their family, its hopes and dreams, and to tell the team when goals were appropriate or too much.

"I think it's [family's role] pivotal, I think it's an opportunity for a family to really learn to be good self advocates too because it is about them. I think their role is really being self reflective and kind of searching within themselves for what it is that is really important to them, and to be able to share that. And I think also just making sure, to let people know if they are comfortable with what's being reflected."

Later, the same early interventionist described the parent participating with the early interventionist in the process:

"So I think between us and the family it is important that we make sure that what they want is reflected in the final document."

Another early interventionist described how some families might change from participating to being more proactive in the process:

“Well eventually what you really want to do is have them identify: ‘okay, I know exactly what I need, this is what I want, this is what I know is working well, I understand my child’s strengths, I understand their needs, this is what I see as being important to me, this is what I’d like to work on; how can you as a team of professionals help me accomplish that?’”

Question 6: How did participants describe families’ quality of life and the role of early intervention regarding quality of life issues?

Families’ responses when asked to indicate their quality of life were very diverse, ranging from favourable or poor. Most families indicated their quality of life was positive. They could identify things that they were thankful for and in which they found joy. Interestingly, even families that did identify a lower quality of life than they would like still discussed parts of their life that brought them joy. One parent eloquently described how she might be frustrated by limited services, but that the quality of their life including their son was great:

“...but, overall quality is fine. Fundamentally, I’m good, he’s exactly the way he’s supposed to be and I’m supposed to be his mom. So really nothing is really broken, it’s more: is this the best health?”

Other families indicated that their quality of life was impacted negatively by circumstances associated with their child’s special needs. Medical needs and social isolation were identified as factors influencing their quality of life. One parent described how a medical crisis could occur suddenly and change a family’s functioning:

“...Boxing day, boom he was in a full episode: wouldn’t eat, wouldn’t drink, was crying from the minute he woke up till the minute he went to bed. He was

up through all hours of the night, and it's just terrible. He was in a full blown episode for four whole days and when he's like that [husband] and I don't even so much as talk to each other because when we do, if we do it's usually snapping at each other. It's not intentional, it's just from stress, from sheer [stress]. And [one] can only listen to someone going "RRRAH" so long. You can't even help it, you are snippy and you don't want to be so we both understand that with each other so we know when we talk [to] each other when we are in these episodes, nothing is meant so we don't, we try not to say anything because we don't want to say anything upsetting. But it's set back because up until recently we didn't think we were ready to have another child, because how are we supposed to have another child if he's going through this every second week or every third week?"

Another parent spoke of the social isolation that resulted when you have a child with significant behavioural concerns. However, this parent still indicated that her quality of life was okay.

"I feel pretty isolated, I use to take her to a play group but I had to stop because the people there were getting really agitated by her behavior and we don't really know anybody or go anywhere. I mean it's not terrible; the isolation is just kind of lousy."

Early interventionists described families' quality of life as positive or negative but qualified their answers. Early interventionists also noted that it was difficult to describe families' quality of life because they are only in their homes a few hours a week and really do not experience it. Each early interventionist spoke to each family being extremely different and therefore their quality of life was equally unique. Quality of life, according to the early

interventionists, is affected by not only the child's diagnosis or condition, but also due to many other factors within the family.

“I think that's individual as it is with any family, every family has their own struggles...Some have a lot more hardships than others and it doesn't necessarily have to deal with living with a special needs child, there are financial hardships that different families face. So I think it's really individual.”

When asked to elaborate on the factors that affect quality of life, one early interventionist discussed the nature of informal supports. When describing a particular family with a strong quality of life, the family had:

“...very strong spiritual beliefs and they had a very strong marriage and they had lots of their own informal supports to draw on, although the circumstances were very challenging at times they learned to take it all in stride...”

Families were asked if there were changes they would like to make regarding their quality of life. Further, depending on their response, some families were questioned as to whether they would discuss these changes with their early interventionist. Most families did not see a role for the early interventionist when addressing quality of life issues. They reasoned that the issues being addressed were broad and outside the parameters of early intervention services or they assumption that early intervention was solely for the child's specific needs. When asked whether there were changes she would like to make in her quality of life, one parent responded:

“I would but I don't even know if you can change it. It would be nice to meet other people that you could spend time with. I mean I've had a couple of friends here but I've lost them since I've been here because they are just

immature and not understanding of my situation. I mean the only people I could probably meet would be people that are in the same situation that I am.”

This parent indicated that she has never brought these issues up with her early interventionist. Moreover, when asked if these concerns were included in her daughter’s IFSP, the response was “No it was just all about her [daughter] needs really.”

Early interventionists were keen to provide a variety of means in which to address quality of life factors with their families. The two main areas identified were family support and linking families with community resources. The early interventionists shared a variety of techniques, which allow them to provide family support and address these factors. Active listening and interviewing families enabled the early interventionists to provide support for families.

“I would go back to just being a good listener and kind of reserving my opinions and letting the families sort of draw those conclusions for themselves, sort of using the reflective listening. ‘What I’m hearing you say is that it’s hard for you and your husband to find time alone’, and then maybe suggesting: ‘have you guys thought of looking into respite’, and those kinds of things...”

Linking families with other resources in the community was also identified as a method to address quality of life factors. All three early interventionists identified connecting parents with other parents and other programs.

“I think we can be supportive and try to link them up with appropriate resources. I mean if there is marital stress because of the issues, maybe they have a child who doesn’t sleep a lot or they have a child with severe high needs I mean obviously it’s going to be stressful, so we try to support them as

much as we can, perhaps link them up with resources in the community. Be it counseling or what have you. Just try to help them without being intrusive.”

Question 7: How did participants describe the impact of early intervention on families, the positives and negatives of the program, and whether they would want to change the program?

