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Early Intervention in Canada: Perceptions of Parents and Service Providers

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Abstract

As the federal government does not mandate Early Intervention in Canada, decisions are left to provincial and territorial jurisdiction, resulting in discrepancies in services and supports across the country. In an effort to examine these differences, 427 Canadian service providers and 381 Canadian parents took part in our study. Provinces and territories were compared with one another on a number of variables including funding, wait times, program intensity, parent and service provider satisfaction, service comprehensiveness, coping strategies, and perceptions of family-centered care.

Canadian service providers were more similar than different in terms of several variables, including average wait times, number of services, and ratings of program satisfaction. Parents from across Canada also reported similarities in terms of average age of service delivery onset, average wait times, parental coping strategies, and perceptions of family-centered care.

Despite many similarities, several differences were also found across Canada. According to parent report, children in Alberta received their diagnosis significantly earlier than children in Quebec. Canadian parents also reported differences in terms of their satisfaction with their respective program, with parents in Nova Scotia and Alberta reporting the greatest levels of satisfaction. Differences were also found across Canada in terms of satisfaction with government support, again with parents in Alberta reporting the greatest levels of satisfaction. The implications for service providers, families, researchers, and other key stakeholders are discussed and directions for future research are explored.

Résumé

Comme le gouvernement fédéral ne favorise pas l’intervention précoce au Canada, les décisions reposent sur les épaules des juridictions provinciales et territoriales. Cela explique les nombreuses divergences au niveau du support et des services à travers le pays. 427 fournisseurs de service canadiens et 381 parents canadiens ont pris part à notre étude. Nous avons comparé les variables des provinces et territoires, incluant le financement, les délais d’attente, l’intensité du programme, la satisfaction des parents et des professionnels du secteur, la globalité des services, les stratégies d’ajustement et la perception des soins centrés sur la famille.

À l’analyse de plusieurs variables telles que les temps d’attente, la quantité de services offerts et le niveau d’appréciation du programme, on remarque plus de similarités que de différences parmi les professionnels canadiens offrant ces services. À travers le Canada, les parents ont aussi rapporté des similitudes en termes de moyenne de délais d’attente, d’âge moyen de début des interventions, de stratégies d’ajustement des familles et de perception des soins centrés sur la famille.

Malgré plusieurs correspondances dans nos statistiques nationales, nous avons aussi relevé quelques différences au pays. D’après le rapport des parents, les enfants albertains reçoivent leur diagnostique considérablement plus tôt que les enfants québécois. Les parents canadiens ont aussi affiché des distinctions en termes de satisfaction face à leur programme respectif ; les parents de la Nouvelle-Écosse et de l’Alberta affectionnant davantage leur programme. Enfin, nous remarquons un niveau de satisfaction variable face à l’appui gouvernemental, les parents albertains démontrant encore une fois un niveau plus élevé de satisfaction. Nous discutons des implications pour les professionnels de service, les familles, les chercheurs et autres joueurs-clef. De nouvelles pistes de recherche sont aussi explorées.

CHAPTER 1 : Introduction

Early Intervention

Early intervention refers to a collection of individual and family supports, services, and systems for young children that need assistance to achieve optimal development (Blackman, 2002; McCollum, 2002). Services can include programs to improve cognitive, adaptive, emotional, social, and physical functioning and systems of support developed to help families meet their child's individual needs (Blackman, 2002). The goal is to enhance the child's developmental competence and minimize the effects of developmental delays (Blackman, 2002; Carpenter, 2005; Majnemer, 1998; Orton et al., 2009). More specifically, the goal is to help young children with developmental delays, improve various skills, such as language, adaptive, or social functioning, to work towards developmental goals that are commensurate with their chronological age.

Children with congenital or acquired developmental delays, as well as those with developmental difficulties who are at-risk, often require early intervention services and supports. The World Health Organization's International Statistical Classification of Diseases and Related Health Problems: 10th Revision (ICD-10) classifies developmental disabilities under F80-89: Disorders of Psychological Development. According to this definition, developmental disabilities have an onset in infancy or early childhood and cause impairment in the development of functions related to the biological maturation of the central nervous system. Developmental disabilities follow a steady course without remission or relapse and functions affected can include language, motor coordination, and visual-spatial skills (World Health Organization, 2007).

Early intervention is crucial for children with developmental delays as the first three years are a period of rapid brain development when crucial neural connections are forming and children have the greatest advantage in terms of learning speed and neural plasticity (Blackman, 2002; McCain, Mustard, & Shanker, 2007; Roberts, Howard, Spittle, et al., 2008). Program effectiveness can be influenced age of onset (Ramey & Ramey, 1998; Roberts et al., 2008; Woods & Wetherby, 2003); program comprehensiveness or breath of services (McCollum, 2002; Ramey & Ramey, 1998); and degree of family support and involvement (Ingber & Dromi, 2009; McCollum et al., 2001; Odom & Wolery, 2003).

Although a great deal of research has been amassed in the field, information is limited in several critical areas. The present project was designed to address two of the current limitations in the field by focusing on a comparative snapshot of early intervention service delivery systems across Canada and to examine the experiences and perceptions of parents with children in early intervention programs across the country.

Service Delivery

The first area of research that is in need of greater attention is the early intervention service delivery frameworks across Canada. As the federal government does not mandate a national policy, early intervention services are left up to provincial or territorial jurisdiction (den Heyer & Kienapple, 2005). Consequently, provinces and territories vary in their support of early intervention programs and specific program components (Lyon, 2002; Sladeczek & Amar, 2005). Although there is a consensus that programs are too variable across Canada and that information on existing programs and program variables is insufficient, a national framework or set of early intervention guidelines does not exist.

Some provinces are significantly ahead of others in terms of early intervention service delivery. For example, a zero-waitlist policy exists only in Newfoundland and Labrador (Ouellette-Kuntz et al., 2009). Intensive behavioural intervention programs are available for any child with autism who meets age criteria in Manitoba, Prince Edward Island, and Newfoundland and Labrador whereas only children at the severe end of the spectrum are eligible for services in Ontario (Ouellette-Kuntz et al., 2009). In British Columbia, programs exist for children over the age of six, whereas in many other provinces, services discontinue after this age. Until recently, children in Ontario would not receive funding after the age of six (Ministry of Children and Family Development, 2006). In Saskatchewan, very few children receive services outside of the school system after the age of six (Ministry of Children and Family Development, 2006). In Quebec, Intensive Behavioural Intervention programs, an intensive form of early intervention typically used for children with autism spectrum disorders, are not paid for by the government after the age of six but children are sometimes entitled to home or school based services, although waitlists are long and services are often fragmented (Ministry of Children and Family Development, 2006). As seen from these few examples, a great deal of inequality exists in Canada in terms of the amount, duration, and type of funding. Variability is also evident in terms of waitlists and service comprehensiveness. These inequalities can result in families having to relocate to meet the needs of their children.

A comparative analysis of early intervention programs on a province-by-province basis has not been conducted in the field. As a preliminary step, a snapshot comparison using five time zone groupings, due to sample size restraints, was initially conducted by the Canadian Early Intervention Research Team in 2007. As provinces and territories are governed by their own respective early intervention policies, making comparisons by time zone rather than individual provinces and territories, was a significant limitation of the aforementioned study. Significant differences would likely exist within any given time zone given the fact that each province and territory sets its own policies and procedures with respect to early intervention.

As such, the present study was designed to make provincial and territorial comparisons across Canada on a variety of variables including average wait time, source of funding, number of services and professionals, satisfaction with program adequacy, child outcomes, and government support. The study was also designed to investigate the critical success factors in early intervention programs and their impact on overall program satisfaction. It is important to investigate services and supports from across Canada to provide insight into what is and is not working well across the country and build upon the strengths of programs variables that contribute to positive outcomes.

Parent Perceptions

As parental involvement is a crucial element to early intervention program success and there is a limited amount of parent perception research in the field, this comprised the second area of focus for the present study. The majority of research studies focus on child outcome variables, ignoring the effects of early intervention programs on the family unit. It is critical to assess the experiences of parents with children in early intervention programs as their experiences likely impact their involvement which, in turn, impacts the child's success (Blackman, 2002; Guralnick, 2005; Ingber & Dromi, 2009; McCollum, 2002; Webster, Feiler, & Webster, 2003).

As such, another focus of the study was to compare parent-reported experiences from across Canada. It is important to investigate the experiences of Canadian parents with children in early intervention programs to determine what factors are important for parental satisfaction and involvement in service provision.

Parent and Service Provider Comparisons

Another area of focus of the present study was on the comparison of parent and service provider perceptions of services across Canada to determine if there were significant differences. Parents and service providers were asked to rate, on a ten-point scale, program adequacy, satisfaction with child outcomes, and the ability of the government to meet the needs of families. The ratings of parents were compared to the ratings of service providers within each respective province. It is important to assess programs from not only a service provider perspective but also from a parent perspective as parent involvement is a crucial factor in program success (Guralnick, 2001).

As family involvement is only one of several factors that influences early intervention program success, an extensive review of the literature was conducted to determine which additional factors were crucial to assess for the purpose of the present study. Guralnick has done extensive work in the field and, based upon empirical research studies, has put together a developmental systems model for early intervention (Guralnick, 2001; see Figure 1). This model largely influences the present research study. According to the model, children should first be screened and, if there is potential that they meet criteria for a developmental delay, a comprehensive, interdisciplinary assessment should then take place. Children that are eligible for services should receive intensive and comprehensive services in a timely manner. The needs, goals, and family characteristics must be taken into account during program development. Finally, monitoring, outcome evaluations, and transition planning should take place.

In summary, Guralnick (2001) focuses on the importance of intervention beginning early in the child's development, comprehensive and coordinated services, family involvement, and evaluation. These variables are central elements that were investigated in the present study. Additional factors that have been deemed critical for program success by other prominent researchers in the field were also included and explored in the review of the literature (e.g., program intensity, funding).

Figure 1

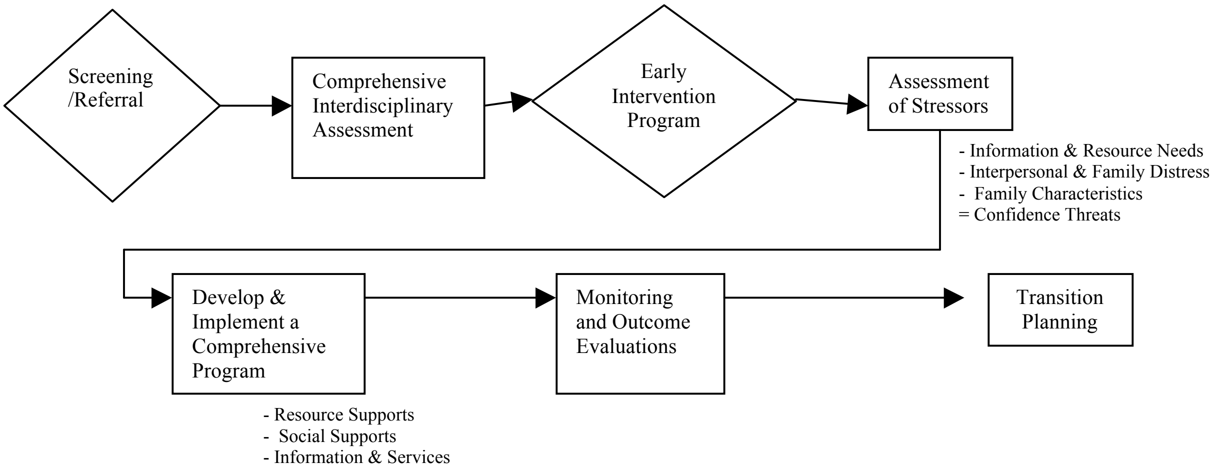

Figure 1. Michael Guralnick's developmental systems model for early intervention for vulnerable children and their families.

In summary, the success of early intervention depends on a variety of factors, many of which have been included in Guralnick’s developmental systems model for early intervention. In an effort to elaborate on the model and include other variables that have been deemed critical for early intervention program success, an extensive review of the literature was conducted. A summary of findings is presented in the following section.

Guralnick’s developmental systems model was not intended to prescribe a uniform set of services and supports across all communities on a global level, but to provide a conceptual basis of variables that have been found to have an impact on the course of young children who are vulnerable (Guralnick, 2005b). Through the International Society on Early Intervention, Dr. Guralnick has been working on international efforts to facilitate research and collaborations on an international level and share knowledge on a global level. Guralnick’s international efforts to bring early intervention clinicians and researchers together, and encourage the field to adopt a systems perspective with regards to early intervention, have guided the development of the current research project.

Chapter Two: Review of the Literature

In the following section, an extensive review of the early intervention literature is presented. First, early intervention services are described, with a focus on the various types of supports, program goals, and importance of intervening early. Subsequently, developmental delays are defined and the importance of early intervention for children with developmental delays is described. Third, the short and long-term effectiveness of early intervention is explored and the factors affecting program success are investigated, with a particular focus on family involvement and perceptions of early intervention. Subsequently, Canadian early intervention policy is explored and a cross-Canada comparison of social policies and service delivery frameworks is presented.

Early Intervention

Early intervention programs target children with established deficits and biological, or environmental risks (Blackman, 2002; Guralnick, 1998; Majnemer, 1998). It is seen as best practice because the first three years of life provide the basis for the development of the child's subsequent skills (Blackman, 2002; Eaves & Ho, 2004). Services are designed to help families and children receive the necessary treatment and information to support child development and learning (Mustard & Shanker, 2007).

Early intervention programs are designed to enhance child development and sustain and support the family (Bailey, Aytch, Odom, Symons, & Wolery, 1999; Blackman, 2002; Carpenter, 2005; Grindle et al., 2009). Programs are designed to help children develop skills in cognitive, social, physical, emotional, and adaptive domains, depending on the individual needs of the child, and offer a variety of supports to families

(Blackman, 2002; Bruder, 2000; Carpenter, 2005; Herrod, 2007; McWilliam & Scott, 2001; Remington et al., 2007). Family supports include parent training, provision of resources and information on the child's disorder, and support groups, to name a few (Blackman, 2002; Bruder, 2000; Carpenter, 2005; McWilliam & Scott, 2001). Family support is essential to improving child outcomes, decreasing stress, and fostering family confidence and competence to provide the necessary supports to their child (Blackman, 2002; Bruder, 2000; Carpenter, 2005; Grindle et al., 2009; Guralnick, 2005; McWilliam & Scott, 2001).

As multiple impairments are common, programs typically offer a variety of services for children in multiple domains of functioning (Guralnick, 2000; Herrod, 2007; McCollum, 2002; Remington et al., 2007). Programs generally include services from various domains, such as occupational therapy, physiotherapy, speech pathology, medical and nursing services, psychological and psychiatric services, assistive technology services, audiology, nutrition services, special instruction, transition services, and social work and family services (Alberta Children's Services, 2008; Autism Treatment Services of Canada, 2006; Individuals with Disabilities Education Act, 2004). These services are often of critical importance for children with developmental delays.

Developmental Delays

Developmental delays, as defined by the World Health Organization's International Classification of Diseases – Tenth Edition (ICD-10), have an onset in infancy or early childhood and cause delay in the development of functions related to the biological maturation of the central nervous system. The delays follow a steady course without remission or relapse. Functions that are often affected include language, motor coordination, and visual spatial skills (World Health Organization, 2007).

The Developmental Disability Assistance and Bill of Rights Act (2000) further specifies that children with developmental delays have established deficits in one or more of the following areas of functioning: self-care, capacity for independent living, learning, mobility, receptive and expressive language, self-direction, and economic self-sufficiency Self-care refers to adaptive skills, such as personal hygiene, and capacity for independent living refers to daily living skills, such as cleaning and preparing meals. Learning limitations for children with developmental delays can be general or specific to certain subject areas. Some children with developmental delays, for example, children with cerebral palsy, have mobility issues due to physical disability. Language delays, in terms of what the child understands receptively and communicates expressively are also common in children with developmental delays. Due to the nature of these limitations, children with developmental delays often have difficulties in the long term with self-direction and economic self-sufficiency.

Over 29,000 Canadian children, between 0 and 9 years of age have been diagnosed with a developmental delay (Statistics Canada, 2001). This is an underestimate as children from the Yukon, Northwest Territories, and Nunavut were not included in the 2001 *Participation and Limitation Action Survey*, from which these statistics were obtained (Statistics Canada, 2001). More recently, Lach and colleagues (2009) reported that it is estimated that up to 9.3% of children under the age of 18 have a neurodevelopmental disorder.

Prevalence estimates differ from one study to the next depending on the target population (e.g., whether or not territories are included in the analysis), definition of developmental delay, and inclusion criteria used in the study. Regardless of the exact number of children affected by a developmental delay, it is evident from studies such as these that there are many children in need of early intervention services and supports given their developmental difficulties. It is crucial that we continue to conduct research in the field so that these families can receive the services and supports needed to achieve optimal development.

Importance of Early Intervention for Children with Developmental Delays

Early intervention is critical for young children with developmental delays (Blackman, 2002; Dunst & Trivette, 2009; Herrod, 2007; McCain et al., 2007). Children who receive services earlier in life have been shown to display greater improvement than those who receive services later in life (Carpenter, 2005; Guralnick, 1998; O'Connor, Bocian, Beebe-Frankenberger, & Linklater, 2010). As learning and development are most rapid during the preschool years, children should be identified early and services should begin as soon as possible (Blackman, 2002; Carpenter, 2005; Guralnick, 1998; Majnemer, Shevell, McCain et al., 2007; Roberts et al., 2008; Rosenbaum, & Abrahamowicz, 2001). It is now known that the first three years of life is a period of intensive synapse production (McCain et al., 2007; Robert et al., 2008). As such, interventions that begin early are typically more effective, both in the short and long-term, than those that begin later.

Effectiveness of Early Intervention

The following section was compiled to examine the effectiveness of early intervention programs. First, studies examining both the short-term and long-term effectiveness are explored. Difficulties in assessing program effectiveness are also discussed and factors influencing program effectiveness are described in detail.

Short-Term Effectiveness

Many researchers have found early intervention programs to have short-term benefits for children with delays. Benefits have included improvements in cognitive or intellectual functioning (Gurlanick, 1998; Ramey & Ramey, 2004), language skills (Diggle and McConachie, 2002; Remington, 2007), adaptive functioning (Remington, 2007), social competence (Cotugno, 2009) and motor skills (Remington, 2009).

Bernhardt and Major (2005) investigated the effects of a language and communication intervention program on speech, language, and literacy skills for children with speech and language delays. Children showed significant gains in speech production and conversation at a three-year follow-up as measured by standardized tests of language and literacy (Bernhardt & Major, 2005). This research study, however, is not without limitations. The sample size was small (n=12), limiting the generalizability of the research findings. Also, twice as many males took part in the study and gender effects were not analyzed. Finally, although children were compared to normative standardization samples, there was no control group included in this research study.

Individual cognitive assessments (Bayley Developmental Quotient, Stanford Binet IQ and McCarthy General Cognitive Index) have also been used as outcome measures to examine the effectiveness of early intervention programs. Ramey and Ramey compared children in a *Partners for Learning* group to children who did not receive any intervention. They found that children in the intervention group performed higher than the national average in terms of cognitive assessments whereas control children performed at the low end of the normal range and an average of 14 points lower than children in the intervention group (Ramey & Ramey, 2004). The generalizability of these findings across cultures is limited as 98% of the children who took part in this study were African American. Also, only cognitive scores were analyzed as an outcome measure. As such, no information is provided with respect to gains in other domains or areas of development (e.g., social, language, adaptive functioning).

Guralnick also investigated the effectiveness of early intervention programs in improving cognitive development. He concluded, based on an extensive literature review of empirical studies, that the typical gap in cognitive ability between children with and without intellectual delays that typically increases over the first five years can be minimized with appropriate early intervention services (Gurlanick, 1998). When looking at research on children with Down Syndrome, Guralnick found that the cognitive decline that is typical between 12 and 18 months of age was almost entirely preventable. This was evidenced in research studies in the United States, Wales, Australia, and Israel, as summarized in Guralnick's review of the literature (Guralnick, 1998). Similarly, positive effects were found with children with biological risk, such as low birth weight, and those that were at-risk due to environmental factors. These results were found consistently through a wide range of programs and populations.

Diggle and McConachie (2002) conducted an extensive review of randomized and quasi-randomized studies of parent-mediated early intervention programs for children age

1 through 6 years 11 months with autism spectrum disorders. Control groups consisted of children who received no treatment, were on a waitlist, or received a different form of intervention. Only studies with at least one objective child-related outcome measure were included. After an extensive review of the literature, only two studies were included (Jocelyn, 1998; Smith, 2000).

Jocelyn (1998) conducted a research study comparing children that received both daycare services and a parent-training program to children who received only daycare supports. Children from the parent-training group scored significantly higher on the language but not cognitive component of the Early Intervention/Preschool Developmental Profile, indicating significant improvements with respect to receptive and expressive language development but not intellectual ability. No significant differences were found on the Autism Behaviour Checklist, which measures the behavioural signs associated with autism (e.g., hand flapping, spinning). With respect to limitations of the study, the sample size was small (n=35) and there were some differences between the treatment and control group that could have impacted the results (e.g., greater percentage of single parent families in the control group). Also, as the study took place in one early intervention program in Winnipeg, the results are not necessarily generalizable to other programs or geographical locations.

Smith (2000) compared families that took part in a parent-training program to families that took part in an intensive treatment program. The children in the intensive treatment group scored significantly higher with respect to cognitive or intellectual functioning and language development than children in the control group. Cognitive functioning was measured with the Stanford Binet Intelligence Scale or Bayley Scales of

Infant Development, depending upon the child's age, and language development was assessed using the Reynell Developmental Language Scale. Parent stress was rated lower with the intensive treatment group than with the parent-training group. With respect to study limitations, there was no standardized diagnostic measure. Children that took part in the study had a previous diagnosis of an autism spectrum disorder but a confirmation of diagnosis was not included as part of the research design. Additionally, the assessment measures were normed on typically developing children rather than children with developmental delays.