Both families and early interventionists felt that the impact of early intervention on families had been positive. Early interventionists noted that families that had learned advocacy skills and felt supported. According to the early interventionists, families learned skills necessary for navigating the system to obtain services and support. Early intervention also provided families with a person with whom they could discuss issues, and who would listen and confirm their decisions. One early interventionist described the change she witnessed in a parent via the skills she learned during their time together:

“...[early intervention] help[s] navigate the systems that are there and understand as much about their child’s concerns and understand ways to incorporate and put things into practice. Like I say [an impact is in] a very successful school transition meeting, when the parent can stand up and lead it...this would be a parent who previously told you that they could never do something like that. That’s hopefully what early intervention looks like to families.”

Further, early interventionists supported families, provided guidance and helped families recognize they are not alone.

“I think that we make them feel, help them feel supported. I’m thinking of one of the little moms I work with and she had said ‘When early intervention came on board, they felt like their little row boat that had been set adrift was rescued by the coast guard.’ And so I think it’s more I’m not alone, I’ve got somebody that’s going to help me guide through this system, I guess.”

Families defined the impact of early intervention slightly different. They noted that early intervention had a major impact on their child with a disability as well as on family functioning as a whole. Families indicated the impact was child specific; they felt that early intervention was providing them with a clear picture of their child’s development and what to expect.

“I think it’s helped us to get a concrete picture of what to expect, or to change expectations... Because at the very beginning we really didn’t have a clue as to how she was going to be in development, or what kind of child will she be like and what will she be able to do, and having the early interventionist come here has just helped us to be able to see what she can do and just to allow her to develop.”

“It had made a huge [impact], from the beginning of when she first started coming until now, it has made a huge difference, I mean in his behaviour and in what he’s learned since she’s been coming here.”

Other families described the impact in terms of family functioning. Families spoke highly of the support and guidance that the early intervention program provides.

“I feel like it’s been that helping hand, that guiding light, that extra push sometimes, the conscience whispering in your ear ‘you do this now’, I find it’s been wonderful.”

When asked to elaborate on the positives and negatives of early intervention both groups were somewhat reluctant in their responses. Early interventionists provided few positives, citing that the impact previously described was all positive. Regarding negatives, the early interventionists provided mostly factors that dealt with public awareness, government funding and organizational issues of the program.

“There is quite a list of negatives actually. But I think they are getting better. The big thing I think is the missing sort of PR [public relations], who we are and what we do kind of piece. Not a lot of people have really heard of early intervention until they become involved... And the fact that there is no specific training to become an early interventionist is a biggie too. I think if everybody had the same background and same training that it might be more, well respected and more recognized by the public.”

One early interventionist spoke of the profound loss when a child with whom you are working with dies. An inability to meet all the family’s needs was also viewed as a negative aspect of early intervention. She concluded that early intervention is not a match for every family, stating: “we can’t meet the needs of the family or a family will identify that no this is not what we want at this time”.

Families’ responses to the positives of early intervention fall into two main categories: teaching parents and family support. It is important to note that the responses were mainly an affirmation of early intervention. Three of the eight families indicated specific positives.

Parents shared stories of how the early interventionist has taught them new skills for interacting with their child:

“She’s just shown me different ways, especially with his temper tantrums, I was just ripping my hair out, and she’s just shown me some positive ways of dealing with him when he’s going through these temper tantrums and different ways, instead of me getting so frustrated, that’s just the main way that she’s help with.”

“I learned so much from the early intervention team, its education is what the parents need for sure and this is kind of great for that. Because I didn’t know anything about autism or how to do reinforcers with children. For me starting off, a lot of things [early interventionist] taught us, I said “well gee that makes sense’ I can do it that way and [child] won’t get upset or scream... it’s just an education for me.”

Only two of the families shared negative aspects of early intervention, the other families only had positive comments. These negative aspects focused on wanting services that are more frequent and more specific for their child.

“...I know there are other programs in the province where some kids get 15 hours a week so I don’t know, I see what [early interventionist] and [early interventionist] did with [child] in an hour and a half once a month that I saw them... I’d love to know what it would look like if it was 15 hours a week...”

“the negative is that I really need the help with behaviour and I really wish that they could do that”.

When asked if there were changes they would like to see in their early intervention program two families indicated a desire for change. One parent who lived very far from the early intervention office wished for a closer program and discussed the need for more government support for families. As previously noted one family indicated a desire for more short-term goals and the use of a curriculum.

“I don’t think I’d change much...I think again probably more of it, curriculum or maybe things like shorter term goals, a better understanding of, yeah maybe shorter term goals like lets say in three months, he should be doing this or he should be, we have that a little bit with speech and stuff like that but then early intervention is sort of a grouping of everything together so that would be hard to do, I would like to see maybe more of it...”

All three early interventionists discussed changes they would like in their early intervention program. Two of the early interventionists spoke to the organization and infrastructure of the program. These early interventionists indicated a need for programming changes. Consistency in IFSPs throughout the province was a needed change as well as more evaluations from families:

“...and the consistency piece, I’d really like to see that become more and more fine tuned across the province so that all of our IFSP are the same...”

“...more evaluations with families, I find the feedback would be useful; we don’t specifically annually do that I mean we certainly have had feedback but that perhaps might be beneficial as a component.”

A final question arose out of the interviews as the discussions occurred. Participants were asked what they believed to be the ultimate goal of early intervention. Of the seven families and one early interventionist to whom this was posed, the responses were distributed evenly between child and family goals. Some families articulated that early intervention was to prepare their child for school and to seize the early years because of their importance in later learning.

“I think probably just setting them [the children] up as best as possible.

Everything I understand about early child learning, these years are so important, so the way I see it, as him being affected with down syndrome was getting him as far along as possible in the first, these are big learning years for him and potentially probably his biggest so, that’s my thing...”