Diggle and McConachie (2002) concluded that the results must be viewed with caution as sample sizes were small and the studies were different in many ways. In the future, randomized control trials involving larger samples must be carried out, involving both long and short-term evaluations as well as cost-benefit or economic evaluations.

Remington et al. (2007) investigated the effects of two years of intensive, early intervention on children with autism and their families. Twenty-three children, enrolled in public or private early, intensive behavioural intervention programs were compared to twenty-one children whose parents opted for less intensive, publicly funded educational provisions (e.g., speech language therapy, picture exchange communication systems). Children in the intensive intervention group showed significantly greater gains in cognitive development, expressive and receptive language, joint attention, and parent-reported daily living and motor skills. Parents in the intensive intervention group also reported greater social improvements with their children and did not report any greater levels of stress or mental health difficulties than the control group.

Cotugno compared 18 children with ASD who received one-hour of weekly social skills programming for 30 weeks to a control group. Children in the treatment group scored significantly greater on the post-test measure of social competence (Walker-McConnell Scale of Social Competence; WMS). In addition, significant gains were made in terms of anxiety management, joint attention, and flexibility or ease of transitions (Cotugno, 2009). Despite the positive findings, the sample size was small, limiting the generalizability of research findings. Also, there was no control group, limiting the validity of the results. Finally, with respect to the assessment measure used in the study (WMS), there is no data on the validity of the tool with individuals with autism spectrum disorders.

Long-Term Effectiveness

Although there have been more research studies investigating the short-term effectiveness of early intervention (i.e., immediately following or shortly after the intervention), several researchers have also documented long-term effectiveness of early intervention, over many years (Currie, 2000; Hanson, 2003; Herrod, 2007; Ramey & Ramey, 2004; Spittle, Orton, Doyle, & Boyd, 2002).

In addition to investigating the short-term effects of the ABC Project, Ramey and Ramey (2004) studied enduring, school-age effects. Those who took part in the preschool intervention scored significantly higher on reading and math tests than control students from kindergarten through grade twelve. Students from the intervention group were also less likely to be held back or placed in special education classes. Subsequently, Ramey and Ramey also followed children into adulthood. Seventy-percent of those who took part in the intervention held skilled jobs and the majority continued to show higher IQ, reading, and math achievement scores than the control group that did not receive the preschool intervention. Both the treatment and control groups received adequate nutrition, supportive social services, and low-cost or free primary health care. In addition, children in the treatment group received 50 hours of intervention per week through the Learning Games school-based curriculum, which focused on cognitive, social, language, and motor development with individualized pacing for each student. As was the case with the short-term effectiveness studies, this study was limited by its narrow definition of program ‘success.’ In the present study, academic and vocational variables were included but social, emotional, and language variables, for example, were not investigated.

Hanson (2003) investigated the lasting gains in children with Down Syndrome and the impact on families who took part in early intervention programs between 1974 and 1977, a time in which early intervention services and supports were likely quite limited. Children and parents were interviewed to investigate child outcomes and parent satisfaction. Nine of twelve original participants were employed and partially independent 25 years after the program. They were able to cook, clean, and take public transit. For families, early intervention provided much-needed hope and support. All parents reported that services were one of their most necessary supports, providing positive yet realistic family expectations (Hanson, 2003). The present study, although informative in terms of long-term outcomes, is limited by a small sample size. Additionally, results cannot be generalized to individuals with other developmental delays as only participants with Down Syndrome were included in the study. The possible effect of social economic status was also not discussed.

The *Perry Preschool Project* is an early intervention project in which children took part in a half-day preschool five days a week and received 90 minutes of weekly home visitation sessions (Schweinhart, Barnes, & Weikart, 1993). Teachers visited the homes to help mothers become involved in education and implement the home-curriculum. This involved having parents work on skills taught in the preschool curriculum so that the child was provided with an opportunity to practice the skills and generalize them to the home environment. This took place for eight months per year for two years. Teacher-to-student ratios were small and all teachers had a Master's degree with training in child development. Long-term positive effects were found in terms of high school graduation rates, grades, earnings, achievement test results, and lower rates of crime and welfare. Early intervention played a major part in increasing the economic and academic success of children that were deemed "at-risk" and minimized negative societal impacts.

Spittle and colleagues (2002) investigated the effects of early developmental intervention programs for preterm infants at risk of developmental problems, including motor and cognitive delays in development. A review of sixteen randomized and quasi-randomized control studies of early intervention programs for pre-term infants, which commenced in the first year of life, was conducted. Children were followed from infancy to school age. Significant improvements in cognitive outcomes were found with children 0-2 years of age (developmental quotient; DQ), and at preschool age (3 to <5 years of age; intelligence quotient). This effect was not sustained at school age (5 to 17 years of age). There was little evidence of early intervention effects on motor development during the infancy, preschool, or school age stages. As there was significant heterogeneity between the interventions included in the review by Spittle and colleagues (2002), further research is needed to determine which interventions are most effective and which are the most cost effective.

More recently, Herrod (2007) conducted a meta-analysis of the literature assessing the long-term effectiveness of early intervention. He sought out to determine the long-term effects of early intervention on health and welfare of adults. Studies with specific outcome measures and control groups were included (e.g., Abecedarian study, Perry Preschool Project; Head Start). He concluded that, returns on investments ranged from $3.23 to $17.07. In other words, for every dollar spent on early intervention services, between $3.23 and $17.07 would be saved in the long term. Early intervention services resulted in a much lower cost to society as individuals that received treatment had greater earning potential and required less remediation in the future. He reported that the greatest improvements were found in behaviour and social skills, rather than cognitive functioning (Herrod, 2007). As such, studies that define success strictly in terms of a measurable change in intellectual functioning, may overlook significant social and behavioural improvements (e.g., decreased problem behaviour, improved social initiation and responsiveness).

Issues in the Assessment of Program Effectiveness

Although many early intervention programs have been deemed effective for children with developmental delays, there are issues to consider with regards to how “effectiveness” is defined and measured. Change in IQ or cognitive ability is a commonly used measure to assess program effectiveness, however, researchers should also consider outcomes such as gains in emotional, social, adaptive, and language domains (Eldevik et al., 2009; Matson, 2007; Matson & Minshawi, 2006; Remington et al., 2007; Woods &

Wetherby, 2003). Persistent benefits tend to be socially and emotionally, rather than cognitively, based (Blackman, 2002; Herrod, 2007; Remington et al., 2007). For example, fewer instances of teenage pregnancy, lower drop out rates, and greater earning potential, have been linked to early intervention (Blackman, 2002; Herrod, 2007).

It is important to consider not only how the researchers are defining "effectiveness" but also to consider the assessment tools or measures being used. Some assessment measures are not designed for very young children and many children are not able to answer questions (Matson, 2007). Additionally, measures used from pre to post-test often differ and may not be sufficiently comparable (Kasari, 2002; Matson, 2007). This is sometimes unavoidable because of age restrictions associated with the particular test; however, this practice does have an impact on clinical interpretation as it is more difficult to make direct comparisons between time points when the assessment tool differs from one time point to the next.

It is also important, when analyzing research studies assessing early intervention effectiveness to determine whether or not there is a control group and, if so, whether or not participants are randomly assigned or matched appropriately (Kasari, 2002; Matson, 2007). Control groups should be matched on age, severity of delay, specific disability, and presence of challenging behaviours (Kasari, 2002; Matson, 2007). If researchers do not match participants in intervention and control groups on variables such as these, it is impossible to determine whether the effects of an intervention are due to the intervention or sample characteristics. For example, if children in the intervention group are higher-functioning and have fewer interfering behaviours than children in the control group, their more favourable outcomes could be attributable to these differences, rather than the intervention itself.

Research studies assessing program effectiveness to date have focused more so on child outcomes rather than parent experiences. Parents should be consulted regarding their satisfaction with the program and child improvement as caregiver involvement is linked to optimal child development (Dunst & Trivette, 2009; Mitchell & Hauser-Cram, 2009). In order for a program to be deemed successful, it should be beneficial both in terms of the child's gains in various domains and in terms of parent satisfaction (Dunst & Trivette, 2009; Grindle et al., 2009; Matson, 2007; Mitchell & Hauser-Cram, 2009).

The present study was designed to address the aforementioned limitation by involving parents in determining program effectiveness. Parent and service provider satisfaction will both be assessed, something that has not been found in the review of present literature and will add a novel element to Canadian early intervention research.

Factors Affecting Early Intervention Effectiveness

Many researchers have validated the importance of providing children with interventions in the early years. There are several other factors that have been researched and shown to have a significant impact on the effectiveness or success of early intervention programs. Programs should have clearly identified goals and a consistent means of evaluating the components of their programs (Bailey, Aytch, Odom, Symons, & Wolery, 1999; Herrod, 2007). Programs are most effective when they focus on enhancing opportunities for the child and family, eliminating risk factors, and promoting access to resources (Bailey et al., 1999; Grindle et al., 2009; Mitchell & Hauser-Cram, 2009). The following section discusses some of the major factors contributing to program success.

Service coordination and comprehensiveness.

According to his developmental system's model Guralnick (2001) states that early intervention services should be comprehensive. Service coordination is a method of systematically helping parents to obtain a variety of appropriate resources and services they need by integrating services from multiple providers (Park & Turnbull, 2003). Integrating various service components is more effective than putting the onus on parents to combine services to comprise a comprehensive plan (Dunst & Bruder, 2002).

Service systems should be integrated to support children and families with special needs by ensuring all beneficial services are available to them and that supports are attained efficiently (Dunst & Bruder, 2002; Guralnick, 2000; Ingber & Dromi, 2009; Zhang, Schwartz, & Lee, 2006). Effective service coordination provides many benefits, including increased quality and support, better information flow, more efficient access, improved relationships, greater availability of funding, empowerment, and improved child outcomes (Dunst & Bruder, 2002; Park & Turnbull, 2003; Ramey & Ramey, 1998).

Fragmented supports have a negative impact as they often result in unnecessary service overlap, resulting in a loss of time and money and frustration or confusion for parents (Dunst & Bruder, 2002; Guralnick, 1998; Kyle, 2000; Park & Turnbull, 2003). As a single agency or discipline cannot usually meet all the needs of the child and family a transdisciplinary team, whereby a variety of professionals from different fields work together to plan an intervention, is most beneficial (McCollum, 2002). Unlike multidisciplinary teams, where team members adhere to domain-specific roles, transdisciplinary teams work across disciplinary boundaries, integrating knowledge from different domains (McWilliam, 2000).

Individualized programs

Early intervention programs should be individualized based on the needs of the specific child and family. Central to Guralnick's developmental systems model of early intervention (2001), is the specification that the needs, goals, and characteristics of the family must be taken into account during program development and implementation. Other researchers in the field have also supported the importance of matching programs to the specific goals of the child and the family (Guralnick, 1998; Hurth et al., 1999; Odom & Wolery, 2003; Rodgers et al., 2008).

Program intensity

Guralnick (2001) spoke of the importance of program intensity in his developmental systems model. Many researchers have empirically supported that intensive programs are more effective than time-limited programs (Hume, Bellini, & Pratt, 2005; Herrod, 2007; Hurth et al., 1999; Remington et al., 2007; Symes, Remington, & Brown, 2006). Programs should be intense in terms of the duration and frequency of sessions, for example, offering 25 to 40 hours of service across five days a week (Guralnick, 1998; Herrod, 2007; Ramey & Ramey, 1998; Remington et al., 2007).

Program flexibility.

Flexible programs, that adapt interventions continually, have resulted in better outcomes than pre-determined programs (Childress, 2004; Ramey & Ramey, 1998). For example, programs that consider how well services fit with a particular cultural group will be more effective than interventions that are not adapted accordingly (Hays, 2001;

Ramey & Ramey, 1998; Rogers & Lopez, 2006). This is something that, although important for program success, is not legislated in Canada despite the multicultural nature of the country. Again, Guralnick (2001) spoke of the importance of individualizing programs. Interventions designed for the child and family will have a greater impact than those that do not adjust to individual family needs (Hays, 2001; Ramey & Ramey, 1998).

Family involvement.

A critical factor in early intervention program success is family involvement or family-centered practice (Blackman, 2002; Dunst & Trivette, 2009; Grindle et al., 2009; Guralnick, 2005; McCollum, 2002; Mitchell & Hauser-Cram, 2009; Webster, Feiler, & Webster, 2003). According to Guralnick's developmental systems model (2001), the needs, goals, and characteristics of the family must be taken into account. Involvement varies from family to family and program to program. Some family members are not involved in the child's program directly but provide indirect support while others are trained to act as therapists, guiding their child through the program at home. Family involvement is central to the current study and is consequently presented in its own section below, with a focus on the importance of involvement, how to involve families, and barriers to family participation.

Family Involvement in Early Intervention

Family-centered models of early intervention services are prominent today, with professionals and parents serving reciprocal functions, including the provision of information, support, and advice (Carpenter, 2005; Ingber & Dromi, 2009; Rodger et al., 2008). As early learning is not solely a function of the child but also involves the environment and as the child's home provides the dominant setting for learning to take place, families should be taught effective ways to help their children (Bruder, 2002; Carpenter, 2005; Law et al., 2003; Mitchell & Hauser-Cram, 2009). The most effective early intervention programs involve and support the family (Blackman, 2002; Dunst & Trivette, 2009; Grindle et al., 2009; McCollum, 2002; Mitchell & Hauser-Cram, 2009; Webster et al., 2003). Family-centered service is critical in promoting parent and child wellbeing (Grindle et al., 2009; King, Teplicky, King, & Rosenbaum, 2004). In Canada, family involvement is seen as best practice (King et al., 2004; Zinga, Bennett, Good, & Kumpf, 2005). For example, each provincial and territorial *Education Act* supports parent involvement in both assessment and service provision (Zinga et al., 2005).

Family-centered service involves providing information, support, partnership, and enabling parents to competently take part in the early intervention process (Grindle et al., 2009; King et al., 2004; Mitchell & Hauser-Cram, 2009). Families are seen as unique and family members are treated as experts and necessary agents for child improvement (Dunst, Boyd, Trivette, & Hamby, 2002; King et al., 2004; Mitchell & Hauser-Cram, 2009). The strengths and needs of all family members are recognized and incorporated into treatment (Grindle et al., 2009; King et al., 2004; Mitchell & Hauser-Cram, 2009).

Importance of Family Involvement.

Family involvement is one of the most critical priorities in effective early intervention (Blackman, 2002; Dunst & Trivette, 2009; Grindle et al., 2009; Guralnick, 2005; McCollum, 2002; Mitchell & Hauser-Cram, 2009; Webster, Feiler, & Webster, 2003). The involvement of parents in early intervention programs dates back thirty years (McConachie & Diggle, 2007). As intervention is best when it begins early, the participation of parents in early intervention programs is important as young children spend the majority of time with their parents (McConachie & Diggle, 2007; O'Connor et al., 2010). Parent involvement is beneficial to both the child and parents (Guralnick, 2005; Kucuker, 2006; Grindle et al., 2009; McConachie & Diggle, 2007).

Child benefits. Family involvement can directly benefit the child by ensuring that services are appropriate for the child, as family members can provide professionals with background and contextual information (Kucuker, 2006; McConachie & Diggle, 2007). Additionally, child competence is enhanced by parent beliefs about early intervention, their own competence, and attitudes (Guralnick, 1999; Ingber & Dromi, 2009). Parent involvement results in parents having more positive beliefs about their ability to help their child and having more positive attitudes towards the program, consequently amplifying the positive effects of the program. Parents that are involved and supported along the way will have the competence to enhance the child's program by actively taking part in the practice and generalization of skills (Guralnick, 1999; Ingber & Dromi, 2009). Researchers have found that family involvement can benefit the child by improving his or her play, social, and communication skills (Grindle et al., 2009).

Parent benefits. Family involvement also provides many benefits to the parents. Involvement can reduce parent stress by providing parents with skills, self-confidence, more free time, and support (Grindle et al., 2009; McConachie & Diggle, 2007). By providing family members with knowledge and skills, they become empowered and more confident in their parenting and teaching abilities and are better able to understand their child (Dempsey & Dunst, 2004; Grindle et al., 2009; McConachie & Diggle, 2007;

McCollum et al., 2001). Parents that are supported typically feel more confident and competent are better able to assist children with special needs (McCollum et al., 2001).

Researchers have shown that parents who take part in early intervention programs have lower levels of stress, isolation, depression, and anxiety (McBridge, 1991; Pelchat, Bisson, Richard, Perrault, & Bouchard, 1999; Robertson & Weismer, 1999; Mazzucchelli, Roberts, Studman, Sanders & Jeffs, 2003; Kennedy, Chretien, & Moxness, 2004). Actively involving parents in intervention programming provides parents with a sense of control and competence (Rodger et al., 2008; Trivette, Dunst, & Hamby, 1996). Providing parents with this sense of control is critical because parents remain central to the child's life over time. Parents that feel competent to help their child are better able to provide the social support that is central to minimizing the negative impact of a developmental delay (Rodger et al., 2008; Trivette, Dunst, & Hamby, 1996).

Outcomes of family-centered practice. Many researchers have focused their research on the outcomes of family-centered practice, or a lack thereof (Grindle et al., 2009; King, King, Rosenbaum, & Goffin, 1999; King, Rosenbaum, & King, 1997; King, Teplicky, King, & Rosenbaum, 2004; Rodger et al., 2008). Several researchers have found that family-centered services lead to increased parent satisfaction and conversely, parents that don't view services as family-centered report being less satisfied (King et. al, 2004; Rodger et al., 2008; Van Riper, 1999).

King et al. (1999) examined parent perceptions of family-centeredness and emotional wellbeing. Parents of 164 children with neurodevelopmental disorders took part in the study. It was found that the parent-reported level of family-centeredness was positively correlated with parent wellbeing. Family-centeredness was also positively correlated with parent satisfaction and negatively correlated with parent stress.

Rodger et al. (2008) interviewed two parents who were least satisfied with early intervention programs to determine what factors influenced their dissatisfaction. Both families reported that they had difficulty collaborating with the service providers and felt the organization was not family-oriented. This influenced their overall stress and lower levels of perceived competence, contributing to their low satisfaction with the program.

Family involvement and family-centeredness in early intervention programs has many benefits to both the child and family. Involving parents in decision-making related to their child's program is an effective way to induce change (Demspey & Dunst, 2004; Grindle et al., 2009). The parent, child, and family function as a complex system and the child's family and context influences his or her development (Bruder, 2000; Dunst & Trivette, 2009; Guralnick, 1999). Child and parent characteristics impact patterns of interaction, which in turn impact child outcomes (Guralnick, 2005).

Involving Families: Important Considerations

There is a great deal of research concerning strategies and considerations when attempting to involve parents in their child's program (Dempsey & Dunst, 2004; McConachie & Diggle, 2006; Paige-Smith & Rix, 2006; Ylven, Bjorck-Akesson, & Granlund, 2006). From a general standpoint, service providers must be flexible when trying to involve parents (Carlhead, Bjorck-Akesson, & Granlund, 2003; Ylven et al., 2006). Using flexible and individualized parent involvement plans is a recommended best practice from the Division of Early Childhood (Trivette & Dunst, 2005).

There are varying degrees of involvement from different families, which depends on the individual family circumstance. Service providers must be aware and respectful of the amount of time that parents have available to take part in their child's program, given their other roles and responsibilities (Gallagher, Rhodes, & Darling, 2004). Parents can take part in many different roles, for example, as educators, planners, or policy makers but it is critical to let parents determine how much or little they will be involved (Gallagher, Rhodes, & Darling, 2004; Winton & DiVenere, 1995). Parent involvement must be individualized on a case-by-case basis (Bailey, 2001).

A related consideration that service providers must take into account is the family's routines, goals, and values (Guralnick, 2005). Interventions must be tailored to the individual child and family needs (Mitchell & Hauser-Cram, 2009; Ylven et al., 2006). Parents must be encouraged to formulate questions and decide what issues or goals are most important to them (Dinnebeil & Hale, 2003). A partnership should exist between parents and service providers whereby parents are actively involved in goal formulation, change implementation, and the progress evaluation (Carlhead et al., 2003; Dinnebeil & Hale, 2003; Trivette & Dunst, 2005). Professionals must understand what parents want and be able and willing to clarify the feasibility of their goals (Dinnebeil & Hale, 2003; Mitchell & Hauser-Cram, 2009).

When involving parents in early intervention, support should be provided in a way that is not deficit or disability-focused (Paige-Smith & Rix, 2006). Services should be asset-based, or identify and build on family strengths (Trivette & Dunst, 2005; Ylven et al., 2006). A strength-focused plan allows family members to be better able to improve the current situation (Dempsey & Dunst, 2004).

Additionally, when involving parents in programs, it is crucial to strive to enhance their level of competence by providing needed information, skills, and resources (Carlhead et al., 2003; Dempsey & Dunst, 2004; Ingber & Dromi, 2009; Ylven et al., 2006). In order to foster competence (and subsequent parental involvement), parents must be given information in a supportive manner, allowing them to feel competent and confident in the partnership (Bruder, 2000; Ingber & Dromi, 2009; Law et al., 2003). After the initial diagnosis, parents need ample opportunities to ask questions and get information about their child's disability, programs, and goals (Carlhead et al., 2003).

Although parents have a great deal of expertise about their child, they sometimes need help meeting all of their needs (Dinnebeil & Hale, 2003). For example, parents may be unaware of the services available to them. They may benefit from information about the disorder or disability, and may require instruction regarding the skills that are central to working with their child (Gamel-McCormick, 1995; Shannon, 2004; Turnbull et al., 2007). Training, resources, and ongoing support for parents are central to involving parents most effectively in their child's program (Dempsey & Dunst, 2004; Grindle et al., 2009; McConachie & Diggle, 2006).