“I would say for the kids to help them to be able to have, basically so the kids can get the best start that they can get and so that the parents can help them along that way...”

Other families addressed the family support they received and how it affected their family in the long term.

“The ultimate goal I would say would be family support and as a resource for families, information for me... So that’s what I got out of intervention. I got support.”

“I think that a lot of it is to help parents find their way. Not only to help them with the issues with behavior and defining the gross motor skills, help the child with developing, but also to give them support, to go with them to the doctors appointments, to help them find somewhere to begin when they don’t know where to start. I think that’s what it is too, and just to know that there is somebody out there that cares.”

When the above parent was asked to elaborate on how families are different after early intervention, she responded:

“I think it helps them find their way, to begin their journey into where their life is going to take them. There is always going to be questions, it never ends, I mean what I find now, I means there’s still so many questions like what is she going to be like 20 years down the road? Is she going to be independent? I mean it gives you a start, is what it does. A really good start anyways. I think.”

In summary, the response of parents and early interventionists indicated a general satisfaction with early intervention. Families and early interventionist spoke with praise of their relationships and enjoyed working together. Important findings regarding family centred practice, IFSP development, and knowledge of issues related to quality of life have been identified. Further discussion and impact on practice is warranted to further advance the field.

Chapter 5

Discussion & Recommendations

Considerable research in the field of early childhood intervention has been carried out in the United States (Bruder, 2000 a, Bruder, 2000 b, Dunst, 2000). Coupled with this research, the US has developed legislation outlining the nature of early intervention service delivery at the state and federal levels. Early intervention in Canada is vastly different. There is neither legislation nor federal guidance on how services should be executed or funded for children with special needs and their families. The lack of an overall deferral vision, legislation and funding has resulted in substantive differences in how early intervention is delivered in each province as well as within individual provinces.

This research project explored the experiences and perceptions of both families and early interventionists as related to their own early intervention program in Nova Scotia. It was designed to gain insight into the personal experiences of each participant regarding family centred practices, the Individual Family Service Plan, and the family's quality of life. The early intervention literature provides comprehensive descriptions of the characteristics of a family centred program and the IFSP process. However, if families do not experience family centred early intervention than a disconnect occurs between best practices and the services being delivered.

To facilitate the dialogue and ensure comfort of participants, interviews were used. Matched questions for parents and early interventionists were utilized to guide the conversation between researcher and individual participant. Information gathered could be used to advance the field of early intervention in NS and to ensure that best practice guidelines are followed. In the following section, the results are examined and explored in relation to the topics presented.

Family centred practice

When familiar with the evolution of family centred practice the relative youngness of the field becomes obvious. It is imperative always to have this in the forefront when debating the daily practice of others. Many early interventionists currently in the field began in an era when early intervention was totally child focused and family centred practice did not exist (Jung & Baird, 2003). Including parents as the workers designated to carry out the early intervention plan or to offer an opinion has traditionally been easy. However, engaging in a partnership with parents, enabling independence, and valuing parents' opinions because they are the expert on their child requires a paradigm shift that not all early interventionists have been able to make (Turnbull, Turbiville & Turnbull, 2000). With these ideas in mind, the definitions of family centred practice provided by participants in this research project were examined.

Both families and early interventionists described the skills that are exhibited in family centred practice, or characteristics associated with it. Families described the program being home based, flexible to the needs of the family, and acknowledging the family as a whole. Early interventionists described being collaborative, good listeners and working in partnership with families, as well as the awareness of the family needs and priorities. When compared to Allen & Petr's (1996) definition of family centred practice, the characteristics noted by participants fit within the main components of family centred practice: family choice, family strengths and acknowledging the family as a unit of support. There was no discussion of working from the strengths of the family yet it was felt to be implied in the conversations with the early interventionists.

While it is apparent that early interventionists are able to describe family centred practice and families are experiencing pieces of it, it became equally clear in other areas that the

principles of family centred practice does not guide all practice. Family descriptions and perceptions of the IFSP process, decisions around goal making and the use of the goals alluded to a disconnect.

Issues related to family's quality of life

A key area of interest for this research project was quality of life issues for families receiving early intervention services. Two main questions embedded within this topic related to whether early interventionists recognized and dealt with quality of life issues and whether families and early interventionists believe this to be part of early intervention.

Both parents and early interventionists provided mixed responses to these questions. It was clear from both groups that family quality of life was extremely individual and was impacted by a variety of factors. Responses from families addressed their joys, satisfactions, frustrations, social isolation and the impact of having a child with special needs. Early interventionists demonstrated a respect for this individuality and noted quality of life was unique for each family with they worked.

A family's quality of life was directly influenced by the degree of support they received. When asked to describe their supports, some families were able to list a variety of both informal (non-paid), such as family or friends, and formal (paid) supports, such as therapists. Unfortunately, two families did say they had no support. When asked to discuss the supports families may rely on, early interventionists mentioned the same types of supports noted by families. Interestingly, none of the early interventionists indicated that some families may have no informal support or limited formal supports.

Discussing family quality of life issues requires one to acknowledge that the purpose of early intervention is not just to ameliorate the special needs of the child. It requires recognition

of the child within the larger family unit and community. This is especially relevant when you consider that despite well-intentioned interventions, most children receiving early intervention services will still require the same amount of special education in school (Bailey, Aytch, Odom, Symons, & Wolery, 1999). Others such as Poston, Turnbull, Park, Mannan, Marqus and Wang (2003), found that early intervention has its greatest impact on family functioning and their quality of life. However, results of the current study seem to indicate that many of the family participants still expected early intervention to focus on preparing children for school when the focus need to be broadened to incorporate quality of life issues.

There are a variety of reasons why a family may have a limited view of purpose of early intervention. When a parent realizes their child has special needs it is natural to go through a variety of emotional reactions. Initially, many parents believe that early teaching will eliminate the special needs and reduce the need for long-term care. While this may be true for some children, it will only be realized with time and effort for many and for a few, not at all. Many of the families who participated in the study had younger children and may still be reacting emotionally to their child's diagnosis. Remarkably, two families who each had two children in early intervention had different perceptions of early intervention. On reflection, both parents were able to describe early intervention as being a support to their family. Early intervention provided these families with information and support for, as one family eloquently described it, "the journey".

If a family is not emotionally ready to cope with broader family issues it is difficult for an early interventionist to broach the topic. For a family who believes the early interventionist is there to teach the child, discussing family quality of life issues (i.e. recreation or spirituality) may be seen as intrusive, inappropriate, and imposing. Conversely, one may argue, it would only be

imposing if the family had a different conceptualization of the early intervention program, such as one that was child-focused to reduce the effects of the disability. It is imperative that early interventionists in the initial contact with families introduce and discuss the concepts of family centred practice and collective empowerment. Other issues to be discussed include the IFSP process, family involvement, meeting the needs of the entire family as well as those of the child with special needs, support systems, and choices. Early interventionists need to recognize the readiness level of families to engage in this process and not overwhelm them. As families become more empowered, the early intervention experience becomes more satisfying and successful for all involved.

There are a variety of tools (family surveys) that have been developed to assist early interventionists in discussions related to family quality of life. No participants in this study alluded to any of these surveys. Further, none of the early interventionists in this study appeared to be aware of the new construct in the field, collective empowerment. This speaks to the need for on-going training and professional development sessions. Early interventionists need to be aware of the current trends and best practices in this ever evolving field and to advocate for changes to bring current practice in line with recommended best practices.

Individual family service plan

The IFSP is considered the guiding document within the practice of early intervention. The IFSP should ensure that the family's priorities and needs are guiding the services that are being provided and that family centred practice is occurring.

Families and early interventionists indicated a vast array of information related to their experiences with the IFSP process and document. Some families articulated the benefits associated with forming goals together in order for everyone to be targeting the same goals.

Other families were not as forthright in their descriptions of IFSPs. Two families did not have an IFSP. Upon reflection, it is evident that one family is extremely new to the program and therefore would not have one yet. Conversely, the other family has been involved in the program for an extended period. When asked how goals were established, this parent happily responded that the early interventionist knew what to work on. Interestingly, this family was extremely happy with the services they were receiving despite the fact that neither protocol nor best practices were being followed. Similar findings have been demonstrated by McWilliam, Tocci and Harbin (1998) who discussed satisfaction with family centred versus child centred services. Families are so grateful to receive services for their child that for them child centred visits seem appropriate, especially if they are not familiar with the true nature and expectations of family centred practice. As this family had an extremely negative experience with medical professionals, the positive relationship with the early interventionist was a relief and not questioned. However, as few families have had experiences with early intervention or IFSPs prior to their direct involvement, they would not know what to expect. Families are guided by the early interventionist.

Early interventionists had mixed feelings about their experiences with the IFSP. On the positive side, it was a guide for them and it allowed the family the opportunity to articulate their goals and needs. On the negative side, it also created tension and stress because of the time restraints imposed by program and policy guidelines in NS. According to provincial guidelines, IFSPs are to be completed within the first three to six months of family's entry into an early intervention program. On times, this can require early interventionists to rush the 'natural relationship building' process that needs to occur when preparing for the IFSP, especially with some families who have difficulty coping and need time to adjust prior to engaging in the IFSP

process. One early interventionist described the challenge of completing an IFSP when families have multiple commitments. If families are required to attend a variety of intensive appointments during the same time period as the IFSP needs to be written, this early interventionist felt that the IFSP was being done because it was required and not as a meaningful guide to services. The entire process was, therefore, compromised to fulfill an arbitrary deadline. While all the early interventionists in this study acknowledged the value of the IFSP, it was felt that more flexibility regarding time line was needed in some cases.

In the United States, the IFSP is a required document that all service providers participate in, with the family, to plan the services. It is a legal document that must precede service delivery. In Nova Scotia, the IFSP is a guide for only early intervention as no other service providers working with the family are required to participate in the IFSP process. Each individual service provider has his or her own documentation that is required. Early interventionists and the other service providers in Nova Scotia have worked diligently to establish collaborative teams for the IFSP process. While team members are willing to participate, they do not feel the same sense of ownership and attentiveness to the goals as the early interventionists' policy guidelines dictates. However, two families described well-established teams that sounded extremely collaborative in the IFSP process. The IFSP for these two families was truly the guide for all services, as well as, an accurate reflection of the families' needs. While these were two different teams in different regions of the province, it is interesting to note that they were both rural communities with team members who had been working together for a period. Further, both children had the same diagnosis which required an immense amount of in-servicing on family centred practice and teaming. For children with this diagnosis in NS, there is agreement that the IFSP should be collaborative document for the family and all service providers. While best practice for family

centred early intervention recommends that the IFSP be a collaborative process (Katz & Scarpati, 1995), this is a reality in NS for only a few families.

Harbin et al. (2004) and Katz and Scarpati (1995) both discussed the challenge in moving from child centred to family centred goals when developing the IFSP. Consistent with this research, not one family member or early interventionist alluded to the IFSP containing anything other than child centred goals. While many of the families described challenges to their quality of life, the IFSP did not address any of these challenges. During discussions, many families appeared pleased with the IFSP and did not seem to realize that the IFSP could address quality of life issues. One parent expressed great sorrow at her current medical situation and articulated that these concerns were not included in the IFSP. She believed there was nothing the early interventionist could do about the situation. While the early interventionist can not address some concerns directly, they can be aware of situations and discuss ways they are directly impacting family functioning and possible ways of lessening the concerns. Further, acknowledging parents' current conditions during home visits and in IFSP documents would better frame the goals for whole family. One early interventionist also noted that family needs and family support were not always mentioned in the IFSP as the other service providers did not want to participate in this discussion. If this separation is occurring, then the IFSP is not a true reflection of service delivery. The IFSP is meant to guide all services, to be a process and a document that outlines what the family wants to achieve. No individual should determine what is included or not. Common training for all disciplines in family centred service delivery and IFSP development is needed to effect change. At no time should team members forget that the family is the constant in the child's life and pivotal for success. Professionals must always engage in reflective practice keeping in mind that their goal is to empower families. This will not occur

unless family proprieties are recognized and celebrated. As early interventionists often act as a 'generalist' as opposed to a 'specialist', it is not far reaching to include family goals within the realm of the generalist's duties.