Barriers to Family Involvement

As family involvement is agreed upon as best practice for early intervention, the barriers to effective involvement must be identified and overcome. Although family-centered practices are most effective, it has been difficult for practitioners to shift from a child to a family-centered model of service delivery as the focus has historically been placed on child-specific goals and improvement (Bruder, 2000; Dunst & Trivette, 2009; Guralnick, 2000).

Service providers have found it difficult to incorporate family change into their programs as this involves the complete restructuring of the service delivery system. Despite the vast amount of research in the field, it has been difficult to close the gap between research and practice in the field and consistently incorporate family involvement into early intervention programs (Dunst & Trivette, 2009; Odom, 2009).

As family-centered practices are relatively new, there have also been challenges translating research into practice (Bruder, 2000; Odom, 2009). The limited research on implementation may be insufficient and service providers may be confused about the successful use of family-centered services (Bruder, 2000). There are not enough effective models to train professionals in family-centered practice and professional standards are not always detailed or clear enough in terms of service provider expectations. Although professionals are mandated to be knowledgeable in family-centered practice, they do not always know how to implement family-centered services (Bruder, 2000; Ingber & Dromi, 2009; Odom, 2009).

Another barrier to involving parents in early intervention programs is that professionals sometimes view families as clients and themselves as experts (Paige-Smith & Rix, 2006). Some professionals have voiced concern that parents do not have enough background knowledge, training, time, education, or resources to contribute to the intervention in the same way that service providers are able to do so (Ingber & Dromi, 2009; Minke & Scott, 1995; Shannon, 2004).

Several researchers have focused on the barriers to effective family-centered practice, as viewed from the parent’s perspective. Carlhead et al. (2003) interviewed parents with children in early intervention programs. They found that parents did not feel confident when working with professionals and were concerned about insufficient information and support. Parents expressed concerns that service providers were sometimes unable to empathize and that their problems were sometimes ignored. Waitlists and employee turnover were also reported as barriers to family involvement (Carlhead et al., 2003).

Similarly, in 2004, Shannon interviewed parents of children in early intervention programs. Parents felt that they were not being told about all of the available services and that the system was insufficient and confusing. Parents also felt that they had to fight with service providers over the intensity and type of services needed for their child.

Paige-Smith and Rix (2006) interviewed parents of children with disabilities in early intervention programs. Again, parents reported that they did not feel heard or that they could make a large impact on the situation as their experience was limited. Parents felt great pressure to support their child however possible. Aware of the importance of intervening early, parents felt they had to pressure professionals to get programs running quickly. As such, relationships with professionals were sometimes strained, making family-centered practice more difficult.

More recently, Ingber and Dromi (2009) researched parent perceptions of family-centered practice with 120 mothers in Israel. Parents reported that, although involvement was encouraged, they felt as though service providers could have better individualized services to meet specific family needs. Although most mothers reported that the overall program philosophies were family-centered, staff did not always actively encourage family involvement. Service providers also recognized the need to continue working towards a more genuine partnership with all parents but that there had been difficulty translating research into practice (Ingber & Dromi, 2009).

In conclusion, there are many barriers to effective family-centered practice from both the service provider and parent perspectives. These barriers must be addressed to optimize program effectiveness. Evidence-based practices are necessary to continue to find the most effective strategies to involve the family in service delivery and to be sensitive to diversity. In Canada, a shift towards family-centered practices is in motion. Although there is still work to be done, an increased emphasis on the empowerment of families in early intervention programs has been increasing since the 1990's (Dworet & Bennett, 2002; Jordan, 2001; Ontario Association of Infant Development, 1994). Family-centered practices are the norm in early intervention services in Canada although they have not been legally mandated (Ontario Association of Infant Development, 1994).

Parental Coping. As concluded from the previous review of the literature, family involvement is central to effective services; however, it does not always come without a cost to parents. Parents are often faced with the pressures of providing their child with intensive therapy and are sometimes faced with tense service provider relationships. The expectations placed on parents of children with developmental delays can result in high stress levels. As such, parental coping is another important research topic in the field.

Many parents adjust to having a child with a disability by adopting effective coping strategies (Hastings et al., 2005; Micthell & Hauser-Cram, 2009). Parent coping strategies are crucial for the wellbeing of children as well as for parents. Lower levels of coping are associated with higher levels of family system strain (Churchill, Villareale, Monaghan et al., 2010; Sivberg, 2002). Coping strategies function similarly for mothers and fathers and are dependent on contextual factors, such as availability of external social support (Carver, Scheier, & Weintraub, 1989; Hastings et al., 2005).

Examples of coping strategies used by parents include denial, problem-focused coping, emotion-focused coping, active avoidance of the negative situation, and positive coping (Gray, 2006; Hastings et al., 2005; Sivberg, 2002). Problem-focused coping is aimed at improving the situation whereas emotion-focused coping focuses on eliminating unpleasant feelings, for example, through the use of relaxation techniques (Gray, 2006). In 2006, Gray concluded that parent coping strategies change over time, with less reliance on service providers and family support and more reliance on religion and emotion-focused coping. Similarly, Lazarus (1996) found that younger parents prefer problem-focused coping and older parents prefer emotion-focused coping.

Several researchers interested in coping strategies used by parents of children with disabilities have focused on the relationship between coping strategies and parent stress (Churchill et al., 2010; Hastings et al., 2005; Hastings & Johnson, 2001; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001). The predominant finding, which is consistent across research studies, is that parental stress levels are lower when positive coping strategies are implemented than when avoidant coping is used (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Hastings & Johnson, 2001; Hastings et al., 2005).

This finding is of critical importance as other researchers have found that parents of children with developmental delays often employ avoidant coping styles in place of problem-focused or social coping (Sivberg, 2002). Avoidant coping strategies involve distracting oneself from the difficult situation whereas problem-focused coping strategies involve working towards finding an appropriate solution and social coping strategies involve ascertaining social support from others. This tendency towards using avoidant coping strategies could impact, at least in part, the higher incidence of parent stress in families with children with autism and other delays (Bromley, Hare, Davison, & Emerson, 2004; Duarte, Bordin, Yazigi, & Mooney, 2005; Hastings et al., 2005; Montes & Halterman, 2007; Sivberg, 2002). Consequently, parent education programs that focus on positive coping strategies could be beneficial for parents of children with developmental delays.

Despite the high levels of stress and coping difficulties often associated with raising a child with a developmental delay, parents can often show resilience in face of adversity. In 2007, Montes and Halterman investigated psychological functioning and coping in parents of 364 children with autism. Having a child with autism was not associated with lower levels of social support and mothers of children with autism displayed as close a relationship with their children as parents with developmentally typical children. The data from the 364 children with autism was compared to the remaining data from the 61,772 children from 4-17 years of age surveyed for National Survey of Children's Health in 2003. Montes and Halterman (2007) also found that parental coping and support were not significantly different when comparing parents of children with autism and developmentally typical children. Many parents, however, reported that they felt the strain of emotional and mental health issues and had to give up a great deal for their children (Montes & Halterman, 2007).

In conclusion, the nature of parent coping changes over time and service providers must be made aware of parent coping strategies (Hastings et al, 2005). Interventions should focus on decreasing maladaptive coping and building on positive coping strategies in order for the family system to function optimally (Hastings et al., 2005; Sivberg, 2002; Mitchell & Hauser-Cram, 2009).

Parent Perceptions of Early Intervention. A simple, time-effective, and family-focused method of evaluating an Early Intervention program and the outcomes or progress is to survey parents regarding their concerns and perceptions of the program (Glascoe, 1999; Grindle et al., 2009; Turnbull et al., 2007). Parent coping strategies, and perceptions of family-centered care, can also be surveyed to provide information on how to best support the family unit. Surveying parents can be an effective method and alternative to standardized screening measures when building initial programs for the child (Glascoe, 1999). Instead of completing a wide array of screening protocols covering many possible problem areas, professionals can interview parents regarding the specific areas of difficulty. This can result in much more detailed, child-specific information. There are also standardized surveys, which can be used to involve parents in program planning by prioritizing their concerns and implementing strategies to address these needs (Glascoe, 1999).

Parent perceptions can also be used to determine how well a program is working and what modifications should be made (Paige-Smith & Rix, 2006; Rodger et al., 2008; Turnbull et al., 2007). Parents can provide information about contextual influences and how well the program is generalized at home as children spend most of their time with their parents (Bruder, 2000; Odom & Wolery, 2003). The programs must target the problem as perceived by the parents or they will not be as satisfied with the outcome. The involvement of parents in the planning process is one way to ensure parent satisfaction (Carlhead et al., 2003; Grindle et al., 2008; Ingber & Dromi, 2009; Rodger et al., 2008).

Although it is virtually unanimous that parents should be an integral part of early intervention programs, the number of parent perception studies is limited (Bruder, 2000; Gallagher et al., 2004; Glascoe, 1999; Guralnick, 2005; Hume, Bellini, & Pratt, 2005; Page-Smith & Rix, 2006). Eight research studies were found through the present review of the literature and are described below.

In 2007, Turnbull and colleagues in the United States, analyzed data from the reports of 2,600 primary caregivers of children in early intervention programs. Data were obtained from two sources, the National Early Intervention Longitudinal Study (NEILS) and a subsequent survey of family perspectives on program adequacy from one state. Ninety-one percent of parents said that service quality was excellent, 75% were satisfied with service quantity and said that services had a great impact on their child. However, only 56% of parents said the amount of family help and information was sufficient and only 64% felt competent to help their child learn and develop (Turnball et al., 2007).

Boyd and Corley (2001) interviewed parents with children enrolled in a community-based Early Intensive Behavioral Intervention (EIBI) program in California. The survey was conducted through a non-profit agency that coordinates assessment and service delivery for individuals with developmental disabilities. The agency services over 6,000 clients, 316 of which are children with autism. Parents of 16 children with autism spectrum disorders took part in this study. A parent questionnaire assessed program satisfaction and perceptions. Forty-four percent of parents were very satisfied with program implementation and 25% were very satisfied with child outcomes. Sixty-three percent of parents said that the amount of intervention was sufficient for their child and

94% reported they would recommend their services to others. Parents concluded that the greatest child gains were made in language, compliance, and pre-academic skills.

The results of this study (Boyd & Corley, 2001) must be interpreted within the limitations of the research methodology. The sample size was small (n=16) and there was not a control group. Also, there was no mental age criterion and children that took part in the study had been receiving treatment for different lengths of time. Duration of treatment could have a large impact on parent satisfaction as children who have been receiving services for longer periods of time may be more likely to make greater gains, resulting in increased levels of parent-reported satisfaction.

Carlhead et al. (2003) conducted research with regards to family perspectives of parents with children between 0 and 7 in early intervention programs in Sweden. Parents participated in semi-structured interviews in the home to determine how they perceived professional support. All parents reported dissatisfaction with staff turnover and wait times for community supports and services. They felt that informal support from other parents, flexibility on the part of service providers, and receiving sufficient information were critical factors. Concerns around limited services, hospital-like settings, insufficient service provider empathy, and insufficient opportunities to ask questions were also raised (Carlhead, 2003). Limitations of the current study include small sample size (n=8) and the subjectivity of the methodological approach as in-depth parent interviews were interpreted qualitatively and psychometric measures were not used.

Shannon (2004) interviewed 22 parents of children in early intervention programs to elicit their major concerns. Families were recruited from 22 different centers, home, and hospital based early intervention programs in Virginia. Parents voiced concerns that the system was confusing and difficult to navigate, and that the services that were offered were offered because they were billable, not necessarily because they best met the child's needs. Parents were also concerned about the limited information they received and lack of service coordination. Middle-class families also faced the difficulty of making too much money to qualify for financial support but not enough to pay for therapy on their own. Limitations include small sample size and limited geographic location, narrowing the generalizability of findings.

Paige-Smith and Rix (2006) also surveyed four parents of children in early intervention programs in England. Overall, parents embraced family-centered practices however; they voiced concern about the stress that was sometimes placed on them. Parents felt a great deal of stress when preparing for professional visits because of the amount of effort involved and limited knowledge in the field. They also expressed concerns about feeling that they were not being listened to and could not make a large impact on their child's outcome. Parents agreed that collaboration was necessary but it was sometimes difficult. They preferred written to verbal information because it helped them better understand their roles and their child's needs (Paige-Smith & Rix, 2006).

Trudgeon and Carr (2007) also interviewed families receiving EIBI services in the United Kingdom. In this study, sixteen families receiving supervised home-based services were interviewed. The researchers examined the effect of programs on family life, program set-up, perceived benefits and disadvantages, facilitators and hindrances. Parents reported several stressors as well as benefits. Stressors included loss of privacy and less time to spend with their children. Benefits included feelings of empowerment and increased access to resources and supports. Parents concluded that the supports outweighed the costs and stresses of the programs (Trudgeon & Carr, 2007). This study is limited by small sample size and the subjectivity of the methodological approach.

More recently, Grindle et al. (2009) conducted semi-structured interviews with 53 parents with children in Intensive Behavioural Intervention (IBI) programs for two years or longer. They focused on parent perceptions of the benefits, pitfalls, supports, and impact of programming on their lives. Parents reported numerous benefits, including improved communication, play, and social skills for the child, increased parent support, and sibling involvement and relationship building. When asked about any difficulties, parents reported almost all parents reported difficulty with therapists (e.g., high staff turnover, lack of reliability, intrusiveness). Seventy-five percent of parents reported difficulties with local education authority and acquiring appropriate funding. Thirty percent of parents also reported concerns that their children were missing out on crucial socialization skills at school. In terms of parent stress, it reportedly fluctuated over time, with overall stress reduction. Almost all parents reported strengthened relationships in the family and 75% of families reported being sure that IBI was the right choice for them. Although the sample size was larger in this study, limitations exist in that researchers used subjective interviewing, which provided detailed, qualitative information but did not include quantitative, psychometric questionnaires, which would have added value to the study (e.g., standardized measures of parent stress and coping).

A major concern regarding parent satisfaction studies to date is that they tend to gauge overall satisfaction instead of looking at particular domains. In 2005, Hume and colleagues assessed overall satisfaction as well as satisfaction with specific services and domains. Participants were recruited throughout the state of Indiana, distributed across urban, suburban, and rural counties. Most children took part in public programs, with speech and occupational therapy being the most frequently used services. Twenty-four percent of children had more than 40 hours of weekly therapy and 44% had less than ten hours. Fifty-nine percent of parents felt that family participation was encouraged. Most parents thought that intervention was effective and they were most satisfied with parent training and speech therapy. The most progress was made in speech, cognitive, adaptive skills, and emotional domains, respectively. Unfortunately, over 25% of respondents were not provided with case management and 66% of families received less than the recommended 25 hours of service per week (Hume et. al, 2005). The larger sample size and distribution of families across rural, urban, and suburban counties was a major strength of this study. However, limitations exist in that subjective parent reporting was used in place of psychometric questionnaires (e.g., Measure of Processes of Care to measure parent perceptions of family-centered care).

Allgood (2005) examined the effects of family-based music therapy programs with four families of children with autism spectrum disorders. Families took part in a seven-week family music therapy program in Illinois. Pre and post-therapy interviews were conducted and focus groups took place. Parents who took part felt that the group became more cohesive over time, the program provided a safe environment to connect with other families, and they were provided with an opportunity to learn about their child's strengths and limitations. The concerns voiced by parents were that there was insufficient modeling and information on the parent's specific roles. The study is limited by a small sample size and lack of quantitative measures of parent satisfaction.

In summary, parents perceive early intervention services as being positive and empowering as well as stressful and demanding. The benefits often outweigh the perceived costs. Research has been conducted on a variety of home and community-based programs however, after an extensive review of the literature no research was found comparing parent perspectives on a national or even provincial or statewide level.

In an effort to obtain an understanding of early intervention policy across Canada, prior to comparing parental perceptions at a national level, a review of the existing literature was conducted. The following section provides information on early intervention policy in Canada.

Canadian Early Intervention Policy. In Canada, information and data for early intervention services is insufficient, definitions of important terms vary, and communication between service providers is insufficient and does not occur frequently enough (Lyon, 2002). A government-wide accountability mechanism in Canada is essential to address some of these issues (Prince, 2004). Current policy is limited by quantity of information, federal and provincial jurisdiction issues, financial constraints, a lack of accountability mechanisms, and fragmented services (Prince, 2004; den Heyer & Kienapple, 2005).

In 2005, den Heyer and Kienapple compiled a report on early intervention policies and services in Canada. Although there is no federal legislation for early intervention in Canada, the *Canadian Charter of Human Rights and Freedoms* provides a set of rules or regulations that must be abided by in each province or territory. For example, *Article 15* prevents discrimination based on physical or mental disability (den

Heyer & Kienapple, 2005). However, there is great variation across Canadian provinces and territories in terms of their support for early intervention services.

In Newfoundland and Labrador, for example, a zero-waitlist policy exists (Ouellette-Kuntz et al., 2009). In Manitoba and Prince Edward Island, intensive behavioural intervention programs are available for any child with autism who meets age criteria whereas only children at the severe end of the spectrum are eligible for services in Ontario (Ouellette-Kuntz et al., 2009). In Ontario, programs exist for children over the age of six, whereas in many other provinces, services discontinue after this age (Ministry of Children and Family Development, 2006). In Quebec, Intensive Behavioural Intervention programs are not paid for by the government after the age of six but children are sometimes entitled to home or school based services, although waitlists are long and services are often fragmented (Ministry of Children and Family Development, 2006). As can be seen from these few examples, there is a great deal of variation across the country in terms of what is available to whom and for how long.

Service providers of Canadian early intervention programs are often non-profit, independent organizations that develop programs based on community needs (Lyon, 2002). This allows resources to be adapted and individual needs to be met, however, the lack of a national, coordinated, high-quality Canadian early intervention system can also be disadvantageous (den Heyer & Kienapple, 2005; Lyons, 2002). As previously mentioned, without a national paradigm, services are often fragmented and inequalities exist across the country. In conclusion, a coherent national policy and set of guidelines to help parents, authorities, and health care professionals evaluate programs and outline best practices does not currently exist in Canada and could be beneficial to ensure equal and appropriate services and supports.

Canadian Special Education. Canadian special education policy is also under provincial jurisdiction, without federal legislation mandating educational policies. (Dworet & Bennett, 2002; Frankel, 2004; Friendly, Beach, & Turiano, 2002). The Ministry of Education in each province or territory has an *Education Act* that school boards must follow (Dworet & Bennett, 2002). These acts support parent involvement, inclusion as a first option, and individualized programs. However, program specifics vary across Canada (Zinga et al., 2005).

Provinces and territories differ in terms of their definitions of exceptionality and eligibility criteria (Dworet & Bennett, 2002). For example, diagnoses or codes are required to receive funding in Ontario and funding is based on *Individual Education Plan* reviews. In British Columbia and Quebec, funding is based on both the degree and category of disability. In the Northwest Territories, however, children do not require a code, as support is not dependent upon diagnoses (Dworet & Bennett, 2002).

Fiscal responsibility within a province or territory is spread between various departments and ministries (Lyon, 2002). Some provinces have vague education policies while others are more clear but difficult to implement (Zinga et.al, 2005). All provinces and territories struggle with special education services, however, system-wide improvements are being made across Canada (Zinga et.al, 2005). For the past twenty years, each province and territory has been fostering integration and improving services (Dworet & Bennett, 2002; Lupart, 1998). Most prioritize inclusive classrooms with the possibility of special external programs as alternatives (Dworet & Bennett, 2002).

Programs are individualized based on the child’s strengths, needs, and resources through collaboration with parents, teachers, and other involved staff (Dworet & Bennett, 2002).

A Province-by-Province Analysis. Provincial and territorial ministry websites provide a wealth of information on service delivery frameworks for children with developmental delays in Canada. The quality and quantity of Early Intervention supports vary as a function of where one resides in Canada. The following tables were developed to provide information on how services and supports vary from province to province or territory to territory. This information provides information with respect to which provinces or territories are providing the most efficient and complete services and how the most effective supports from the various regions can be combined to develop a national system of early intervention for children and families with developmental delays in Canada.