Once more, consistent with past research, one family articulated concerns related to the type of goals and their functionality (Harbin et al., 2004; Katz & Scarpati, 1995). While a thorough IFSP was created, this parent wished for functional goals that would be part of everyday life. Evidently, the IFSP was not a useful document for this family. This may be because the family was not comfortable in expressing what they truly wanted to address or that time constraints resulted in a document that was completed by the deadline to no ones satisfaction. Regardless, the IFSP needs to be reviewed and changed to meet the family's ever evolving needs and strengths.

The disconnect between the early interventionists' belief in what they are doing versus what the families are experiencing was noticeable. There are a variety of reasons that could cause this disconnect. From preparation to completion the IFSP requires a great deal of time for both early interventionists and families. An IFSP cannot be introduced, discussed and completed in one visit. It is a dynamic process that begins with the first visit with the family and concludes with mutually agreed upon goals and services. Some early interventionists may be more comfortable getting an initial plan in place so that home visits can be organized and may involve taking shortcuts with the IFSP process. Likewise, early interventionists who have been in the field for some years may come from a child centred philosophy and have difficulty making the shift to family centred practices.

Coupled with philosophical differences and timeline concerns early interventionists in Nova Scotia have a large number of families on their caseload. Within this past year the

government increased the required caseload range from 15 – 17 to 18 – 20. This increase requires the early interventionist to complete more IFSPs in the same amount of time. While best practices for developing IFSPs are outlined in the literature (Bruder, 2000 b) and policy documents, the reality of working with so many families, travel, home visits, timelines and documentation make engaging in meaningful IFSP discussions difficult, if not impossible. However, as the IFSP process is the cornerstone of family centred practice, early interventionists must continue to adhere to recognized best practices while advocating for changes in funding, policy and caseload numbers.

Summary

This study was designed to gauge parents and early interventionists perspectives on family centred practice and the Individual Family Service Plan. It is important to note that a relatively small group of participants was used and therefore the results may not be generalized to the larger group in NS. However, the participants did share their personal experiences with early intervention with the researcher which resulted in several interesting findings. These new insights will provoke an enhanced understanding.

As previously noted, all participants were extremely pleased with their early intervention experience, both as family members and staff. Respect for children with special needs and their families was evident throughout the conversations. Families respected their early interventionists for their knowledge and their compassion in dealing with their family. Early interventionists were obviously listening to families and supporting families as they learned to advocate for themselves.

This examination has demonstrated that the concept of family centred practice is understood at the conceptual level. Both groups were able to briefly discuss the topic and

present examples alluding to it. The disconnect occurred when discussing other topics (IFSP, quality of life) and it became evident that the family centred nature of early intervention did not permeate through all interactions with the family. Further, the concept of collective empowerment was not discussed or evident through discussions of practice. The incomplete shift toward family centred practice, as discussed in the literature, was evident in this study.

When summarizing all results and discussions the key component that emerges is the need for training in NS. Early interventionists lack a common training program that focuses on understanding and implementing best practices. With this in mind, it must be recognized that early intervention is a new and evolving field with new issues and concepts constantly emerging. For example, the role of quality of life and collective empowerment in early intervention are relatively new in the literature. Early interventionists in NS need a means to share the current research and ensure that early interventionists and programs are integrating new techniques and philosophies into their practice. This can only lead to more family focused and family led IFSPs. Continued in-depth training into the philosophies of family centred practice and collective empowerment will help the early intervention community to truly understand and appreciate the notion of empowering each other and result in early intervention programs that truly reflect best practices.

Recommendations

Research

1. This study had a small number of participants thereby limiting the generalizability of the results. However, the data does provide initial insight into family centred practice, IFSP and quality of life issues for the participants. It would be interesting to increase the

number of interviews conducted, ensuring equal numbers of both families and early interventionists.

2. Interviews were the method of data collection; using a survey might provide additional information and insight. People may be more comfortable in responding to a survey as opposed to an interview.
3. Data was collected in three rural areas; the urban centre of NS was not included in this study. Including that area would increase the population to draw from and may provide different experiences.
4. Provincial comparisons throughout Atlantic Canada and the entire country need to occur. As there is no Federal Government input in these programs, each province differs dramatically in the service they deliver. Studying these differences will provide extremely helpful information.
5. As there is no set training requirement in the field, other than a degree, we must garner more knowledge of the training current early interventionists have and what they need. We may be expecting early interventionists to work within family centred practice and acknowledge issues related to family quality of life without any training in these areas.
6. In order to develop training programs in NS, we must first identify what other areas are doing to share information and to train regarding family centred practice, IFSPs and family quality of life issues.

Early Interventionists / Families

7. Communication between families and early interventionists regarding the IFSP process and document is key to ensure common understanding. Every effort should be made to

engage families in the process, even if it means ignoring time lines. If a family is not involved, it defeats the purpose of family centred early intervention.