Table 1

Ministries and Departments Providing Early Intervention Services

Province	Ministries or Departments
British Columbia	Ministry of Health Ministry of Children and Family Ministry of Education
Alberta	Alberta Children and Youth Services Ministry of Education
Saskatchewan	Ministry of Social Services Ministry of Education
Manitoba	Department of Family Services and Housing Department of Education and Training
Ontario	Ministry of Children and Youth Services Ministry of Community and Social Services Ministry of Education and Training
Quebec	Ministère de la Santé et des Services Sociaux Ministère de l'Éducation, du Loisir et du Sport
Nova Scotia	Department of Community Services Department of Health Department of Education
New Brunswick	Department of Social Development Department of Health
Newfoundland & Labrador	Department of Health and Community Services Department of Education
Prince Edward Island	Department of Health Department of Education and Early Child Development Department of Social Services and Seniors
Yukon Territory	Department of Health and Social Services Department of Education
Northwest Territories	Department of Health and Social Services Department of Education, Culture and Employment
Nunavut	Department of Health and Social Services

Table 2

Early Intervention Service Coordination

Province	Service Coordination
British Columbia	Community Living British Columbia
Alberta	Cross-ministry collaboration Collaboration with regional authorities
Saskatchewan	Provincial network of Early Childhood Intervention Programs (ECIPs)
Manitoba	Integrated Service Delivery Initiative (Manitoba Family Services and Housing)
Ontario	Interministerial joint coordination and planning
Quebec	Ministère de la Santé et des Services Sociaux coordinates and integrates Quebec services
Nova Scotia	Interministerial Collaboration through the use of Early Childhood Development Regional Collaboration (ECDRC) Teams
New Brunswick	Interministerial Collaboration through the Early Childhood Initiative (Dept. of Family and Community Services and Dept. of Health)
Newfoundland & Labrador	Model for the Coordination of Services to Children and Youth (adopted by the Department of Health, Community Services, and Education)
Prince Edward Island	Department of Education formed an interdepartmental health and social services committee on children.
Yukon Territory	Case Management through Health and Social Services
Northwest Territories	Case Management through Health and Social Services
Nunavut	All services in Department of Health and Social Services

Table 3

Key Early Intervention Initiatives and Acts in Canada

Province	Key Initiative or Act
British Columbia	Early Childhood Development Action Plan
Alberta	Family Support for Children with Disabilities Act Alberta Children and Youth Initiative Universal Screening for Newborns
Saskatchewan	Comprehensive Prevention and Early Intervention Initiative
Manitoba	Healthy Child Manitoba Early Child Development Initiative
Ontario	Accessibility for Ontarians with Disabilities Act Universal Screening for Newborns
Quebec	Youth Action Plan
Nova Scotia	Early Language and Learning Initiative
New Brunswick	Early Childhood Development Agenda
Newfoundland & Labrador	Early Childhood Development Initiative
Prince Edward Island	Healthy Child Development Strategy
Yukon Territory	Information not found
Northwest Territories	Healthy Children Initiative Early Childhood Development Action Plan
Nunavut	Healthy Children Initiative

Table 4

Key Early Intervention Programs in Canada

Province	Key Early Intervention Programs
British Columbia	Infant Development Program (0-3 years) Early Intervention Therapy Services (0-school entry) Supported Child Development Outreach and Professional Supports Support Services for Children with Special Needs Early Intensive Behavioral Intervention (ABA) School Age Therapies Nursing Support Services
Alberta	Early Intervention Funding (to community groups) Early Identification Services Preschool Services Health and Developmental Services Interdisciplinary Intervention Program Family and Community Support Services Supportive Education
Saskatchewan	Kids First Program Early Childhood Intervention Services (0-5 years) Community School Pre-kindergarten Program ECE for Children with Disabilities Program
Manitoba	Children's Special Services (0-5 years or school entrance) Provincial Outreach Therapy for Children (0-5 years or school entrance)
Ontario	Infant Development Program (0-4 years) Infant Hearing Screening Program Best Start Program Ontario Early Years Program Behavior Management Program Respite Supports IBI Autism Program Child Care and Recreation Programs Residential Programs Children's Treatment Centres
Quebec	Programme de Stimulation Precoce Centres de Sante et des Services Sociaux (CLSCs) Centres de Réadaptation en Déficience Intellectuelle (CRDIs)

Nova Scotia	Early Intervention Program Family Supports Program Early Intensive Behavioral Intervention (EIBI) program
New Brunswick	Early Childhood Initiatives Home-based Early Intervention Early Childhood Social Work Services Services for Preschool Children with ASD Community-based Services for Children with Special Needs
Newfoundland & Labrador	Healthy Beginnings (0 - school age) Specialized Services Intervention Services Social Work Services
Prince Edward Island	Public Health Nursing (0-4 years) Respite Care Intensive Intervention Program Home-based Behavioral Supports Specialized Services Best Start Program
Yukon Territory	Child Development Centre Healthy Families Program Respite Programs Intensive Behavioral Therapy Supported Child Care Program
Northwest Territories	Community Action Program for Children
Nunavut	Special Residential Care Community Action Program for Children

Table 5

Program Funding Options and Extra Income Support

Province	Funding Options and Extra Income Support
British Columbia	Autism Funding (up to $20,000 for 0-6; up to $6,000 after) At-Home Program (financial support to families for medical and respite needs)
Alberta	Persons with Developmental Disabilities Boards (funding to choose own therapy and staff) No extra income support available to families
Saskatchewan	ECE for Children with Disabilities Program (funds service providers) Outreach Program (financial support to families)
Manitoba	Children's Special Services (funding for service providers) Children's Special Services (financial support to families for respite, equipment, transportation, and supplies)
Ontario	Special Services at Home (fund services and supports unavailable elsewhere) Assistance for Children with Severe Disabilities (extra income support for families)
Quebec	Allowance for Handicapped Children (income support)
Nova Scotia	Supported Child Care Program (funds service providers) No extra income support available to families
New Brunswick	No extra income support available to families
Newfoundland & Labrador	Special Child Welfare Allowance (financial support to families of children with special needs)
Prince Edward Island	Child Disability Supports Program & Special Needs Grant (funds service providers); No family income support
Yukon Territory	Community Action Program for Children (funds coalitions)
Northwest Territories	Information not available
Nunavut	Healthy Children Initiative

Summary of public programs. In Canada, different ministries or departments within the province or territory often share responsibility for Early Intervention services. This can result in unnecessary overlap, fragmented services, and 'passing the buck' or avoiding responsibility by counting on other government bodies to meet the needs of the family (Dunst & Bruder, 2002; Guralnick, 1998; Kyle, 2000; Park & Turnbull, 2003). Service coordination is crucial in successful programming. Each province and territory is responsible for developing a strategy to allow for collaboration between the relevant departments or ministries. However, several regions do not have a coordinating body for children's policy or disability policy in general. As such, the level of service coordination varies from province to province, resulting in discrepant services.

The number and nature of the initiatives and policies for children with special needs also varies by region. For example, Alberta is the only province with a legislative act for children with special needs. Funding for children with special needs is a discretionary, provincial expenditure, resulting in further inequality across Canada. Similarly, the breadth of programs and age groups supported depends on where one lives. Program funding options and extra income supports are also provincial or territorial expenditures. Some provinces, such as British Columbia, provide funding for children over six years of age while many other provinces fund only through preschool.

In summary, government-run Canadian early intervention programs are more dissimilar than alike across Canada. Differences can be found in the comprehensiveness and availability of programs (and consequent wait times), service co-ordination, investment in early intervention, and funding availability and options. As federal legislation does not mandate service provision, these inequalities and discrepancies in services will persist. A national consensus clearly does not exist in terms of government services and supports for Canadian children with developmental delays. As such, a national paradigm shift, whereby appropriate and equal services are available across Canada can be seen as a definitive goal for early intervention policy.

Private programs and individual comparisons. Although information on early intervention services across Canada can be obtained through ministerial or departmental websites, this only provides information on public programs. Information on private early intervention programs is not easily accessible. In addition, information obtained through governmental websites is broad and does not inform of individual program variables and outcomes. After an extensive review of the available literature, very few publications comparing Canadian early intervention services were found. Provincial or territorial reports on public programs typically describe the types of services, rather than comparing the effectiveness of various programs. The majority of efficacy studies are implemented to look at one program or service delivery model rather than making regional comparisons. A comparison of services across Canada has not been published in the empirical literature.

As such, the current study was designed to undertake this research endeavor. A survey of early intervention services across Canada has been conducted to investigate programs in public, private, and not-for-profit organizations. An investigation of the best practices, critical success factors, and gaps in current service delivery systems will provide a more complete picture of early intervention programming in Canada that can be shared with directors, parents, policy makers, and other key stakeholders.

Present Study

As very few publications have addressed early intervention services in Canada and comparative research investigating provincial differences does not exist, this project has been designed, in part, to address these limitations. By researching services across Canada, best practices and gaps in service delivery will be identified. This information will help researchers determine what strategies are working, what strategies are not, and will highlight effective program variables for service providers looking to revise and improve their program.

As cross-province comparative studies are not available and information on private early intervention programs is scarce and difficult to find, the present study has been designed to investigate early intervention services in public, private, and non-profit organizations. This will provide a snapshot of early intervention programming in Canada to date. The results from this research study can also hopefully be used to aid program directors looking to improve and incorporate new elements into their programs. The results can also be use to provide information to parents who are looking into various supports and services for their child in Canada.

As research into parent perceptions of early intervention programs is also limited at present, it is consequently another focal point of this study (Paige-Smith & Rix, 2006; Turnbull et al., 2007). As family involvement in early intervention programs and satisfaction is a critical factor to successful outcomes, research into parent perceptions is crucial. Until recently, most researchers have focused their attention solely on child factors and very little research has been conducted on parent satisfaction with early intervention programs (Blackman, 2002; Guralnick, 2005; McCollum, 2002; Webster, Feiler, & Webster, 2003). Parents are central to program success and the factors that they deem important should be incorporated into services. Parental coping is largely influenced by the relationship with the service providers and the involvement and empowerment regarding their child's program (Dempsey & Dunst, 2004; Dunst & Bruder, 2002). Consequently, research must be conducted to determine the key concerns and goals of parents with children in Canadian early intervention programs and to determine how family-centered Canadian parents perceive programs to be at present.

This study was designed to address the limitations with early intervention service provider, parent perception, and parental coping research at present. The four overarching goals are to make cross-province and territory comparisons, investigate parent perceptions of early intervention programs and parental coping, compare service provider and parent perceptions of program success, and examine relationships between early intervention program components (e.g., wait time, intensity, family centered care) and parental coping variables.

Goal one: Cross-province comparisons

The first goal of the present study was to determine if and how provinces and territories differ across Canada in terms of early intervention services for children with developmental delays. Responses from service providers in each province and territory across Canada were compared with one another to determine whether or not significant differences exist across Canada in terms of the number of early intervention professionals and services, waitlists, and perceptions of satisfaction. Provincial results were analyzed on an individual basis and territorial results were grouped together due to sample size limitations.

These analyses are exploratory as this is the first investigation of individual provincial and territorial comparisons and research is not readily available to direct hypotheses. Each province and territory served as the independent variable. They were compared with one another in terms of the seven dependent variables outlined below.

a) average number of services offered through the early intervention program

b) average number of professionals working for the early intervention program

c) wait time for assessment and/or service delivery

d) percentage of private and non-profit funding sources

e) service provider satisfaction with child outcomes

f) service provider perception of program adequacy and ability to respond to client needs

g) service provider perception of the provincial and /territorial government's ability to meet the needs of children and families with developmental delays

Goal two: Parental perceptions

Secondly, the study was designed to assess parent perceptions and experiences with early intervention programs as well as parental coping and satisfaction with service providers. Again, comparisons were made across provinces and territories to determine how similar or different experiences with early intervention were across Canada. An analysis of differences across Canada with regards to the following parent-reported dependent variables was conducted:

a) average age of diagnosis

b) average age of service delivery onset

c) average number of service hours per week

d) general parental satisfaction with the early intervention program

e) parental perceptions of the government's ability to meet family needs

f) amount of informal social support sought out by the family

g) amount of community support sought out by the family

h) parental perceptions of their involvement in the decision making for their child's program

i) parental perceptions of how respected they feel by support staff

j) parental perceptions of how well their informational needs are being met

Goal three: Parent versus service provider perceptions

This research study is the first of its kind to compare parent and service provider perceptions of early intervention across Canada. In order to address the third goal, service provider data was collapsed across provinces and territories and compared to parental perception data, also collapsed across province and territory. As ratings of satisfaction are subjective and may be euphemized when provided by service providers, these perceptions were compared to perceptions of parents with children attending early intervention programs to determine how comparable or discrepant the ratings were. Both service providers and parents were asked to rate, on a ten-point scale, their satisfaction with child outcomes, perceptions of program adequacy, and perceptions of the government's ability to meet the needs of families in Early Intervention programs in their respective province or territory. The following research questions were investigated based on this data:

1) Do significant differences exist between service provider and parent ratings of satisfaction with child outcomes?

2) Do significant differences exist between service provider and parent ratings of program adequacy?

3) Do significant differences exist between service provider and parent ratings of the government's ability to meet the needs of families in Early Intervention programs in their respective province or territory?

Goal four: Early intervention program and parent perceptions

In order to examine the relationship between early intervention program variables and parent perceptions, data from the service provider and parent questionnaires, Measures of Processes of Care – 20 (MPOC-20), and Family Crisis Oriented Personal Evaluation Scales (FCOPES) were collapsed across provinces and territories. Several questions were posed based on the data collected from the parent questionnaire, MPOC, and FCOPES. The research conducted several analyses on the relationships between the variables presented below:

a) *age at service onset and parent satisfaction with child progress*
b) *number of services and parent and service provider satisfaction with child progress*
c) *weekly hours of service and parent satisfaction with child progress*

d) *parent perceptions of their involvement in the decision-making process and program satisfaction*

e) *parent perceptions of how well their informational needs are being met and program satisfaction*

f) *parental coping strategies and parental program satisfaction*

Chapter Three: Method

Participants

Early intervention service providers. In 2006, an early intervention service provider questionnaire was sent electronically or by mail to the program directors of 588 private, public, and non-profit early intervention programs across Canada. Only multidisciplinary programs that provided direct services for children with developmental delays were included in this study. Although 932 prospective programs were initially identified, after careful inspection, only 588 were deemed appropriate. One hundred and forty-eight programs were excluded because they did not provide direct services, 34 programs were no longer in operation, and 162 did not meet our criteria based on the demographics of the children served or the nature of their services.

The present study is a continuation of a Master's project completed in 2007. For the first project, 184 valid responses were collected from Canadian service providers. An additional 243 surveys were subsequently collected. In total, 427 Canadian service providers, out of a total of 588 potential respondents, took part in our study. Table 6 provides a breakdown of the number of programs targeted in each region, the number who took part, and the respective response rates. Our target response rate of 65%, which has been deemed acceptable and typical for self-completed surveys (Kelly, Clark, Brown, & Sitzia, 2003; Sitzia & Wood, 1998) was achieved as 427 of 588 prospective service providers took part in our study, a response rate of 73%.

Response rates were also calculated for each individual province and territory. The goal of attaining at least a 65% response rate in each region was achieved in 10 of 13 provinces/territories. The response rates were lower than expected in Newfoundland and

Labrador (52%), Quebec (52%), and the Yukon (50%). The low response rate in Quebec was likely related to the language barrier. French versions of the questionnaire were not introduced until several months into the study, which could have posed an initial barrier to participation. It is unclear as to why the response rate in Newfoundland and Labrador and the Yukon were below the targeted response rate. However, after targeted recruitment to increase the response rate, the researchers were unable to reach the target of 65%. It is also important to mention that due to the small number of service providers in the territories, responses from Nunavut, the Yukon, and the North West Territories were grouped together for statistical analysis.

Early intervention parents. The parent survey, which included the MPOC-20 and FCOPES, was sent to the service providers who participated in the study. Families with children 0 to 9 years of age were targeted for the study. The MPOC-20 is a standardized questionnaire regarding parent perceptions of family-centered care. The FCOPES is a standardized measure of parent reported coping strategies. Both instruments, as well as the parent questionnaire constructed by the Canadian Early Intervention Research Team, are described in detail in the instrumentation section. Service providers were asked to post or distribute pamphlets, recruiting parents for this part of the study. A target sample size of 200 to 300 parents was decided upon. In the end, 407 Canadian took part in the study. Unfortunately, 20 parents were excluded, as they did not meet the age-limit criteria for the study (i.e., children 0-9 years of age). An additional 6 parents from Prince Edward Island, Nunavut, the Yukon, and Northwest Territories were excluded because the responses from these regions were too small to conduct our analyses. As such, a total of 381 parents were included in the present analysis. Table 7 provides a breakdown of parents who participated in each province and territory.

Table 6

Service Provider Targeted and Actual Participants and Response Rates by Province or Territory

Province or Territory	Target Number	Number of Responses	Response Rate (%)
British Columbia	111	77	69%
Alberta	78	67	86%
Saskatchewan	28	26	93%
Manitoba	18	15	83%
Ontario	168	124	74%
Quebec	58	30	52%
Nova Scotia	30	22	73%
New Brunswick	39	29	74%
Newfoundland & Labrador	23	12	52%
Prince Edward Island	12	10	83%
Yukon Territory	6	3	50%
Northwest Territories	7	5	71%
Nunavut	10	7	70%
TOTAL	588	427	73%

Table 7

Parent Participants by Province or Territory

Province or Territory	Parent Participants
British Columbia	55
Alberta	76
Saskatchewan	28
Manitoba	22
Ontario	116
Quebec	30
Nova Scotia	18
New Brunswick	18
Newfoundland & Labrador	18
TOTAL	381

Instrumentation

Early intervention inventory. In 2006, the Early Intervention Inventory was created by the Canadian Early Intervention Research Team. The questionnaire was given to 144 attendees of the *National Conference on Early Intervention, Policy, Practice and Services for Children with Developmental Delays*. Feedback was provided by several participants and incorporated into the revised survey. The survey was then emailed to members of the team and colleagues in the field to ensure that the length and format were appropriate and the questions were clear. It was also piloted to ensure there weren't any email or online technical difficulties with the questionnaire. Based on the feedback, the survey was revised to its final version.

The service provider questionnaire was designed to obtain information on early intervention programs across Canada in several domains. The survey questions can be divided into five areas of interest. Questions were designed to elicit information regarding child demographics, service delivery and models, wait lists, funding and costs, and staff and parent satisfaction (see Appendix B).

Demographic information includes contact information, number of children in the program with developmental delays, and the age ranges of children receiving services. Information pertaining to service delivery and models of service delivery includes types of services and providers in the program, average weekly hours of service, models, and the general approach to service delivery. Service models included home versus centre-based programming, and parent-child groups. The general approach to service delivery reflected whether the program staff followed a multidisciplinary, interdisciplinary or transdisciplinary approach.

Questions pertaining to wait lists were included in the survey. Information was gathered on whether wait lists existed for assessment and intervention and, if so, the average length that a child must wait for assessment and intervention services. Questions were also posed about funding and cost for assessment and intervention. Information regarding sources of funding and average costs for the family in terms of assessment and direct services was investigated. The final items on the questionnaire pertain to staff and perceived parent satisfaction with the program, outcomes, and government support. Questions relate to perception of parent satisfaction, overall satisfaction with child outcomes, satisfaction with the program's resources and ability of the government to meet the needs of children with developmental delays in the respective region.

Early intervention parent questionnaire. A 23-item questionnaire (see Appendix C) was designed to obtain information from parents with children attending early intervention programs across Canada. The questionnaire was pilot-tested with several mothers of children with developmental delays from Ontario and Quebec to ensure that the questions were clear and appropriate.

The survey questions can also be divided into five categories. Questions were designed to elicit information regarding demographics, service delivery and models, wait lists, funding and costs, and parent satisfaction. These areas, as well as many of the individual questions, coincided with the questions from the service provider questionnaire to allow for direct comparisons.

In terms of demographic information, parents were asked about their child's age, diagnosis, and the age at which their child was diagnosed and began receiving services. Parents were also be asked about service delivery, including questions regarding the sources of services, number of service providers, models and types of service delivery, and professionals that work with their child.

As with the service provider questionnaire, wait list questions were included to assess wait time for both assessment and intervention. Funding questions were included to tap into the direct costs to the parents for both assessment and intervention. Finally, parents were asked to rate their satisfaction on a ten-point scale with the program, their child's progress, program adequacy, and the government's ability to meet the needs of their child and family.

Family Crisis Oriented Personal Evaluation Scales (FCOPES). Parents were asked to complete the FCOPES (McCubbin, Olson, & Larsen, 1981). The FCOPES is a thirty-item self-report measure designed to assess parental coping strategies and adjustment to life stressors (see Appendix D).

Norms were based on a population o f 2,740 individuals. Overall reliability of the FCOPES using Cronbach's Alpha ranges from .77 to .86. Subscale coefficients range from .64 to .87 (McCubbin, Olson, & Larsen, 1981). Overall test-retest reliability is .81 with individual scales ranging from .61 to .95. Parents are asked to rate items on how applicable they were to them on a five-point Likert scale. There are five subscales on the FCOPES, as outlined below.

Questions from the a*cquiring social support* domain assess how likely parents are to seek advice from family and friends, as well as others in a similar situation. The *reframing* domain assesses how frequently parents look at family difficulties from a different, more positive perspective (e.g., facing problems head-on, believing that problems are manageable). The *seeking spiritual support* domain assesses the degree to which parents attend church services and seek spiritual guidance and support. The *mobilization* domain assesses the degree to which parents seek assistance through community programs, family doctor, or counselor, for example. Finally, the *passive appraisal* domain assesses the degree to which an inactive approach to dealing with the problem is taken (e.g., just accepting stressful events, watching television).

Measure of Processes of Care-20 (MPOC-20). Parents were also asked to complete the MPOC-20 (King, Rosenbaum, & King, 1995). The MPOC-20 is a twenty-item self-report measure designed to measure of parents' perceptions of the extent to which specific behaviours of health care professionals occur (see Appendix E). Parents are asked to rate the occurrence of several components of family-centered services on a seven-point Likert scale. The MPOC-20 is a shorter version of the original, 56-item MPOC-56. Psychometric properties were derived the initial pilot study (N=653) and regional cleft palate study (N=151). Cronbach's coefficient alpha was calculated for each of the five scales and ranged from .81 to .96 in the pilot study and .82 to .96 in the field testing study. A test-retest reliability study was conducted with 29 parents. Intraclass correlation coefficients for the five scales ranged from .78 to .88.

There are five domains or subscales on the MPOC-20. The *enabling and partnership* domain includes things such as involving parents in treatment decision-making and fully explaining treatment choices. The *providing general information* assesses the degree to which parents believe information is provided to them regarding available services, the child's disability, and ways to get in touch with other parents in similar situations. The *providing specific information about the child* domain assesses the degree to which parents feel they are provided with specific information about their child's progress, successes, and setbacks. The *coordinated and comprehensive care* domain assesses how consistent and comprehensive parents believe care to be. Finally, the *respectful and supportive care* domain assesses how competent, respected, involved, and supported parents feel.

Procedure

Early intervention inventory. In order to ensure consistency and target as many Early Intervention programs as possible the following procedures were undertaken for recruitment. Early Intervention programs were sought through national programs and provincial and territorial Associations for Community Living. Programs were also sought through the Canadian Association of Family Resource Programs, Child and Family Canada, Canadian Health Network, and the Canadian Association for Young Children. Contact information for the Centres of Excellence across Canada was provided by the Public Health Agency of Canada. Programs were also targeted through the Government of Canada website and Community Action Programs for Children. The Research Alliance for Children with Special Needs also provided contact information for a variety of Early Intervention programs across Canada.