8. Early interventionists need to discuss Quality of Life issues with families, such as support systems, spirituality and recreation among others. There are tools (family surveys) which early interventionists can use to ensure that these topics are covered in a meaningful, non-obtrusive manner.
9. Families need to take a proactive role in their early intervention experience, specifically the IFSP process. Being aware of their rights in EI will ensure they take a proactive role.
10. Families need to communicate with their early interventionist regarding what they want their service to look like. When issues are not addressed or when there is confusion, it needs to be discussed to ameliorate the situation.
11. Families can participate in training opportunities that are for the early interventionists. This will ensure common understanding of the practice.

Government / Policy

12. Early intervention programs are currently 'making do' with the limited funds that are provided. While there have been attempts in the past years to address this situation, it is not enough. Early intervention programs need to be adequately funded to manage programs that offer best practice.
13. Early intervention programs are currently attempting to offer best practice because they believe in it, not because it is truly enforced. Policy needs to be developed for early intervention programs to adhere to. Leadership needs to be provided by policy makers who truly understand early intervention and the role it plays with families. These same

policies must be shared with families in order for them to be knowledgeable consumers of the services.

14. Policy needs to acknowledge the newly formed professional association. Policy can dictate that programs hire staff who are members of the association.
15. Policies need to acknowledge that quality early intervention services are impacted by caseload size. Caseloads need to be re-examined and adjusted to allow early interventionists appropriate time to engage in a best practices defined IFSP process.

Professional Groups

16. The Early Childhood Interventionist Association of NS (ECIANS) needs to be aware of new practices and innovative techniques in the field of early intervention. These need to be shared with the membership through formal training events.
17. ECIANS needs to advocate for formal recognition and accreditation for the field.
Accreditation of early interventionists will ensure a base level of knowledge and training.
18. ECIANS needs to lobby for a formal training program for early interventionists that will meet the needs of accreditation.
19. ECIANS needs to monitor the practice of early interventionists in NS via the Code of Ethics.
20. ECIANS needs to lobby to the other disciplines with whom early interventionists interface with for joint training on family centred practices, specifically within the training programs.
21. IFSPs and family centred practice are relatively new topics. Early interventionists must be aware of this and lobby for further training opportunities.

22. Early intervention requires constant reflection on one's practice. Early interventionists need to support and listen to each other to ensure that everyone is reflecting and changing their practice accordingly. Smaller, rural programs need to find ways to connect with others to prevent isolation.
23. Early interventionists need to believe in their field and desire for it to continue evolving. The newly formed professional association is a step in this direction. All early interventionists in NS should be a member of this group.
24. Policy needs to provide the framework for training requirements for early interventionists. Like early childhood educators, speech language pathologists or occupational therapists, there must be policy and legislation dictating a required training level / distinction.

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APPENDIX A

Demographic Surveys

Demographic Information – Service Providers

Gender MALE FEMALE

Age 18-25 26-30

31-35 36-40

41-45 >45

Ethnicity: _____

Education Some high school High school diploma

Community college University degree

Graduate degree other: _____

Number of years practicing in Early Intervention: _____

Was any of your training specific to the field of early intervention? YES NO

If yes, please indicate types of training specific to the field:

Number of children in your household, and their ages:

Do you have any children diagnosed with a delay, disorder, or disability?

YES NO

If yes, please indicate the diagnosis, and age of diagnosis of your child:

APPENDIX B
Interview Questions

Interview Questions – Families

1. Tell me about your family. (If only immediate noted cue – are there others you view as or like family?)
2. Many of us rely on others, could you share with me who you rely on for support? (cue formal / informal networks)
3. I know you are currently involved with Early Intervention, but what did you know about Early Intervention prior to becoming involved?
 - a. What were your expectations of your EI program?
 - b. Do you feel these expectations have been met?
4. Currently most EI programs are adhering to a family centred philosophy. How would you describe a family centred program?
5. One of the main components of family centred EI is the IFSP. Are you familiar with the IFSP?
 - a. Could you share with me your experiences with the IFSP?
 - b. Who was involved?
 - c. What were their roles?
 - d. How were decisions made regarding what to include in IFSP?
 - e. Are you comfortable with the IFSP process or would you like to see changes? If yes, what kind of changes?
 - f. How do you see the family's role in the IFSP process?
6. How would you describe your family's quality of life overall?
 - a. Please tell me how you view your interactions? Overall well-being (social-emotional)?
Your environment?

- b. Are there changes you would like to make? (Cue if necessary – please share them with me.)
- 7. In your opinion, how has being involved in EI affected your family?
 - a. Could you share some of the positives and negatives of EI you have experienced?
 - b. What, if anything, would you change or include in your EI program?

Interview Questions – Service Providers

1. Tell me about your profession
2. Many of us rely on others, could you share with me who the families you work with rely on for support? (cue formal / informal networks)
3. Can you tell me what did you know about Early Intervention prior to becoming employed with it?
 - a. What were your expectations of your EI program for families?
 - b. Do you feel these expectations are met?
4. Currently most EI programs are adhering to a family centred philosophy. How would you describe a family centred program?
5. One of the main components of family centred EI is the IFSP. Are you familiar with the IFSP?
 - a. Could you share with me your experiences with the IFSP?
 - b. Who is typically involved?
 - c. What are their roles?
 - d. How are decisions made regarding what to include in IFSP?
 - e. Are you comfortable with the IFSP process or would you like to see changes? If yes, what kind of changes?
 - f. How do you see the family's role in the IFSP process?
6. Can you please describe the quality of life of families with whom you work? (cue if necessary – what factors enhance or decrease Quality of Life?)
 - a. How do you address these factors with a family?
7. In your opinion, what is the impact of EI on families?

a. Could you share some of the positives and negatives of EI you have observed?

What, if anything, would you change or include in your EI program?