Subsequently, relevant provincial and territorial ministries were contacted to locate government-sponsored programs. Ministries of education, social service, family and children, and health were targeted to locate programs in each respective province or territory. The ministries in charge of Early Intervention for children with developmental delays varied from province to province. Therefore, every ministry mandating service provision to children and individuals with special needs was examined.

Disability organization websites were also searched to locate Early Intervention programs across Canada. Provincial and territorial Autism and Down Syndrome societies were targeted. Enable Link, Charity Village and Autism Today also provided a listing of various programs for children with developmental delays in each province and territory.

Key-word searches were also conducted to locate Early Intervention programs that may have been overlooked by the aforementioned searches. Examples of keywords included in the search included early intervention, developmental delay, intellectual disabilities, special services, intervention services, infant development, and early childhood development. Canada 411 searches were also conducted for Early Intervention programs and child development centres. Finally, province or territory-specific websites provided information for additional programs to target for the study. Specific websites included Inform Alberta, Alberta Association of Services for Children and Families, Ontario Association for Infant Development, Manitoba Parent Child-Centered Coalition, and Saskatchewan Child Development Centres.

Once all of the early intervention programs were identified, over an intensive period spanning several months, through the efforts of many students and volunteers, an email or letter explaining the study and requesting participation was sent to the director of each program (see Appendix F). This consent letter explained the purpose and benefits of participation. A reminder email was sent to potential respondents who had not yet completed their survey every 10 weeks. After completion of the study, a letter to debrief each of the participants and thank them for participation was sent out (see Appendix H).

Early intervention parent questionnaire. A recruitment letter was then sent to the directors of the Early Intervention programs who completed the service provider questionnaire (see Appendix G). Directors were asked to post or distribute the letter to give parents the opportunity to complete the questionnaire online or contact the team for an email or hard copy version of the questionnaire.

FCOPES and *MPOC-20.* Similarly, parents were asked to complete the FCOPES and MPOC-20, which were made available online. Total completion time for the parent questionnaire, FCOPES, and MPOC-20 was fifteen to twenty-five minutes.

A second request was sent to service providers who did not respond to our request after 10 weeks. After completion of the study, a letter to debrief each of the parents and thank them for participation was sent (see Appendix I).

Chapter Four: Results

The first goal of the present study was to determine if and how provinces and territories differ across Canada in terms of early intervention services for children with developmental delays. For each of the seven dependent variables, an Analysis of Variance (ANOVA) was conducted to analyze the effect of location (province or territory) on the respective dependent variable. When there are several dependent variables, a Multivariate Analysis of Variance (MANOVA) can be conducted, however, only if the dependent variables are not highly correlated (Glass & Hopkins, 1996). A Pearson Product Moment correlation procedure was conducted with the data collected from the Canadian Early Intervention Research Team's preliminary analysis in 2007 to determine if any of the dependent variables were correlated. As several variables were correlated, separate ANOVAs were conducted to analyze the data in the present study.

The second goal of the study was to assess parent perceptions and experiences with early intervention programs as well as parental coping and satisfaction with service providers. Again, the province or territory served as the independent variable and the ten aforementioned queries as dependent variables. Results were analyzed using ANOVA rather than MANOVA as several dependent variables were again correlated (e.g., age of diagnosis, and service delivery onset).

The third goal of the study was to compare parent and service provider perceptions of early intervention. Three separate t-tests were conducted to compare service provider and parent ratings of satisfaction with child outcomes, ratings of program adequacy, and ratings of perceived government support.

The fourth and final goal of the study was to examine the relationship between early intervention program variables and parent perceptions. With respect to data analysis, Pearson Product Moment Correlations were computed for each of the aforementioned research questions to examine the relationships between each of the early intervention variables above and their respective ratings of satisfaction.

In the following section, the results from the current study are presented as follows. First, descriptive statistics are presented to compare service providers and parents from across Canada. Overall Canadian findings are also presented. Subsequently, cross-province comparisons from both the service provider and parent reports are presented (Goal One and Two). Parent-reported ratings of satisfaction are also compared with those of service providers (Goal Three). Finally, the results from the analyses relating to family-centered care and parent coping strategies are presented (Goal Four).

Descriptive Statistics

Service provider comparisons. Descriptive statistics are presented to compare service provider reports from each province and territory across Canada. Provinces were compared on an individual basis and territories were grouped together due to sample size restrictions. Table 8 provides information on the mean number of services that children receive through the program (e.g., occupational therapy, IBI, speech therapy), as well as the standard deviation and range. Table 9 provides information on mean wait times (in months) for an initial assessment and Table 10 provides information on subsequent wait times prior to the commencement of services after a diagnosis has been made. Finally, Tables 11 through 14 were constructed to provide information on provincial and territorial differences in terms of satisfaction ratings (i.e., perceived parental satisfaction,

satisfaction with child outcomes, program adequacy, and government adequacy, respectively). Success was rated on a 10-point scale with a score of 1 indicating the lowest level of satisfaction and 10 representing the greatest level of satisfaction.

Table 8

Mean Number of Services per Program

Province/Territory	*Mean Number of Services*	*Standard Deviation*	*Range*	*1-5 (%)*	*6-10 (%)*	*11-15 (%)*	*16+ (%)*
British Columbia	10	5.10	3-22	13	42	28	17
Alberta	9	5.12	2-21	26	29	33	12
Saskatchewan	11	3.71	2-16	8	50	27	15
Manitoba	11	6.18	2-22	34	28	1	27
Ontario	9	4.50	2-26	22	37	25	16
Quebec	9	4.87	2-19	28	48	14	10
New Brunswick	9	4.74	2-17	25	38	31	6
Newfoundland/ Labrador	9	3.46	3-18	42	33	17	8
Nova Scotia	11	4.16	2-14	13	59	23	5
Prince Edward Island	15	5.45	3-16	40	40	0	20
Northern Territories	11	3.69	2-16	46	31	15	8
CANADA	**10**	**4.78**	**2-26**	**22**	**38**	**24**	**16**

Table 9
Mean Service Provider Wait Times for Assessment

Province/Territory	*MeanWait Time (months)*	*Standard Deviation*	*Range*	*0-10 (%)*	*11-20 (%)*	*>20 (%)*
British Columbia	1	2.28	0-12	97	3	0
Alberta	2	3.51	0-7	100	0	0
Saskatchewan	3	4.47	0-18	88	12	0
Manitoba	3	6.42	0-6	100	0	0
Ontario	2	3.28	0-24	94	5	1
Quebec	2	3.38	0-12	96	4	0
New Brunswick	2	3.70	0-9	100	0	0
Newfoundland/ Labrador	<1	0.71	0-6	100	0	0
Nova Scotia	4	4.94	0-6	100	0	0
Prince Edward Island	2	2.87	0-6	100	0	0
Northern Territories	1	2.72	0-6	100	0	0
CANADA	**2**	**3.53**	**0-24**	**96**	**3**	**1**

Table 10

Mean Additional Wait Times for Commencement of Services

Province/Territory	*MeanWait Time (months)*	*Standard Deviation*	*Range*	*0-10 (%)*	*11-20 (%)*	*>20 (%)*
British Columbia	4	7.88	0-24	90	6	4
Alberta	3	3.73	0-24	92	6	2
Saskatchewan	5	6.23	0-9	100	0	0
Manitoba	5	7.10	0-8	100	0	0
Ontario	3	5.05	0-24	96	3	1
Quebec	5	12.83	0-60	77	8	15
New Brunswick	2	2.68	0-12	96	4	0
Newfoundland/ Labrador	2	2.83	0-12	90	10	0
Nova Scotia	7	12.70	0-18	81	19	0
Prince Edward Island	3	2.50	0-12	87	13	0
Northern Territories	5	12.07	0-36	83	0	17
CANADA	**4**	**7.05**	**0-60**	**92**	**5**	**3**

Table 11

Mean Service Provider Ratings of Perceived Parental Satisfaction

Province/Territory	*Mean Satisfaction Rating*	*Standard Deviation*	*Range*
British Columbia	8	1.15	5-10
Alberta	8	0.98	5-10
Saskatchewan	8	0.92	5-10
Manitoba	8	1.11	7-8
Ontario	8	0.86	5-10
Quebec	8	0.91	5-10
New Brunswick	9	1.10	5-10
Newfoundland/Labrador	8	1.20	7-10
Nova Scotia	9	0.95	7-10
Prince Edward Island	9	0.58	6-8
Northern Territories	9	0.63	7-10
CANADA	**8**	**0.98**	**5-10**

Table 12
Mean Service Provider Ratings of Satisfaction with Child Outcomes

Province/Territory	*Mean Satisfaction Rating*	*Standard Deviation*	*Range*
British Columbia	8	1.35	5-10
Alberta	8	1.18	5-10
Saskatchewan	8	1.19	5-10
Manitoba	8	1.14	7-9
Ontario	8	1.06	5-10
Quebec	8	1.14	5-10
New Brunswick	8	1.24	5-10
Newfoundland/Labrador	8	1.28	6-9
Nova Scotia	8	1.02	5-10
Prince Edward Island	8	0.50	5-9
Northern Territories	8	1.10	5-10
CANADA	**8**	**1.16**	**5-10**

Table 13
Mean Service Provider Ratings of Satisfaction with Program Adequacy

Province/Territory	*Mean Satisfaction Rating*	*Standard Deviation*	*Range*
British Columbia	8	1.63	4-10
Alberta	8	1.44	4-10
Saskatchewan	8	1.58	5-10
Manitoba	8	2.39	5-10
Ontario	7	1.59	3-10
Quebec	8	1.88	5-10
New Brunswick	7	1.99	5-10
Newfoundland/Labrador	7	2.46	5-10
Nova Scotia	7	1.26	5-9
Prince Edward Island	8	0.82	6-8
Northern Territories	8	1.47	2-9
CANADA	**8**	**1.65**	**2-10**

Table 14

Mean Service Provider Ratings of Satisfaction with Government Support

Province/Territory	*Mean Satisfaction Rating*	*Standard Deviation*	*Range*
British Columbia	5	2.09	1-10
Alberta	5	1.82	1-8
Saskatchewan	5	1.57	1-7
Manitoba	4	1.88	1-9
Ontario	5	2.01	1-10
Quebec	5	2.16	2-8
New Brunswick	5	1.55	3-7
Newfoundland/Labrador	4	2.15	3-8
Nova Scotia	5	1.85	1-10
Prince Edward Island	6	0.96	4-7
Northern Territories	5	2.08	1-9
CANADA	**5**	**1.94**	**1-10**

Parent comparisons. Descriptive statistics were also calculated to compare parent reports from across Canada. Unfortunately, a sufficient number of parents could not be recruited from the northern territories or Prince Edward Island for this component of the study given the limited number of service providers who participated in the first part of the study. As fewer than ten parents were recruited in each of these regions, the territories and PEI are excluded from the tables below due to insufficient power and limited generalizability. Table 15 provides information on the mean age at diagnosis and Table 16 provides information on the mean age when services began. Tables 17 provides information on the mean number of services available through the early intervention program and Table 18 provides information on the mean intervention hours per week. Table 19 provides information on the mean number of months families waited for an initial assessment and Table 20 outlines the average additional wait time for families prior to receiving services in each province, after a diagnosis is made.

Tables 21 through 24 provide family ratings of program success (i.e., perceived parental satisfaction, satisfaction with child outcomes, program adequacy, and government adequacy). Again, ratings are on a 10-point scale with a score of 1 indicating the lowest level of satisfaction and 10 representing the greatest level of satisfaction. Table 25 provides a breakdown of the 5 domains from the FCOPES by province and finally, Table 26 provides a breakdown of the 5 domains from the MPOC-20 by province.

Table 15
Mean Age in months at Diagnosis

Province/Territory	*Mean Age*	*Standard Deviation*	*Age Range*	*0-24 (%)*	*25-48 (%)*	*49-72 (%)*	*>72 (%)*
British Columbia	32	25.15	0-108	33	50	10	7
Alberta	25	14.65	0-48	50	50	0	0
Saskatchewan	39	24.28	0-84	14	57	22	7
Manitoba	25	20.14	0-72	43	53	4	0
Ontario	29	19.18	0-108	35	51	12	2
Quebec	35	12.76	0-60	23	70	7	0
New Brunswick	28	14.80	0-50	28	66	6	0
Newfoundland	24	18.84	0-108	45	40	5	10
Nova Scotia	26	16.76	0-72	39	56	5	0
CANADA	**29**	**19.42**	**0-108**	**36**	**53**	**9**	**2**

Table 16
Mean Age in months at Service Onset

Province/Territory	*Mean Age*	*Standard Deviation*	*Age Range*	*0-24 (%)*	*25-48 (%)*	*49-72 (%)*	*>72 (%)*
British Columbia	27	19.11	0-108	47	40	7	5
Alberta	26	13.08	2-51	49	49	2	0
Saskatchewan	33	22.80	2-106	31	50	11	8
Manitoba	27	19.71	2-72	43	48	9	0
Ontario	29	20.78	0-108	45	39	12	4
Quebec	38	17.07	2-72	18	64	18	0
New Brunswick	29	14.96	1-51	39	56	5	0
Newfoundland	28	16.66	0-108	32	58	5	5
Nova Scotia	26	16.97	0-54	50	44	6	0
CANADA	**29**	**18.55**	**0-108**	**43**	**46**	**8**	**3**

Table 17
Mean Number of Services Received

Province/Territory	*Number of Services*	*Standard Deviation*	*Range*	*1-10 (%)*	*11-20 (%)*	*>20 (%)*
British Columbia	6	3.68	1-15	89	11	0
Alberta	9	4.83	1-22	67	29	4
Saskatchewan	6	4.64	1-22	88	8	4
Manitoba	6	2.84	1-16	95	5	0
Ontario	6	3.70	1-15	89	11	0
Quebec	4	2.39	1-10	100	0	0
New Brunswick	6	2.75	3-13	94	6	0
Newfoundland	6	3.73	1-11	88	12	0
Nova Scotia	6	4.32	1-15	82	18	0
CANADA	**6**	**4.10**	**1-22**	**86**	**13**	**1**

Table 18
Mean Number of Service Hours per Week

Province/Territory	*Number of Hours*	*Standard Deviation*	*Range*	*<1-15 (%)*	*16-30 (%)*	*>30 (%)*
British Columbia	11	11.24	<1-42	76	17	7
Alberta	15	9.82	<1-35	66	28	6
Saskatchewan	8	9.94	<1-35	80	12	8
Manitoba	12	19.50	<1-78	74	9	17
Ontario	12	19.38	<1-52	71	25	4
Quebec	11	9.41	<1-41	76	21	3
New Brunswick	13	8.82	1-24	47	53	0
Newfoundland	16	11.96	1-32	53	42	5
Nova Scotia	2	1.20	<1-5	100	0	0
CANADA	**12**	**14.22**	**<1-78**	**71**	**24**	**5**

Table 19
Mean Wait Time for Initial Assessment

Province/Territory	*Number of Months*	*Standard Deviation*	*Range*	*0-12 (%)*	*13-24 (%)*	*>24 (%)*
British Columbia	6	6.53	0-36	88	8	4
Alberta	4	4.88	0-18	93	7	0
Saskatchewan	8	7.42	0-24	84	16	0
Manitoba	3	2.76	0-9	100	0	0
Ontario	7	7.31	0-36	82	13	5
Quebec	8	5.77	0-24	93	7	0
New Brunswick	3	3.09	0-9	100	0	0
Newfoundland	6	4.95	0-18	90	10	0
Nova Scotia	5	6.90	0-24	97	13	0
CANADA	**6**	**6.34**	**0-36**	**88**	**10**	**2**

Table 20
Mean Additional Wait Time for Service Commencement

Province/Territory	*Number of Months*	*Standard Deviation*	*Age Range*	*0-12 (%)*	*13-24 (%)*	*>24 (%)*
British Columbia	7	11.99	0-48	82	8	10
Alberta	3	4.60	0-30	99	0	1
Saskatchewan	4	6.33	0-36	88	4	8
Manitoba	2	2.30	0-7	100	0	0
Ontario	9	10.29	0-84	75	17	8
Quebec	8	6.12	0-24	93	7	0
New Brunswick	1	1.34	0-4	100	0	0
Newfoundland	4	2.96	0-10	100	0	0
Nova Scotia	3	3.78	0-12	100	0	0
CANADA	**6**	**8.43**	**0-84**	**88**	**7**	**5**

Table 21
Mean Parent Satisfaction Ratings

Province/Territory	*Mean Satisfaction*	*Standard Deviation*	*Range*
British Columbia	7	2.44	1-10
Alberta	8	2.41	1-10
Saskatchewan	6	3.05	1-10
Manitoba	7	2.58	1-10
Ontario	7	2.70	1-10
Quebec	7	2.64	1-10
New Brunswick	7	2.73	2-10
Newfoundland	5	2.20	1-8
Nova Scotia	8	2.41	2-10
CANADA	7	**2.63**	**1-10**

Table 22
Mean Parent Satisfaction with Child Outcomes

Province/Territory	*Mean Satisfaction*	*Standard Deviation*	*Range*
British Columbia	7	2.27	1-10
Alberta	8	1.90	2-10
Saskatchewan	6	2.87	1-10
Manitoba	7	2.75	1-10
Ontario	7	2.39	1-10
Quebec	6	2.43	1-10
New Brunswick	8	1.92	5-10
Newfoundland	7	1.96	4-10
Nova Scotia	7	2.45	1-10
CANADA	**7**	**2.35**	**1-10**

Table 23

Mean Parent Satisfaction with Program Adequacy

Province/Territory	*Mean Satisfaction*	*Standard Deviation*	*Range*
British Columbia	8	2.19	1-10
Alberta	8	2.52	1-10
Saskatchewan	6	2.42	1-9
Manitoba	7	2.79	1-10
Ontario	7	2.78	1-10
Quebec	7	2.59	1-10
New Brunswick	7	2.77	2-10
Newfoundland/Labrador	6	2.67	2-10
Nova Scotia	8	2.48	2-10
CANADA	**7**	**2.62**	**1-10**

Table 24

Mean Parent Satisfaction with Government Support

Province/Territory	*Mean Satisfaction*	*Standard Deviation*	*Range*
British Columbia	3	2.39	1-10
Alberta	6	2.48	1-10
Saskatchewan	3	2.37	1-10
Manitoba	5	2.78	1-8
Ontario	4	2.69	1-10
Quebec	2	1.88	1-8
New Brunswick	5	2.85	1-10
Newfoundland/Labrador	3	1.79	1-5
Nova Scotia	3	2.17	1-9
CANADA	**4**	**2.66**	**1-10**

Table 25

*Mean Parental coping Scores**

Province/ Territory	*Social Support*	*Reframing*	*Spiritual Support*	*Mobilization*	*Passive Appraisal*
British Columbia	3	4	3	3	2
Alberta	3	4	3	3	2
Saskatchewan	3	4	3	3	2
Manitoba	3	4	3	3	2
Ontario	3	4	3	4	2
Quebec	3	4	3	3	2
New Brunswick	3	4	3	4	2
Newfoundland/Labrador	3	4	3	3	2
Nova Scotia	3	4	3	3	2
Canada	**3**	**4**	**3**	**3**	**2**

** 1 (Strongly Disagree), 2 (Moderately Disagree), 3 (Neither Agree or Disagree), 4 (Moderately Agree), 5 (Strongly Agree)*

Table 26

*Mean Family Centered Care Scores**

Province/ Territory	*Enabling & Parntnership*	*General Information*	*Specific Information*	*Coordinated Care*	*Respect & Support*
British Columbia	5	4	5	5	5
Alberta	5	4	5	5	5
Saskatchewan	4	3	4	4	4
Manitoba	5	4	5	5	5
Ontario	5	3	5	5	5
Quebec	4	3	5	5	5
New Brunswick	5	4	5	5	5
Newfoundland/Labrador	5	3	5	5	5
Nova Scotia	5	5	5	5	5
Canada	**5**	**4**	**5**	**5**	**5**

** 0 (Not Applicable), 1 (Not at All), 2 (To a Very Small Extent), 3 (To a Small Extent), 4 (To a Moderate Extent), 5 (To a Fairly Great Extent), 6 (To a Great Extent),7 (To a Very Great Extent)*

Canadian findings. Based on the results from the service provider questionnaires, descriptive statistics were computed, collapsing across provinces and territories, to provide a general overview of Early Intervention service provision in Canada. On average, service providers offered 10 services (min=1, max=26) and employed 5 types of professionals (min=1, max=17). Canadian children attended programs for an average of 26 months (min=1, max=108), after waiting an average of 2 months (min=1, max=24) for an assessment and 4 additional months (min=1, max=60) to begin services. Many service providers received financial contributions from several sources. The most common source of funding was the provincial or territorial government, which funded 83% of Early Intervention programs. In addition, 11% of programs received funding from private sources, and 6% received support from non-profit sources.

Based on the results from the parent survey, the average age of Canadian children currently in Early Intervention programs is 5 years, 0 months (min=8 months, max=9 years). It is important to note that only children between 0 and 9 years of age were included for this research study. The average age at diagnosis is 2 years, 5 months (min=0, max=9 years). Canadian children began receiving Early Intervention services at an average of 2 years, 5 months of age (min=0, max=9 years). However, this does not indicate that parents did not have wait lists as many parents paid for services privately before being provided with publicly funded services. On average, Canadian families report waiting 6 months for an initial assessment (min=0, max=30), followed by waiting an additional 6 months before services commence (min=0 max=48), for an average wait time of 12 months (min=0, max=78).

Forty-nine percent of children received all services from one provider and 51% of children received services from multiple sources. Canadian children within our study were offered an average of 6 different services (min=2 max=22), provided by 5 different types of professionals (min=2 max=14). Sixty-four percent of children attended government programs, 15% of families received strictly private services, 7% attended non-profit programs, and the remaining 14% received a combination of services.

Both service providers and parents were asked to rate their satisfaction with Early Intervention program variables (on a scale of one to ten) in four domains. First, service providers rated their perception of parental satisfaction as eight on a ten-point scale (min=5, max=10) whereas parents reported their overall satisfaction as seven (min=0, max=10). Secondly, service providers reported their satisfaction with child outcomes as eight (min=5, max=10) whereas parent satisfaction was again rated as seven out of ten (min=1, max=10). In terms of ratings of program adequacy, or the ability of the program to meet the needs of children and families with developmental delays, service providers gave an average rating of eight (min=1, max=10) while parents again gave an average rating of seven (min=1, max=10). Finally, both service providers and parents gave the lowest ratings on their perception of the government's ability to meet the needs of children and families with special needs, with an average of five for service providers (min=1, max=10) and four for parents (min=1, max=10).

Parents from across Canada were also asked to complete the FCOPES, a standardized questionnaire designed to investigate parental coping strategies. The five coping domains from the FCOPES are: *acquiring social support, reframing, seeking spiritual support, mobilizing to acquire and accept help,* and *passive appraisal*. The most commonly used strategy for Canadian parents was to reframe the situation in a more positive manner (e.g., facing problems head on, accepting unexpected difficulties, believing that the problem can be solved). The least commonly used coping strategy was passive appraisal (e.g., knowing that luck plays a big part in family outcomes, believing the problem will go away on it's own in time).

Canadian parents were also asked to complete the MPOC-20, a standardized questionnaire designed to investigate parent-reported perceptions of family-centered care. The five areas in which service providers were rated by parents in terms of the family-centered care are as follows: *enabling and partnership, providing general information, providing child-specific information, coordinated and comprehensive care,* and *respect and support.* Canadian parents reported that Early Intervention service providers were most family-centered in terms of their ability to provide respectful and supportive care (e.g., providing a caring atmosphere, helping parents feel competent, providing enough time to talk). They were least successful in providing families with relevant general information (e.g., providing information about community services and how to get in touch with other parents, providing disability-specific information).

After collecting relevant demographic data, the data was analyzed to address the four aforementioned research goals : *analysis of cross-province comparisons, analysis of cross-province parental perceptions, comparison of service provider and parent percentions,* and *a global analysis of Early Intervention program and parent perception variables.*

Goal One: Analysis of Cross-Province Service Provider Comparisons

Each province was compared with the other provinces and the territorial grouping (Nunavut, Yukon, Northwest Territories) on seven dependent variables: (a) number of services, (b) number of professionals, (c) combined wait time for assessment and onset of services, (d) percentage of private and non-profit funding sources, (e) satisfaction with child outcomes, (f) satisfaction with program adequacy, and (g) satisfaction with the government's ability to meet the needs of children with developmental delays.

For each of the seven variables, an Analysis of Variance (ANOVA) was conducted to analyze the effect of location (province/territory) on the respective dependent variable. The ANOVA technique was run in place of MANOVA as several dependent variables were highly correlated. When dependent variables are highly correlated, it is recommended that separate ANOVAs be conducted instead of using a MANOVA procedure (Glass & Hopkins, 1996; Norman & Streiner, 2008).

In summary, no significant differences were found when comparing each of the provinces and territories on the aforementioned variables. Provinces and territories were comparable in terms of the average number of services they offered ($F(10, 413) = 2.06$, $p = .03$); availability of professionals ($F(10, 413) = 1.95$, $p = .04$); average wait times ($F(10, 366) = 1.59$, $p = .11$); sources of funding; or ratings of satisfaction with child outcomes ($F(10, 393) = .48$, $p = .91$), program adequacy ($F(10, 396) = .79$, $p = .64$), or government support ($F(10, 393) = 1.28$, $p = .24$.).

In taking account the number or proportion of children per province with a developmental delay prior to making the aforementioned comparisons, it is possible that the results may have differed. However, given our stipulated age range of 0-9, it was impossible to find this data as the majority of provincial and territorial data that is publically available focuses on 0-18 as the stipulated age range and does not provide specific information on the number or proportion of children with developmental delays in that specific age range.

Goal Two: Analysis of Cross-Province Parental Reports

A second goal of the study was to compare parent perceptions and experiences with Early Intervention services across Canada. As there were not sufficient parent participants from Prince Edward Island or the northern territories, they were excluded from the following analyses. Parent responses from each province were compared on ten dependent variables: (a) age at diagnosis, (b) age at service onset (c) number of service hours per week, (d) parent satisfaction, (e) satisfaction with government supports, (f) degree of sought out social support (FCOPES*)*, (g) degree of sought out community support (FCOPES), (h) perception of involvement in programming (MPOC-20), (i) perception of respect from service providers (MPOC-20), and (j) perception of how well their informational needs are being met.

For each of the ten variables, an Analysis of Variance (ANOVA) was conducted to analyze the effect of province or territory on the respective dependent variable. ANOVA was used in place of MANOVA as many of the dependent variables were correlated. The results of each of the ten analyses are presented sequentially below:

Age at diagnosis. The nine provinces included in these analyses were compared to determine if significant differences existed across Canada in terms of the average age at diagnosis. Although the ANOVA showed significant differences across Canada ($F(8, 379) = 2.29$, $p = .02$), the effect size was small to modest (Cohen, 1992). The partial Eta squared was .05, which means that the provincial grouping by itself accounted for 5% of the overall variance with respect to age at diagnosis. A Games-Howell post hoc test was run to determine how the specific provinces differed. It was found that the average wait time was significantly shorter in Alberta (25 months) than in Quebec (35 months). No additional significant differences were found between other provinces or territories.

Age at service onset. Provinces were compared to determine whether differences existed in terms of the average age at which children began services. Significant differences were not found across Canada $F(8, 380) = 1.60$, $p = .13$.

Number of service hours per week. In order to examine the intensity of programs, comparisons were made across Canada in terms of average number of services per week. Although the ANOVA showed significant differences across Canada ($F(8, 361) = 2.10$, $p = .04$), the effect size was again small to modest. The partial Eta squared was .05, which means that the provincial grouping accounted for little of the overall variance. A Games-

Howell post hoc test revealed that Nova Scotia provided fewer weekly hours of service (2 hours) than Newfoundland & Labrador (16 hours), Alberta (15 hours), New Brunswick (13 hours), Ontario (12 hours), British Columbia (11 hours), and Quebec (11 hours).

Parent satisfaction. Parental ratings of overall satisfaction (on a ten-point scale), were also compared across Canada. Again, although significant differences were found ($F(8, 371) = 2.60$, $p = .01$), the partial Eta squared was .05, indicating a small to modest effect size. Using a Games-Howell post hoc test, it was found that parents in Newfoundland and Labrador reported lower levels of overall satisfaction (5/10) than parents in Alberta (8/10), Nova Scotia (8/10), and British Columbia (7/10).

Government support. Parental ratings of satisfaction with their government's ability to support children and families with special needs (on a ten-point scale) were compared across Canada. Significant differences were found $F(8, 376) = 8.00$, $p <.01$. The effect size, as estimated with partial Eta squared, was large (.15), indicating that provincial grouping explained approximately 15% of the overall variance. A Games-Howell post hoc test revealed that parents in Alberta had greater levels of satisfaction with government support (6/10) than parents in Quebec (2/10), Nova Scotia (3/10), British Columbia (3/10), Saskatchewan (3/10), Newfoundland & Labrador (3/10), and Ontario (4/10). Additionally, parents in Manitoba (5/10) and Ontario (4/10) were significantly more satisfied with child outcomes than were Quebec parents (2/10).

Social and community support. Parental responses on the *Acquiring Social Support* and *Family Mobilization* domains of the FCOPES were compared across Canada. Significant differences were not found in terms of reliance on social $F(8, 306) = .44$, $p = .89$ or community support $F(8, 306) = .84$, $p = .57$ as parental coping strategies.

Respect and informational support. Parental perceptions of family-centered care in terms of the *General Information* and *Respectful and Supportive Care* domains of the MPOC-20 were compared across Canada. Significant differences were not found in terms of parent perceptions of respectful and supportive care $F(8, 316) = 1.55, p = .139$ or the provision of general information $F(8, 308) = 1.00, p = .44$.

Goal Three: Parent versus service provider perceptions.

The third goal of this research study was to compare parent and service provider perceptions of Early Intervention across Canada, in terms of their satisfaction ratings with different elements of Early Intervention service provision and outcomes. Both service providers and parents were asked to rate, on a ten-point scale, their satisfaction with child outcomes, perceptions of program adequacy, and perceptions of the government's ability to meet the needs of families in programs across the province. Independent-samples t-tests were conducted to compare parent and service provider satisfaction ratings.

Child outcomes. Parent and service provider ratings of satisfaction with child outcomes (on a ten-point scale) were compared using an independent-samples t-test. There was a significant difference in terms of satisfaction ratings by service providers (M=8.00, SD=1.17) and parents (M=7.01, SD=2.35); $t(777) = 6.90$, $p <.01$. Parents rated their satisfaction with child outcomes one point lower, on average, than service providers.

Program adequacy. Parental and service provider ratings of program adequacy (i.e., how able service providers were to meet the child and family's needs) were compared using an independent-samples t-test. There was a significant difference in the satisfaction ratings reported by service providers (M=7.60, SD=1.65) and parents

(M=7.04, SD=2.63); t(781) = 3.55, p <.01. On average, parents rated their satisfaction with program adequacy half a point lower than service providers on a ten-point scale.

Government support. Finally, parental and service provider ratings of government contributions (i.e., how successful they perceived the government's ability to meet the needs of children and families in Early Intervention in their particular province) were compared using an independent-samples t-test. There was a significant difference in the satisfaction ratings reported by service providers (M=4.88, SD=1.92) and parents (M=3.85, SD=2.66); t(778) = 6.19, p <.01. On average, parents rated their satisfaction with government support one point lower than service providers on a ten-point scale.

Goal Four: Early Intervention program and parent perceptions

In order to examine the relationship between early intervention program variables and parent perceptions, data from the service provider and parent questionnaires, the MPOC-20, and the FCOPES were collapsed across Canada. The research questions and results are presented sequentially below. In terms of data analysis, Pearson Product Moment Correlations were computed to examine the relationship between variables.

Service delivery onset and child outcomes. Based on the vast amount of research validating the importance of services beginning early for optimal results (Carpenter, 2005; Guralnick, 1998; Woods & Wetherby, 2003), it was expected that children who began programming at a younger age would make greater gains, resulting in higher levels of parental satisfaction with their child's progress. As expected, a negative correlation was found between age at service onset and parent perceptions of child outcomes (r = -.14, p <.01). Although significant, the correlation was small, indicating that there are likely a multitude of other variables impacting parent satisfaction with child outcomes.

Number of services and child outcomes. Researchers have found that multidisciplinary programs, which offer various services and supports, are often more effective than single service programs (Blackman, 2002; Guralnick, 1998). As such, it was expected that as the number of services available to families increased, parent and service provider satisfaction with child outcomes would also increase. As expected, a significant, albeit small, positive correlation was found when examining parent reports of satisfaction with child outcomes and the number of services available through the program (r = .12, p<.01). The relationship between service provider satisfaction with child outcomes and the number of services available was not significant (r = .09, n.s.).

Program intensity and child outcomes. Intensive programs have been found to be more effective than programs with fewer weekly hours of service (Hume, Bellini, & Pratt, 2005; Symes, Remington, & Brown, 2006). As such, it was expected that as the number of hours increased, parent-reported satisfaction with child outcomes would also increase. As expected, a significant but small positive correlation was found (r = .18, p<.01) between parent reports of satisfaction with child outcomes and program intensity.

Parent involvement and program satisfaction. As family involvement is critical in early intervention success (Guralnick, 2005; Page-Smith & Rix, 2006), it was expected that as parents reported more involvement, overall satisfaction with the program would improve. As expected, a significant, moderate, positive correlation was found (r = .33, p<.01) when examining parent reports of involvement and program satisfaction.

Informational needs and program satisfaction. Family involvement includes ensuring that the informational needs of parents are being met (Turnball et al., 2007). Training, support, and resources are central to effectively empowering and involving parents (Dempsey & Dunst, 2004; McConachie & Diggle, 2006). It was predicted that a positive relationship would exist between parental perceptions of how well their informational needs were being met and overall program satisfaction. As expected, a significant but small positive correlation was found (r = .25, p<.01).

Parental coping strategies and parent satisfaction. Positive, problem-focused coping strategies have been found to result in lower levels of parent stress than passive or avoidant coping strategies (Hastings et al., 2005; Dunn et al., 2001). It was predicted that problem-focused coping strategies (e.g., acquiring social supports, mobilization to acquire resources and help, seeking spiritual guidance) would be positively correlated to overall parent satisfaction. Reframing, an emotion-focused coping strategy, was also expected to positively correlate with parent satisfaction, although to a lesser degree. On the other hand, passive appraisal (which is a less active and problem-focused strategy) was predicted to correlate negatively with parent satisfaction in that, the more parents relied on passive strategies, the lower their overall satisfaction.

As expected, a significant positive correlation was found between parent scores on the *acquiring social support* domain and overall level of satisfaction (r = .15, p<.01). A significant, positive, correlation was also found between parent scores on the *mobilization to acquire resources and help* domain and parent-reported satisfaction (r = .14, p<.01). Parent-reported scores on the *seeking spiritual support* domain were also positively correlated with overall levels of satisfaction (r = .19, p<.01). A significant correlation was not found between parent reports on the *reframing* domain of the FCOPES and parent satisfaction (r = .09, n.s.) as expected.

Chapter Five: Discussion and Conclusion

Service Provider Comparisons

The aim of the present study was to compare individual and family supports and services for children with developmental delays across Canada. Based on the literature review of Canadian Early Intervention policy and practice, as programs are left to provincial or territorial jurisdiction, significant variation across Canada was expected. Through an initial review of services, based on ministerial websites, public intervention programs appeared more dissimilar than alike across Canada (see Tables 1 through 5). For example, some provinces and territories had developed strategies to encourage cross-ministry collaboration while others had not. The number of relevant initiatives and acts varied from province to province and the variety and breadth of programs and age groups supported were dependent on the province or territory in which one lived. Program funding options and extra income supports were also variable across the country. For example, some provinces, such as British Columbia, provided funding for children over six years of age while many other provinces fund only through preschool.

Despite what has been found through ministerial websites and what has been stated in the literature thus far (Canadian Autism Intervention Research Network, 2004; denHeyer & Kienapple, 2005; Dworet & Bennett, 2002; Lyon, 2002; Prince, 2004; Zinga et al., 2005), there may not be as substantial of differences across the country as was previously thought. Results from the present study indicate that service providers across the country are comparable in terms of number of service professionals they have available to families, average wait times, funding sources, and self-reported satisfaction with program adequacy, child outcomes, and government support.

These results can be explained, in part because the information on the specific variables we analyzed was not available in the literature. For example, ministry websites did not provide information on average wait times in each province, a variable that has been found to be crucial to early intervention success (McCain, Mustard, & Shanker, 2007; Roberts, Howard, Spittle, et al., 2008) and central to the present study. Information on self-reported satisfaction was also not available on provincial or ministerial websites or readily accessible through online searches. As such, the basis on which researchers and political stakeholders have made their claim as to the discrepancies in service delivery across Canada was not based on the same factors or variables under investigation in the present study. The current study is more in-depth and in line with current thinking in the field with respect to what constitutes effective early intervention programs. As such, the results can be considered a more valid representation of the current situation in Canada than anecdotal reports found on the internet and in the media.

The similarities found between early intervention programs across Canada, although unexpected, are very informative and point to some national strengths for early intervention service delivery systems in Canada. First, the finding that there are an average of ten different services available in programs across Canada, with professionals from an average of five different domains implies that services from multiple disciplines are available to families under one roof. As researchers have concluded that services should be comprehensive and coordinated for parents (Guralnick, 2001; Dunst & Bruder, 2002; Park & Turnbull, 2002), service providers across Canada are on the right track in terms of this crucial variable. Effective service coordination provides many benefits for families and children, including increased quality and support, better information flow, more efficient access, improved relationships, greater availability of funding, empowerment, and improved child outcomes (Dunst & Bruder, 2002; Park & Turnbull, 2003; Ramey & Ramey, 1998).

Surprisingly, average wait times across Canada were also similar from province to province. Canadian families waited an average of six months before receiving services. An average of six months is lower than one might expect based on public perceptions and media reports. However, although Canadian service providers seem to be doing a satisfactory job in terms of getting children services as early as possible overall, there is too much variation between individual programs in each province. For example, while some Canadian families received an initial assessment immediately at the point of referral, other service providers have a waitlist of up to two years for an initial assessment. While some Canadian families began services immediately after a diagnosis was given, other service providers have a waitlist of up to five years.

With regards to wait times, it is not possible to determine or control for whether or not families were on multiple wait lists at the same time. Also, wait times were reported estimated by parents and service providers, rather than obtained through a standard procedure, such as obtaining information through early intervention program databases. As such, wait times can only be considered rough estimates and may not be directly comparable from one report to the next.

Although the Canadian average, at first glance, may appear satisfactory, it is important to take into account the range of wait times. Service providers with an average wait list of up to two years for an assessment and five years for services to commence are not able to meet family needs in terms of providing services early in the child's developmental trajectory. As greater gains are made when services begin early, as the first three years are a time of intensive brain development (McCain et al., 2007; Roberts et al., 2008), it is critical that children across Canada are provided with assessment and treatment in a timely manner.

By looking more in greater depth at programs where wait times are shortest, information could be gleamed with regards to service delivery variables that facilitate early assessment and intervention. This information could then be used to facilitate the development of a national policy for early intervention across Canada, in an effort to work towards more equal and appropriate services across the country. This will not be an easy task to accomplish, and will require a great deal of financial support, however, investigating the specific programs where wait times are at their shortest, will likely prove to be a step in the right direction.

Service provider satisfaction ratings were also comparable across Canada. Service providers were satisfied with child outcomes and the adequacy of their programs overall, despite insufficient support from their respective government. An important next step could be to determine what factors are impacting the negative service provider ratings in terms of government supports. By determining the factors involved in this reported dissatisfaction and targeting these concerns, factors that impede the optimal progression of children and their families can be pinpointed and changed.

In summary, the analyses of responses from service providers across Canada indicate that services and supports are more similar than dissimilar. Although there continues to be room for improvement, service providers offer coordinated service, with shorter average wait times, on average than one may expect based on reports in the media. It is, however, important to keep in mind that, although wait times seem short overall, the variability between wait times in individual programs is large, resulting in some families having to wait several years for services while others are provided with services almost immediately. A shift towards equal and appropriate access for all families is necessary.

Canadian service providers are satisfied with the adequacy of their programs and the progress that children in their respective programs are making. However, they do not feel as though they are being supported sufficiently by the provincial or territorial government, which could, in turn, impede the progress of children and families in Canadian early intervention programs.

Parent Comparisons

Based on the literature review of Canadian early intervention policy and practice, significant variation across Canada was expected in terms of parent-reported early intervention factors (i.e., wait list, program intensity, satisfaction with child outcomes and government supports, coping strategies, and perceptions of family-centered care). However, as this was the first Canada-wide study of early intervention from a family perspective, no specific predictions were made, as the research study was exploratory in nature. However, based on the differences in early intervention policy across Canada, it was expected that differences would exist in some, if not all, domains.

As was the case with the service provider comparisons, there were many similarities in terms of parent experiences with early intervention across Canada. The average age that children began services was comparable across Canada. This finding was particularly surprising as some provinces have specific policies in place to minimize wait times (e.g., zero wait-list policy in Newfoundland and Labrador) while many others do not. Canadian parents reported waiting an average of 6 months for an initial assessment and an additional 6 months for service onset after a diagnosis has been made. This 12-month average waitlist is double the average wait time reported by Canadian service providers. This could be explained by a potential bias whereby parents that are dissatisfied with services may be more likely to participate in order to have their concerns heard whereas parents that are satisfied with services (for example, those who receive expedient services) may have less of a vested interest in participation. Alternatively, waitlist fluctuations could also influence the differences between service provider and parent-reported wait times. For example, service providers likely reported on current wait times whereas parents with children already receiving services would have reported on the wait time at the time of their assessment and entry into services. Waitlists could have become shorter over time due to increased staff or funding, decreased referrals, or the development of additional early intervention programs improving accessibility.

In the present study, parental coping strategies, particularly in terms of acquiring social and community support, were also comparable across the country. In addition, parent perceptions of how family-centered services were through the program were comparable, specifically in terms of parent reports of how respectful and supportive service providers were and how much relevant information was provided. As previous studies have not been conducted to compare parental coping or perceptions of family-centered care across Canada, a prediction was not made beforehand in terms of the cross-country similarities or differences in terms of these specific variables.

Families reported using active, problem-focused coping strategies (specifically, acquiring social and community support) to a moderate degree overall. Although Canadian families are using effective coping strategies to a certain degree, they would likely benefit from additional training to further improve their use of helpful coping techniques. As parenting a child with special needs can be stressful and parental stress levels can be decreased through the use of positive coping strategies ((Hastings et al., 2005; Hastings & Johnson, 2001; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001), it is crucial that parents have the support necessary to use problem-focused coping strategies as much as possible.

Canadian parents felt as though care was somewhat family-centered in terms of the amount of relevant information they received and how respected and supported they felt. Although parents perceive services as being moderately family-centered, these findings indicate that there remains room for improvement. Family-centered care is one of the most crucial components of effective early intervention programs, resulting in benefits to both the child and family (Blackman, 2002; Guralnick, 2005; King et al., 2004; McCollum, 2002; Webster, Feiler, & Webster, 2003). Benefits include enhanced skill development, appropriate programming based on family goals, and successful skill generalization. Researchers have found that parental confidence in their ability to support their child with special needs is improved and stress, anxiety, and isolation are reduced when parents are involved in the their child's program (McBridge, 1991; Pelchat, Bisson, Richard, Perrault, & Bouchard, 1999; Robertson & Weismer, 1999; Mazzucchelli, Roberts, Studman, Sanders & Jeffs, 2003; Kennedy, Chretien, & Moxness, 2004).