APPENDIX C

Letter to Executive Directors

(letterhead)

Executive Director
Early Intervention Program

Date

Dear _____,

My name is Sarah Melanson and I am an early interventionist in Halifax, Nova Scotia. I am also a graduate student in the Master of Arts (Child and Youth Study) program at Mount Saint Vincent University. As part of my degree requirements, I am conducting research to investigate family centred practices in early intervention. The aim of this research is to gain deeper insight into family centred practices in Nova Scotia. I hope to gain a more thorough understanding of family and service provider's perceptions of family centred practice, the extent to which the Family Service Plan describes services being offered, and how service providers support families.

In order to do this research I am asking that you distribute the enclosed packages to your staff and to the parents of all the families currently receiving home visits in your program. In order to maintain confidentiality, I ask that you affix address labels to the research packages and mail them to families currently enrolled in your program. Packages are already stamped and labels are enclosed. Each package contains an introductory letter outlining the purpose of the study and participants' rights as well as a consent form for one of the parents to sign if he/she is willing to participate. A copy of this information has been enclosed for your reference. I realize that preparing the labels may result in additional costs for your program; I am willing to reimburse these costs. In addition, I am requesting permission to use a space at your centre for interviews if your staff or a parent agrees to participate and would like to complete the interview there. Interviews would take place during your regular business hours or after hours if it involved a staff member who has access to your space.

Those interested in participating can return their signed consent form indicating they are willing to participate in an individual interview on family centred early intervention and family services plans. Before beginning the interview, parents/service providers will be asked to complete a demographic survey. They will be told that they are not required to complete any questions that they are uncomfortable answering. The survey data will help the researcher describe the participants in general terms and conceptualize the data. The actual interview and survey completion should take approximately 40-60 minutes. The interview will be audio-taped and take place at a mutually convenient place. If more parents/service providers consent to an interview than are needed for the research, I will randomly select six to eight parents/service providers. Those not selected will be contacted and thanked for their willingness to participate.

Please understand that participation in this study is completely voluntary, and parents/service providers may decline to participate or withdraw at any time, without penalty. Participants may skip or decline to respond to any questions that they are uncomfortable answering. All

information obtained in this study will be kept strictly confidential and should not influence employment status or participation in the program. The surveys and interviews will be numerically coded and destroyed after they have been transcribed. Once the transcriptions are completed, participants will be contacted and given the opportunity to review their own transcript of the interview to determine if it reflects their perceptions and to suggest changes if necessary. All data will be stored in a locked file cabinet in the researchers office and electronic files will be password protected.

The results of this study will be presented as group data. Only my supervisor and I will have access to the interview transcripts. Quotes from the interviews will be used in the thesis and may be used in future publications and presentations to illustrate themes arising from the data, however no name or identifying information will be reported. A summary of the research findings will be shared with your program and participants through the addresses they provide when the thesis is completed.

Should you have any further questions or concerns regarding this study, please contact me, Sarah Melanson, at [REDACTED] or [REDACTED] ([REDACTED]) or my thesis supervisor Dr. Carmel French at 457_6187 (carmel.french@msvu.ca). If you have questions about how this study is being conducted, you may contact the Chair of the University Research Ethics Board (UREB) c/o MSVU Research and International Office, who is not directly involved in the study, at 457_6350 or via e-mail at research@msvu.ca.

I would like to thank you for considering my research project. It is my hope that this research will advance field of early intervention. I will contact you in the near future to follow up.

Sincerely,

Sarah Melanson
Graduate Student
Mount Saint Vincent University

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

APPENDIX D

Letters to participants

(letterhead)

Dear Parent/Guardian,

My name is Sarah Melanson and I am an early interventionist in Halifax, Nova Scotia. I am also enrolled in the Master of Arts (Child and Youth Study) program at Mount Saint Vincent University. As part of my degree requirements, I am conducting research to investigate family centred practices in early intervention. The proposed study will involve gathering information on your perspectives of and experiences with early intervention and family centred practices. My goal is that this information will enhance the services we are providing to families in Nova Scotia. The Director of your families' Early Intervention program has labeled the research packages and mailed them to you as I do not have access to such confidential information.

If you (only one parent per family) are willing to participate in an individual interview on family centred early intervention and family services plans, please complete the enclosed consent form and return it in the enclosed envelope. Before beginning the interview, you will be asked to complete a demographic survey. You do not have to respond to any questions on the survey that you are uncomfortable answering. The survey data will help me, as the researcher, describe the participants in general terms and conceptualize the data. The interview and survey should take approximately 40 to 60 minutes and the interview will be audio-taped. I will contact you to arrange a mutually convenient place for the interview. If more parents consent to an interview than are needed for the research, I will randomly select six to eight parents. Those not selected will be contacted and thanked for their willingness to participate.

Please understand that your participation in this study is completely voluntary and that you may decline to participate or withdraw at any time, without penalty. Participants may skip or decline to respond to any questions that they are uncomfortable answering. All information obtained in this study will be kept strictly confidential and will not influence your participation in your early intervention program. The surveys and interviews will be numerically coded and destroyed after they have been transcribed. Once the transcriptions are completed, participants will be contacted and given the opportunity to review the transcript of their interview to determine if it reflects their perceptions and to suggest changes if necessary. All data will be stored in a locked file cabinet in the researcher's office and electronic files will be password protected.

The results of this study will be presented as group data and no individual participants will be identified. Quotes from the interviews will be used in the thesis and may be used in future publications and presentations to illustrate themes arising from the data, however no name or identifying information will be reported. A summary of the research findings will be shared with your program and you through the address you provide when the thesis is completed.

Should you have any further questions or concerns regarding this study, please contact me, Sarah Melanson, at [REDACTED] or [REDACTED] or my thesis supervisor Dr. Carmel French at 457-6187 (carmel.french@msvu.ca). If you have questions about how this study is being conducted, you may contact the Chair of the University Research Ethics Board (UREB) c/o MSVU Research and International Office, who is not directly involved in the study, at 457-6350 or via e-mail at research@msvu.ca.