Although many similarities were found across Canada in terms of parent-reported early intervention variables, differences were also apparent. First, although the majority of provinces were similar in terms of the average age at diagnosis, significant differences were found between Quebec and Alberta. The average age at diagnosis was significantly earlier in Alberta (25 months) than in Quebec (35 months). It would be helpful to look at cultural differences as this may play a part in the differences between provinces. For example, differences may exist with respect to willingness to seek external support. Also, it is important to note that the majority of parents and service providers from Quebec who took part in the study were bilingual or Anglophone. As such, this is not a representative sample of Quebec and results could be different with the Francophone community.

It is unknown why children in Alberta were diagnosed an average of ten months earlier than children in Quebec. However, there are many potential factors that could be impacting the difference in age at diagnosis. It is possible that differences in terms of funding allocated for diagnostic assessments could play a role. Another possibility is that there may be fewer professionals working in the field in Quebec that are able to conduct diagnostic assessments for children with developmental delays. There could also be greater focus in Alberta in terms of early warning signs and parent education, resulting in parents speaking to their family doctors about concerns earlier on and consequently being referred for an assessment at an earlier age. The differences in average age of diagnosis could also be due to differences in political priorities of the current politicians and key stakeholders within the provinces (e.g., greater funding allocation in some provinces or territories). It is worth noting that Alberta is the only province in Canada that has a legislative act for children with special needs.

Although it is unknown why the average age at diagnosis is so much earlier in Alberta than in Quebec, we know that children who begin services earlier in their development often make greater gains. As such, an important area of future research could involve looking at current services and supports in Alberta in more detail to determine what factors contribute to their ability to assess and identify children with disabilities at an earlier age. For example, the fact that Alberta is the only province with childhood disability legislation could impact their earlier average age at diagnosis.

Significant differences were also found across Canada in terms of parent-reported intensity of service (i.e., average number of service hours per week). Parents in Nova Scotia reported significantly fewer hours of intervention per week than parents in Newfoundland and Labrador, Alberta, New Brunswick, Ontario, British Columbia, and Quebec. Parents in Nova Scotia received an average of 2 hours of weekly services whereas parents in the other provinces reported an average of 11 to 16 hours per week.

One hypothesis could be that children in Nova Scotia whose parents took part in the study were higher functioning and consequently entitled to fewer supports and services. It could also be that the proportion of children with specific diagnoses played a role in these differences. For example, children with a diagnosis of Autism Spectrum Disorder are typically entitled to more intensive services than children with a diagnosis of Down Syndrome. In comparing program intensity in Canada based on diagnosis alone in the present study, it was found that children with a diagnosis of ASD received, on average, 16 hours of intervention per week whereas children with a diagnosis of Down Syndrome received only 3 hours of weekly service.

Another difference was found in terms of parent-reported satisfaction with early intervention programs. Parents in Newfoundland and Labrador reported lower levels of overall satisfaction than parents in Alberta, Nova Scotia, and British Columbia. Again, one cannot predict with any level of certainty why parents in Newfoundland and Labrador were less satisfied than parents in the other provinces. As Albertan parents were most satisfied, a reasonable hypothesis could be that parents in Alberta were most satisfied as this is the province in which children are diagnosed earliest, resulting in improved child outcomes and parent satisfaction.

Similarly, parents from Alberta reported greater levels of satisfaction than parents in Quebec, Nova Scotia, British Columbia, Saskatchewan, Newfoundland and Labrador, and Ontario. Parents in Quebec reported the lowest overall rating of satisfaction with government contributions.

As previously mentioned, diagnosis occurs earliest in Alberta, which could result in parents having a better understanding of their child's needs early on and finding appropriate services more quickly. Even though children in Alberta did not begin early intervention services earlier than other Canadian children, it is possible that parents in Alberta were able to implement other supports in the meantime (e.g., single service supports, parent-implemented interventions, alternative therapies), resulting in greater levels of satisfaction.

The provincial policies particular to Alberta could also impact the parent-reported satisfaction with government supports. For example, Alberta is unique in that parents can choose the Direct Funding option and receive funds to choose their own therapy and staff or the Service Funding option where services and supports are provided by a pre-determined agency. This option, also available in Ontario, could also partly explain why parents in Ontario also reported greater levels of government satisfaction than several other provinces. It is possible that parents that are afforded the opportunity to choose their own services and staff are more satisfied with the government because they feel as though they are given more control in terms of their child's treatment.

Alberta also has several provincial acts and initiatives, specific to families with disabilities. This could impact parent ratings of government contributions in that they perceive themselves as being more supported as there is specific legislation to protect and support their families. For example, the *Family Support for Children with Disabilities Act* mandates support for any child with a disability, as outlined in the act. A variety of services and supports, which are not typically provided in other provinces (e.g., disability related clothing and footwear, up to 240 hours of respite per year, costs covered for attending medical appointments) are available. The support made available to families with special needs on the basis of acts such as this one could certainly impact parent ratings of overall satisfaction with government support.

Parents in Quebec reported the lowest level of satisfaction with government supports in Canada. This could be due, at least in part, to the finding that families in Quebec must wait the longest for an initial diagnostic assessment. Children in Quebec do not receive an assessment, on average, until 36 months of age whereas children in Alberta, for example, are diagnosed by 25 months of age, almost one year earlier. This could result in parents being upset with the provincial government because their children are not being diagnosed early enough, resulting in a delay of supports and consequently, potentially less optimal outcomes as researchers have concluded that results are more favourable when intervention occurs early (Ramey & Ramey, 1998; Roberts et al., 2008; Woods & Wetherby, 2003)

The specific policies in place for children with special needs and their families in Quebec could also be seen as insufficient, resulting in lower ratings of parent satisfaction with government support. For example, a provincial act, like the Family Support for Children with Disabilities in Alberta, does not exist in Quebec. Parents may not feel as though enough is being done for children with special needs in Quebec.

Parent reports from across Canada have been both similar and dissimilar, depending on the variable in question. Canadian children receive services at approximately the same age and families use similar coping strategies and report programs as being moderately family-centered. In terms of differences across Canada, diagnosis occurred earliest in Alberta. Similarly, Alberta parents reported the greatest levels of overall program satisfaction and satisfaction with government supports. Parents in Nova Scotia attended the least intensive programs (i.e., fewest hours of service per week) and Quebec parents were the least satisfied with government supports.

Now that the provinces with the most satisfied parents have been identified, an important next step will be to determine what factors result in this greater level of satisfaction. Conversely, an investigation of provinces that are most dissatisfied could also be useful in informing policy makers what parents believe is lacking in their respective province or territory. This information can then be used to help policy makers move forward in terms of the provision of equal and appropriate services and supports for all Canadian children with special needs and their families.

Service Provider and Parent Comparisons

The satisfaction ratings of Canadian parents and service providers were compared to determine whether parents and professionals agree or disagree in terms of their perceptions of the current state of affairs of early intervention in Canada. Service providers rated their satisfaction with child outcomes, program adequacy, and government supports significantly more favourably than Canadian parents. Although definitive conclusions cannot be made on the nature of these differences, several hypotheses exist.

It could be that service providers are reportedly more satisfied with child outcomes than parents because children typically make gains with service providers prior to generalizing the skills with their parents in the home. For example, a child may be able to match picture cards at an early intervention center, while sitting at a table with his or her instructor therapist, but be unable to generalize the concept of matching to his or her home (e.g., by matching socks with mom or dad). Therefore, child progress may look more successful to service providers before parents are able to see the progress in various domains, having an impact on the discrepancies of parent and service provider satisfaction ratings. In addition, parents do not typically come to the table with the same degree of training in terms of behaviour modification and teaching strategies. It may take parents longer to get the desired results in the home, resulting in lower ratings of child progress early on.

Service providers also reported significantly greater levels of satisfaction with program adequacy. If service providers are seeing results faster than parents, as can be seen with the greater ratings in terms of child progress, they may then conclude that their program is more effective. Parental judgments in terms of program adequacy may increase once they begin to see results in the home. An alternative or additional explanation for lower parent ratings of program adequacy could have to do with expectations. As parents typically want the very best for their child, they may give more conservative estimates in terms of program adequacy until they are absolutely sure that the program is optimally beneficial for their child. Service providers, on the other hand, have seen success with other children, often over many years, strengthening their opinion that their programs are sufficiently adequate.

Finally, service provider ratings of the government's ability to meet the needs of children with special needs were also higher than parental ratings. One possible explanation for this is that the majority of service providers that took part in the study were publicly funded programs. As such, they would be more inclined to stand behind their provincial government and hesitant to report anything that could be construed as negative or judgmental. Parents, on the other hand, may feel resentment towards the government because of waitlists or limited availability of services within their region. Parents that may have paid for private services while on public waitlists would also likely rate government support less favourably because of the impact of the financial burden. Another possibility is that parents are more aware of their child's needs and how well they are, or are not, being fulfilled as this is their reality on a day to day basis.

Early Intervention Program and Parent Perception

Based on a review of the early intervention literature looking at factors linked to program success, various predictions were made both in terms of service provider and parent reports. As expected, parents were more satisfied with programs when services began earlier and multiple services were made available. The age of service delivery onset and comprehensiveness of programs are key elements in Gurlanick's (2001) Developmental Systems Model for Early Intervention. As researchers have found that beginning services early and providing a multitude of services and supports is most beneficial for child progress, parents in the present study reported greater levels of satisfaction when services began early. Similarly, parents were more satisfied with child outcomes when programs were more intensive (i.e., greater number of service hours per week). It is important to note, however, that the above correlations were weak, indicating that each variable on its own cannot predict much variation in perceived parental satisfaction. There are likely many variables influencing parental satisfaction, having a cumulative effect overall.

The strongest relationship was found between parent satisfaction with child outcomes and perceived parental involvement. Again, parent involvement is a key tenet of the Developmental Systems Model (Guralnick, 2001) as the majority of learning in the early years takes place in the home and this is a period of rapid brain development. The provision of informational needs, a component of family-centered care, was also positively correlated with parent satisfaction. Family involvement is one of the most critical priorities in effective early intervention (Bruder, 2000; Guralnick, 2005; Hume, Bellini, & Pratt, 2005; Page-Smith & Rix, 2006). As such, parents were more satisfied when programs were family-centered, involving and supporting family members throughout the process. Parents that are involved and supported along the way will have the competence to enhance the child's program by actively taking part in the generalization and practice of skills (Guralnick, 1999), resulting in greater overall levels of satisfaction. In addition, the involvement of parents in early intervention provides parents with a sense of control and competence (Trivette, Dunst, & Hamby, 1996).

Finally, the relationship between parental coping strategies and parent satisfaction was examined. Positive and problem-focused coping strategies (i.e., *acquiring social support, mobilization,* and *seeking spiritual support)* were most strongly correlated with parent satisfaction. *Reframing,* an emotionally-focused coping strategy and *passive appraisal* were not significantly correlated with parent satisfaction.

Limitations and Future Directions

Despite the contributions that have been made to the field through the current research study, there are also several limitations. First, there was no way to control for which parents and service providers took part in the study. Parents that were dissatisfied with the current state of affairs in their province may have been more inclined to take part in the research study than parents who were satisfied with service provision. Time constraints, access to the internet, and degree of literacy may have had an influence on which parents and service providers took part in the study.

A second limitation of the present study is that, as the majority of questionnaires were completed online, it is unknown whether the person who completed the questionnaire was the person for whom the questionnaire was intended. For example, we asked that the program directors or managers at each early intervention program complete the questionnaires. However, some directors may have asked administrative support staff or other employees to complete the questionnaire due to time or resource constraints. In the future, telephone surveys with program directors, although more costly and timeconsuming, could ensure that there was consistency with respect to who completed the questionnaire at each program.

Third, although the questions in the questionnaire were designed to be straightforward and user-friendly, the possibility exists that some of the questions were difficult for certain respondents to understand. Contact information for the primary researcher was provided within the questionnaire in case questions or difficulties arose to help control for this. However, the effort required to contact the researcher, may have been a limiting factor for the respondent to seek out clarification. There is also the chance that some of the questions could have been misinterpreted, impacting the validity of the results. In the future, telephone or in-person interviews could control for this limitation. However, the financial cost and amount of time and resources needed to use such a methodology would be significantly greater than relying on online questionnaires.

Fourthly, closed-ended questions were typically used in the present study to allow for ease of interpretation and data analysis. This could also be considered a limitation from the point of view of some of the respondents, as they may not have felt as though the response options captured their particular experience or allowed for enough detail or elaboration. Open-ended questions in future research studies, although more difficult to analyze and interpret, would provide additional information to research teams.

The time frame of the present study could also be seen as a disadvantage of the present study. Service providers took part in the study from 2006-2010 and parents from 2008-2010. As such, by the time the results were analyzed in 2010, some of the practices and procedures from the programs where individuals responded earlier (e.g., in 2006) may have changed. Due to practical constraints and resource limitations, this could not be avoided with the present study, however, in the future, researchers should try to complete similar studies in shorter time frames if possible.

Another limitation with the present study is that it was difficult to get a sufficient response from certain provinces and territories. For example, the northern territories were excluded from the parent component of the research study because there were so few early intervention programs to begin with that recruitment through programs was nearly impossible. Internet availability is also limited in the northern territories, making it difficult to recruit potential parents online.

The reliance on self-report data could also be seen as another limitation of the present research study. Self-report data leaves room for error as parents or service providers may guess at answers or forget important information. For example, with respect to reported wait times, institutional or administrative databases, if available, would provide more reliable information than self-report data which is subject to error and inaccuracy. Finally, the lack of personal contact with online or mail-in surveys is another limitation with the present study. As such, the study cannot be explained in-person, individual questions cannot be answered, and the researcher cannot judge the quality of the responses in each case.

Conclusion

Despite the limitations of the present study, the results provide a strong basis for future research, which can hopefully improve on the limitations mentioned above. This research study is of great importance to the field as it is the first of its kind to compare early intervention programs across Canada. It has allowed for a snapshot of comparisons across the country with respect to a wide variety of service delivery variables, including wait lists, number of services and service providers, funding, and satisfaction ratings. In addition, parent experiences with early intervention services, including their perceptions of family-centered care and coping strategies, were compared and contrasted.

Contrary to popular belief, service providers and parents across Canada were more similar than expected in many ways. This is one of the most surprising findings in the current research study. The areas in which significant differences were identified could help in informing policies and procedures on a national level. For example, as parents in Alberta were most satisfied overall and reported shorter wait times for assessment and service delivery, it would be helpful to get more information about how wait times are reduced and what factors are contributing to increased parent satisfaction. This could be informative for other provinces, where wait times are longer and parents are reportedly less satisfied with the current state of affairs.

Another interesting finding was that service providers rated government support as being insufficient in all provinces and territories across Canada. Despite satisfaction with programs and child outcomes, both parents and service providers felt as though government support was lacking in each province and territory across Canada. Parents were more dissatisfied than service providers overall but even service providers felt as though more could be done in their respective province or territory.

As research should inform clinical practice (Dunst & Trivette, 2009), the results of the study could facilitate service providers in examining alternative models and could encourage them to re-examine current policies and practices and encourage the addition of new elements into their existing service delivery framework. Of particular importance, is the contribution in terms of incorporating parent input into early intervention research.

Program evaluations often focus on child outcomes, ignoring the effects of services on the family. It is crucial to ensure that services are appropriate for both the child and the family, as the majority of the child's learning and development takes place in the home.

As the gap between evidence-based practice and actual practice is as wide as ever, we must work on closing this gap to ensure that the best outcomes for children are possible (Dunst & Trivette, 2009; Odom, 2009). As the research-based programs are often most effective (Herrod, 2007; Odom, 2009) research endeavours like the present study must not only continue to be conducted but also brought forth to clinical and political decision-makers to facilitate change and ensure best practice across Canada for children and families with special needs.

As policy decisions typically move faster than research and scientific findings are only one factor that goes into policy formation, improving research-based practice in Canadian Early Intervention is no easy feat (Huston, 2008). Researchers must continue to replicate findings and insist on bringing results to the forefront so that policymakers and other key stakeholders can see the value in the research findings (Huston, 2009). As such, it is not sufficient to conduct research and submit publications to scientific journals. It is also necessary to speak the language of social policy and help key stakeholders learn to interpret, evaluate, and incorporate research findings in social policy development.

This research study provided an original contribution to the field of early intervention research and will hopefully prove to be a stepping-stone for future research endeavors in this area. As previously mentioned, this is the first research study to compare early intervention services across Canada, from both a service provider and parent perspective. This study has provided a snapshot of Canadian early intervention services and supports and the results can be used to guide future research endeavours, where more information can be gleamed with respect to key variables for program success and appropriate services across Canada.

This research study was largely influenced by Guralnick's developmental systems model for early intervention (Guralnick, 2005b). This model was not intended to prescribe a uniform set of services and supports across all communities. Instead, it was intended to provide an overview of variables that have been found to have an impact on the course of young children who are vulnerable and consequently guide service development and delivery from a broader perspective.

In keeping with the developmental systems model, the results of the current study can be used to inform clinicians, policy makers, and other key stakeholders about some of the policies and practices across Canada. Given the diversity of Canada, the goal is not to put together a universal paradigm whereby services and supports are the same across the country. It is our hope that the results of studies such as these will help service providers, policy makers, and other key stakeholders develop appropriate, rather than equal services, given the communities individual needs and differences. The study was designed to provide insight into various practices across the country so that individual provinces can incorporate different elements into their policies and practices.

In light of Guralnick's efforts to facilitate research and collaborations on an international level and share knowledge globally, this research study will hopefully be one of many contributions world wide that can be used to facilitate future research studies, inform practice, and create dialogues between key stakeholders in the field of early intervention around the globe.

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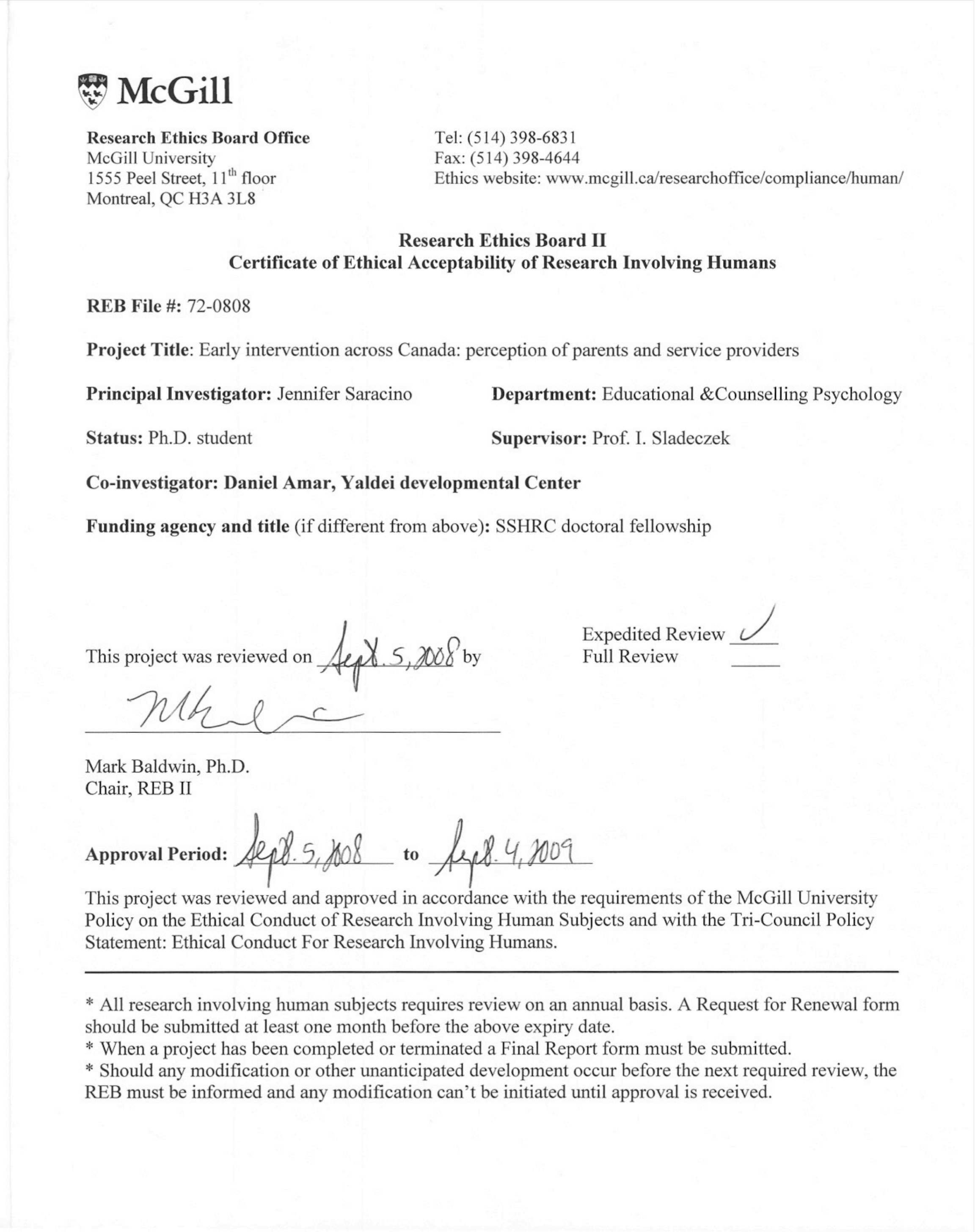
Appendices A: Certificate of Ethical Acceptability



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Research Ethics Board II
Certificate of Ethical Acceptability of Research Involving Humans

REB File #: 72-0808

Project Title: Early intervention across Canada: perception of parents and service providers

Principal Investigator: Jennifer Saracino

Department: Educational &Counselling Psychology

Status: Ph.D. student

Supervisor: Prof. I. Sladeczek

Co-investigator: Daniel Amar, Yaldei developmental Center

Funding agency and title (if different from above)**:** SSHRC doctoral fellowship

This project was reviewed on Sept. 5, 2008 by

Expedited Review ✓
Full Review

Mark Baldwin, Ph.D.
Chair, REB II

Approval Period: Sept. 5, 2008 **to** Sept. 4, 2009

This project was reviewed and approved in accordance with the requirements of the McGill University Policy on the Ethical Conduct of Research Involving Human Subjects and with the Tri-Council Policy Statement: Ethical Conduct For Research Involving Humans.