I would like to thank you for considering my research project. It is my hope that this research will directly influence the services we provide to families.

Sincerely,

Sarah Melanson
Graduate Student
Mount Saint Vincent University

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

(Letterhead)

Dear Early Interventionist,

My name is Sarah Melanson and I am an early interventionist in Halifax, Nova Scotia. I am also enrolled in the Master of Arts (Child and Youth Study) program at Mount Saint Vincent University. As part of my degree requirements, I am conducting research to investigate family centred practices in early intervention. The aim of this research is to gain deeper insight into family centred practices in Nova Scotia. Specifically, I hope to gain a greater understanding of: a) family centred practice from the perspective of parents and early interventionists, b) the extent to which Family Service Plans describe services currently being offered, and c) how service providers support families.

If you are willing to participate in an individual interview on family centred early intervention and family services plans, please complete the enclosed consent form and return them in the enclosed envelope. Before beginning the interview, you will be asked to complete a demographic survey. You do not have to respond to any questions that you are uncomfortable answering. The survey data will help me, as the researcher, describe the participants in general terms and conceptualize the data. The interview and survey should take approximately 40 to 60 minutes and the interview will be audio-taped. I will contact you to arrange a mutually convenient place for the interview. If more service providers consent to an interview than are needed for the research, I will randomly select six to eight. Those not selected will be contacted and thanked for their willingness to participate.

Please understand that your participation in this study is completely voluntary and that you may decline to participate or withdraw at any time, without penalty. Participants may skip or decline to respond to any questions that they are uncomfortable answering. All information obtained in this study will be kept strictly confidential and will not influence your employment in the your early intervention program. The surveys and interviews will be numerically coded and destroyed after they have been transcribed. Once the transcriptions are completed, participants will be contacted and given the opportunity to review the transcript of their interview to determine if it reflects their perceptions and to suggest changes if necessary. All data will be stored in a locked file cabinet in the researchers office and electronic files will be password protected.

The results of this study will be presented as group data. Quotes from the interviews will be used in the thesis and may be used in future publications and presentations to illustrate themes arising from the data, however no name or identifying information will be reported. A summary of the research findings will be shared with your program and you through the address you provide when the thesis is completed.

Should you have any further questions or concerns regarding this study, please contact me, Sarah Melanson, at [REDACTED] or [REDACTED] or my supervisor Dr. Carmel French at 457-6187 (carmel.french@msvu.ca). If you have questions about how this study is being conducted, you may contact the Chair of the University Research Ethics Board (UREB) c/o MSVU Research and International Office, who is not directly involved in the study, at 457-6350 or via e-mail at research@msvu.ca.

I would like to thank you for considering my research project. It is my hope that this research will advance our current knowledge of the early intervention field.

Sincerely,

Sarah Melanson
Graduate Student
Mount Saint Vincent University

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

APPENDIX E

Informed Consent Form

(Letterhead)**FREE AND INFORMED CONSENT**

I, _____, am willing to participate in a one on one interview as part of a research study, *Family Centred Practices in Early Intervention in Nova Scotia: Quality of Life Issues for Families*, being carried out by Sarah Melanson, a graduate student in the Department of Child and Youth Study at Mount Saint Vincent University. The aim of this research is to gain deeper insight and perspective into family centred practice in Nova Scotia.

I have been informed that my time commitment for the individual interview and Demographic survey will be approximately one hour. I understand that I do not have to respond to any questions on the demographic survey or during the interview that I am uncomfortable answering.

I am aware that the interview will be audio-taped and that once the interview has been transcribed I can review it and suggest modifications. I understand that the transcripts will be kept in a locked file cabinet in the researcher's office and that electronic files will be password protected. All transcriptions and data will be destroyed after two years.

I understand that my participation in this research is entirely voluntary and that I can withdraw at any time without consequence. I understand that all information obtained in this study is confidential and that no participant will be identified. However, if any concerns are presented during the interview that have legal implications, they must be reported to the proper authorities.

I am aware that all tapes, transcripts, and surveys will have a numerical code to maintain confidentiality. I also understand that quotes from interviews will be used in the thesis and future publications and presentations to illustrate themes arising from the data. However, no identifying information will be reported and my identity will not be revealed in any way.

I am aware that a copy of the research findings will be sent to me when the thesis is completed.

I understand that that this research has the approval of the Mount Saint Vincent University Research Ethics Board, Mount Saint Vincent University, Halifax, Nova Scotia. If I have questions, I may freely direct them to Sarah Melanson, at [REDACTED] or [REDACTED] or the thesis supervisor Dr. Carmel French at 457-6187 (carmel.french@msvu.ca). If I have questions about how this study is being conducted, I may contact the Chair of the University Research Ethics Board, c/o MSVU Research and International Office, who is not directly involved in the study, at 457-6350 or via e-mail at research@msvu.ca.

I have read the information provided above. I understand that by signing below that I am agreeing to participate in this research study.

Signature: _____ Date: _____

Address: _____

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

Times I may be reached at: _____

Researcher's signature: _____

Address or email for summary of the results:

APPENDIX F

Sample Coded responses

Coded responses

Question 4: How did participants describe a family centred program? (Family responses)

Level 2

- Everyone is involved
- All caregivers can be involved
- Whoever in house is involved

- Everybody is learning so that everyone can help
- Everyone understands

- See how family works as a whole
- Take lead from family
- Based on what is best for child within their family
- See situation family is in
- Take into consideration family needs and wants
- Concerned about siblings
- Concerned about entire family

- Activities for the family
- Playgroups

- Work around family schedule
- Home visits
- show family what to do

Level 3

Many people involved

Learning and understanding

Following the family's lead

Programming for the entire family

Visits / modeling / flexibility

Level 4

Process oriented

Service oriented