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* All research involving human subjects requires review on an annual basis. A Request for Renewal form should be submitted at least one month before the above expiry date.
* When a project has been completed or terminated a Final Report form must be submitted.
* Should any modification or other unanticipated development occur before the next required review, the REB must be informed and any modification can't be initiated until approval is received.

Appendices B: Early Intervention Service Provider Questionnaire

Early Intervention Service Provider Questionnaire

1) * Please provide the following information.

Contact Name ____________________________
Affiliation ____________________________
Address ____________________________
City ____________________________
Province ____________________________
Email ____________________________
Phone Number____________________________

2. Please provide the following optional information

Fax Number ____________________________
Website ____________________________

3. What is the total number of children enrolled in your program?

____

4. What is the age range of children enrolled in your program? (check all that apply)

☐ 0 - 2 years 11 months

☐ 3 - 5 years 11 months

☐ 6 - 9 years 11 months

☐ 10 + years

5. Approximately how many children with a developmental delay in the following age categories are enrolled in your program? [Note: developmental delay is defined as a chronological delay in the appearance of normal developmental milestones achieved during infancy and early childhood, caused by organic, psychological, or environmental factors].

0 - 2 years 11 months: ☐

3 - 5 years 11 months: ☐

6 - 9 years 11 months: ☐

10 + years: ☐

6. What types of services are offered through your program? (check all that apply)

☐ ASSISTIVE TECHNOLOGY (services that assist a child with a device to aid their functional capabilities

☐ AUDIOLOGY (services that assist children with/at risk of a hearing related problem, provide auditory rehabilitation and determine individual amplification needs)

☐ SERVICE PLANNING (services that help families to understand and meet their child's needs)

☐ MEDICAL SERVICES (diagnostic and evaluative services provided by a licensed physician as part of the child's assessment)

☐ NURSING SERVICES (services that assess the health status of the child, including the administration of medications)

☐ NUTRITION SERVICES (services provided by a registered nurse to help address the nutritional needs of the child, including the identification of feeding problems and skills and food habits)

☐ OCCUPATIONAL THERAPY (services that relate to self-help skills, adaptive behavior and play, and sensorimotor development to improve functional task performance)

☐ PHYSICAL THERAPY (services to prevent or lessen movement's dysfunction and related functional problems to promote effective environmental adaptations)

☐ PSYCHOLOGICAL SERVICES (services that assess and address the psychological development of a child including information on learning, mental health, and development)

☐ SERVICE COORDINATION (services that provide families with partnerships to connect to services in the community and obtain their rights)

☐ SOCIAL WORK/FAMILY SERVICES (services which work to assess the social and emotional strengths and needs of a child and family, provide individual or group counseling or training and link families with community resources)

☐ SPECIAL INSTRUCTION (services that involve designing learning environments and activities to promote child development and provide families with information, support and skills)

☐ SPEECH LANGUAGE PATHOLOGY (services that address speech and/or language development and pathology, such as problems with articulation, language or fluency)

☐ VISION SERVICES (the evaluation and assessment of visual functioning

☐ HEALTH SERVICES (health-related services that are required to enable the child to benefit from other early intervention services)

☐ TRANSPORTATION AND RELATED COSTS (services that cover the cost of travel and parking necessary for the child and family to be able to obtain services)

☐ CASE REVIEW (annual or semi-annual meetings designed to evaluate and modify the child's treatment plan)

☐ TRANSITION SERVICES (coordination of services between the centre and school)

☐ TOY/RESOURCE LIBRARY (a library of resources for parents and children)

☐ INFANT DEVELOPMENT/STIMULATION (program directed at children 0-3years of age)

☐ RESPITE SERVICES (services providing temporary relief for families of children with disabilities)

☐ PRESCHOOL SERVICES (pre-academic skill building program for children prior to school entry)

☐ SCHOOL SERVICES (educational services modified to fit the child's specific needs)

☐ SERVICES FOR MEDICALLY FRAGILE CHILDREN (medically necessary services that allow for service provision to children with special medical needs)

☐ OTHER (Please Specify)

7. Please list the professionals who provide services through your program. (check all that apply)

☐ PSYCHOLOGIST (A professional specializing in diagnosing and treating diseases of the brain, emotional disturbance, and behavior problems)

☐ PSYCHIATRIST (A physician (M.D.) who specializes in the prevention, diagnosis, and treatment of mental illness)

☐ EDUCATIONAL SPECIALIST (An individual that assists children with diverse learning needs by making educational gains by making program accommodations, assisting with the learning process and monitoring success)

☐ LICENSED EDUCATOR (a professional with an background in educational instruction (i.e. a teacher)

☐ PHYSICAL THERAPIST (therapist who treats injury or dysfunction with exercises and other physical treatments of the disorder)

☐ SPEECH LANGUAGE PATHOLOGIST (a professional that provide services to assist people with communication and swallowing difficulties)

☐ DIETICIAN/NUTRITIONIST (a specialist in nutrition that can help patients with special needs, allergies, health problems, or diet plans)

☐ PARAPROFESSIONAL (any professional with special training in the field that is not necessarily with a professional order)

☐ OCCUPATIONAL THERAPIST (a professional that helps with adaptive or sensorimotor skills and works on improving the individual functional skills of the child)

☐ SOCIAL/FAMILY SERVICE WORKER (a professional that provides support to the child and family, often with counseling, training and home visitation)

☐ PEDIATRICIAN/DEVELOPMENTAL PEDIATRICIAN (a physician who specializes in the care of infants and children)

☐ BEHAVIORAL CONSULTANT (a consultant that specializes in the modification and improvement of a child's behaviour eg. poor school performance, problem behaviors)

☐ EARLY INTERVENTION SPECIALIST (a certified professional with educational background in service provision for infants and young children in need of special assistance)

☐ RECREATION/ART/PLAY/MUSIC THERAPIST (professional using one of those four modalities to improve the functioning of children in need of special services)

☐ OTHER (Please Specify)

8*. On a scale of 1 to 10, please rate your general perception of parent satisfaction with your centre/program (1 = not at all satisfied; 5 = somewhat satisfied; 10=completely satisfied)

____

9*. On a scale of 1 to 10, please rate your overall satisfaction with child outcomes in your centre/program (1 = not at all satisfied; 5 = somewhat satisfied; 10=completely satisfied)

____

10*. On a scale of 1 to 10, please rate your overall satisfaction with the adequacy of your professional services and programs in their ability to respond to your client needs (1 = not at all satisfied; 5 = somewhat satisfied; 10=completely satisfied)

____

11*. On a scale of 1 to 10how would you rate the ability of your government to provide adequate responses to children with developmental delays (1 = not at all satisfied; 5 = somewhat satisfied; 10=completely satisfied)

____

12. On average, how many hours of service does a child with a developmental delay (in each of the specificied age ranges) receive in a weekly period through your program?

0 - 2 years 11 months:	☐
3 - 5 years 11 months:	☐
6 - 9 years 11 months:	☐
10 + years:	☐

13. Which service model(s) does your program employ?

☐ HOME AND COMMUNITY-BASED VISITS (services are provided to the child and/or family in the home or other natural environments)

☐ CENTRE-BASED VISITS (services to the child and/or family by appropriate qualified personnel at an approved early intervention provider's site)

☐ PARENT-CHILD GROUPS (group comprised of caregivers, children and at least one qualified provider of early intervention services at a centre or community-based site (ie. daycare)

☐ FAMILY SUPPORT GROUPS (services are provided to family members to enhance their capacity to support, educate, care for and enhance the development of the child)

☐ GROUP RESIDENTIAL PROGRAM (services are provided by qualified personnel to a group of children usually under three years of age at an early intervention centre or community-based setting. Typical peer involvement is common in these programs)

☐ DAY TREATMENT PROGRAM (services are provided by qualified personnel at a centre during the day but children return home at night)

☐ OTHER (Please specify)

14. In general, please check the model that best represents your program's approach?

○ MULTIDISCIPLINARY (professionals from several disciplines work independently of each other in a side-by-side but separate fashion with parents being responsible for service coordination)

○ INTERDISCIPLINARY (parents and professionals form teams with formal channels of communication. Professionals separately assess cases but teams collaborate on the intervention plan)

○ TRANSDISCIPLINARY (teams composed of parents and professionals cross disciplinary boundaries, maximizing communication and interaction. Families are critical in goal setting and decision making. Mutual training is common and decisions are made by team consensus)

15. On average, how long (e.g., weeks, months, years) does a child/family receive services in your program?

____

16. Is there a waiting list for assessment in your program?

☐ Yes

☐ No

17. Is there a wait list for services in your program?

○ Yes

○ No

18. On average, how long (weeks, months, years) is the wait list before a child is assessed for services?

____

19. On average, how long (weeks, months, years) is the wait list before a child is admitted for services?

____

20. How is your program funded?

○ PRIVATE

○ PRIVATE, NOT FOR PROFIT

○ PUBLIC

21. Please enter the percentage of funding received from each source.

GOVERNMENT:	
PRIVATE:	
OTHER (please specify):	

22. On average, what is the range of cost for a complete assessment for the child?

____

23. What is the average monthly cost for direct services at your centre (please exclude overhead and indirect costs)?

____

Appendices C: Early Intervention Parent Questionnaire

Early Intervention Parent Questionnaire

1) * Please provide the following information.

Name ____________________________
City ____________________________
Province ____________________________
Email ____________________________
Phone Number____________________________

2. What is your child's diagnosis?

____

3. How old is your child?

____

4. How old was your child when he/she received his/her diagnosis?

____

5. How old was your child when he/she began receiving early intervention services?

____

6. On average, how many weekly hours of early intervention services does your child receive?

____

7. Does your child receive early intervention services from one service provider or from multiple sources?

○ One Service Provider

○ Multiple Service Providers

8. How long has your child been receiving services from his or her current service provider(s)?

____

9. Which models of early intervention service delivery are provided to you and your child? (check all that apply)

☐ HOME AND COMMUNITY-BASED VISITS (services are provided to the child and/or family in the home or other natural environments)

☐ CENTRE-BASED VISITS (services to the child and/or family by appropriate qualified personnel at an approved early intervention provider's site)

☐ PARENT-CHILD GROUPS (group comprised of caregivers, children and at least one qualified provider of early intervention services at a centre or community-based site (ie. daycare)

☐ FAMILY SUPPORT GROUPS (services are provided to family members to enhance their capacity to support, educate, care for and enhance the development of the child)

☐ GROUP RESIDENTIAL PROGRAM (services are provided by qualified personnel to a group of children usually under three years of age at an early intervention centre or community-based setting. Typical peer involvement is common in these programs)

☐ DAY TREATMENT PROGRAM (services are provided by qualified personnel at a centre during the day but children return home at night)

☐ OTHER (Please specify)

10. What types of services does your family receive through your early intervention service provider(s)? (check all that apply)

☐ ASSISTIVE TECHNOLOGY (services that assist a child with a device to aid their functional capabilities

☐ AUDIOLOGY (services that assist children with/at risk of a hearing related problem, provide auditory rehabilitation and determine individual amplification needs)

☐ SERVICE PLANNING (services that help families to understand and meet their child's needs)

☐ MEDICAL SERVICES (diagnostic and evaluative services provided by a licensed physician as part of the child’s assessment)

☐ NURSING SERVICES (services that assess the health status of the child, including the administration of medications)

☐ NUTRITION SERVICES (services provided by a registered nurse to help address the nutritional needs of the child, including the identification of feeding problems and skills and food habits)

☐ OCCUPATIONAL THERAPY (services that relate to self-help skills, adaptive behavior and play, and sensorimotor development to improve functional task performance)

☐ PHYSICAL THERAPY (services to prevent or lessen movement's dysfunction and related functional problems to promote effective environmental adaptations)

☐ PSYCHOLOGICAL SERVICES (services that assess and address the psychological development of a child including information on learning, mental health, and development)

☐ SERVICE COORDINATION (services that provide families with partnerships to connect to services in the community and obtain their rights)

☐ SOCIAL WORK/FAMILY SERVICES (services which work to assess the social and emotional strengths and needs of a child and family, provide individual or group counseling or training and link families with community resources)

☐ SPECIAL INSTRUCTION (services that involve designing learning environments and activities to promote child development and provide families with information, support and skills)

☐ SPEECH LANGUAGE PATHOLOGY (services that address speech and/or language development and pathology, such as problems with articulation, language or fluency)

☐ VISION SERVICES (the evaluation and assessment of visual functioning

☐ HEALTH SERVICES (health-related services that are required to enable the child to benefit from other early intervention services)

☐ TRANSPORTATION AND RELATED COSTS (services that cover the cost of travel and parking necessary for the child and family to be able to obtain services)

☐ CASE REVIEW (annual or semi-annual meetings designed to evaluate and modify the child's treatment plan)

☐ TRANSITION SERVICES (coordination of services between the centre and school)

☐ TOY/RESOURCE LIBRARY (a library of resources for parents and children)

☐ INFANT DEVELOPMENT/STIMULATION (program directed at children 0-3years of age)

☐ RESPITE SERVICES (services providing temporary relief for families of children with disabilities)

☐ PRESCHOOL SERVICES (pre-academic skill building program for children prior to school entry)

☐ SCHOOL SERVICES (educational services modified to fit the child's specific needs)

☐ SERVICES FOR MEDICALLY FRAGILE CHILDREN (medically necessary services that allow for service provision to children with special medical needs)

☐ OTHER (Please Specify)

11. Please list the professionals that work with your child and family. (check all that apply)

☐ PSYCHOLOGIST (A professional specializing in diagnosing and treating diseases of the brain, emotional disturbance, and behavior problems)

☐ PSYCHIATRIST (A physician (M.D.) who specializes in the prevention, diagnosis, and treatment of mental illness)

☐ EDUCATIONAL SPECIALIST (An individual that assists children with diverse learning needs by making educational gains by making program accommodations, assisting with the learning process and monitoring success)

☐ LICENSED EDUCATOR (a professional with an background in educational instruction (i.e. a teacher)

☐ PHYSICAL THERAPIST (therapist who treats injury or dysfunction with exercises and other physical treatments of the disorder)

☐ SPEECH LANGUAGE PATHOLOGIST (a professional that provide services to assist people with communication and swallowing difficulties)

☐ DIETICIAN/NUTRITIONIST (a specialist in nutrition that can help patients with special needs, allergies, health problems, or diet plans)

☐ PARAPROFESSIONAL (any professional with special training in the field that is not necessarily with a professional order)

☐ OCCUPATIONAL THERAPIST (a professional that helps with adaptive or sensorimotor skills and works on improving the individual functional skills of the child)

☐ SOCIAL/FAMILY SERVICE WORKER (a professional that provides support to the child and family, often with counseling, training and home visitation)

☐ PEDIATRICIAN/DEVELOPMENTAL PEDIATRICIAN (a physician who specializes in the care of infants and children)

☐ BEHAVIORAL CONSULTANT (a consultant that specializes in the modification and improvement of a child's behaviour eg. poor school performance, problem behaviors)

☐ EARLY INTERVENTION SPECIALIST (a certified professional with educational background in service provision for infants and young children in need of special assistance)

☐ RECREATION/ART/PLAY/MUSIC THERAPIST (professional using one of those four modalities to improve the functioning of children in need of special services)

☐ OTHER (Please Specify)

12. Please indicate the weekly hours that your chlid works with the following professionals.

PSYCHOLOGIST:	☐
PSYCHIATRIST:	☐
EDUCATIONAL SPECIALIST:	☐
LICENSED EDUCATOR:	☐
PHYSIOTHERAPIST:	☐
SPEECH LANGUAGE PATHOLOGIST:	☐
DIETICIAN/NUTRITIONIST:	☐
PARAPROFESSIONAL:	☐
OCCUPATIONAL THERAPIST:	☐
SOCIAL/FAMILY SERVICE WORKER:	☐
OTHER (please specify)::	☐

13. Was your child put on a waiting list before being ASSESSED?

☐ Yes

☐ No

14. If there was a wait time for assessment, how long (weeks, months, years) did you and your child have to wait before receiving an assessment?

____

15. After being assessed, was your child put on a waiting list before RECEIVING SERVICES?

○ Yes

○ No

16. If there was a wait time how long (weeks, months, years) did you and your child have to wait before receiving services?

____

17. What was the initial cost to YOU to have your child assessed?

____

18. What is the average monthly cost to YOU for your child's early intervention services?

____

19. What type of program does your child attend?

○ PRIVATE (parents cover cost)

○ NOT FOR PROFIT (parents cover partial costs; fundraising/donations cover the rest)

○ PUBLIC (government covers the cost)

○ Other (Please Specify)

20*. On a scale of 1 to 10, please rate your general satisfaction with your child's centre/program (1 = not at all satisfied; 5 = somewhat satisfied; 10=completely satisfied)

____

21*. On a scale of 1 to 10, please rate your overall satisfaction with your child's outcomes or progress (1 = not at all satisfied; 5 = somewhat satisfied; 10=completely satisfied)

____

22*. On a scale of 1 to 10, how would you rate the adequacy of your child's service providers in their ability to respond to your child's needs (1 = not at all adequate; 5 = somewhat adequate; 10=completely adequate)

____

23*. On a scale of 1 to 10, how would you rate the ability of your government to provide adequate responses to children with developmental delays (1 = not at all able to meet their needs; 5 = somewhat able to meet their needs; 10=completely able to meet their needs)

____

Appendices D: Family Crisis Oriented Personal Evaluation Scales (FCOPES)

F-COPES
Family Crisis Oriented Personal Evaluation Scales
McCubbin, H., Olson, D., & Larsen, A.

Purpose

The Family Crisis Oriented Personal Evaluation Scales is designed to record problem-solving attitudes and behaviours which families develop to respond to problems or difficulties.

Directions

First, read the list of "Response Choices" one at a time

Second, decide how well each statement describes your attitudes and behaviours in response to problems or difficulties. If the statement describes your response very well, then circle the number 5, indicating that you strongly agree. If the statement does not describe your response at all, then circle the number 1 indicating that you strongly disagree; if the statement describes your response to some degree, then select a number 2, 3, or 4 to indicate how much you agree or disagree with the statement about your response.

Please circle a number (1,2,3,4,5) to match your response to each statement. Thank you.

When we face problems or difficulties in our family, we respond by:	Strongly Disagree	Moderately Disagree	Neither Agree nor Disagree	Moderately Agree	Strongly Agree
1. Sharing our difficulties with relatives	1	2	3	4	5
2. Seeking encouragement and support from friends	1	2	3	4	5
3. Knowing we have the power to solve major problems	1	2	3	4	5
4. Seeking information and advice from persons in other families who have faced the same or similar problems	1	2	3	4	5
5. Seeking advice from relatives (grandparents, etc.)	1	2	3	4	5
6. Seeking assistance from community agencies or programs designed to help families in our situation	1	2	3	4	5

7. Knowing that we have the strength within our family to solve our problems	1	2	3	4	5
8. Receiving gifts and favors from neighbors (e.g., food, taking in mail, etc.)	1	2	3	4	5
9. Seeking information and advice from the family doctor	1	2	3	4	5
10. Asking neighbors for favors and assistance	1	2	3	4	5
11. Facing the problems “head-on” and trying to get solution right away	1	2	3	4	5
12. Watching television	1	2	3	4	5
13. Showing that we are strong	1	2	3	4	5
14. Attending church services	1	2	3	4	5
15. Accepting stressful events as a fact of life	1	2	3	4	5
16. Sharing concerns with close friends	1	2	3	4	5
17. Knowing luck plays a big part in how well we are able to solve family problems	1	2	3	4	5
18. Exercising with friends to stay fit and reduce tension	1	2	3	4	5
19. Accepting that difficulties occur unexpectedly	1	2	3	4	5
20. Doing things with relatives (get-togethers, dinners, etc.)	1	2	3	4	5

21. Seeking professional counseling and help for family difficulties	1	2	3	4	5
22. Believing we can handle our own problems	1	2	3	4	5
23. Participating in church activities	1	2	3	4	5
24. Defining the family problem in a more positive way so that we do not become too discouraged	1	2	3	4	5
25. Asking relatives how they feel about problems we face	1	2	3	4	5
26. Feeling that no matter what we do to prepare, we will have difficulty handling problems	1	2	3	4	5
27. Seeking advice from a minister	1	2	3	4	5
28. Believing if we wait long enough, the problem will go away	1	2	3	4	5
29. Sharing problems with neighbors	1	2	3	4	5
30. Having faith in God	1	2	3	4	5

Appendices E: Measure of Processes of Care (MPOC-20)

MEASURE OF PROCESSES OF CARE
(MPOC-20)

We would like to understand and measure the experiences of parents who have a child with a disability. In particular we wish to know about your perceptions of the care you have been receiving over the past year from the health care organization that provides services to your child. This may be your local children's treatment (rehabilitation) centre, your community care access centre, or another organization.

The care that you and your child receive from this organization may bring you into contact with many individuals.The questions on this form are grouped by who these contacts are, as described below.

PEOPLE: refers to those individuals who work directly with you or your child. These **may include** psychologists, therapists, social workers, doctors, teachers, etc.

ORGANIZATION: refers to all staff from the health care organization, whether involved directly with your child or not. In addition to health care people they **may include** support staff such as office staff, housekeepers, administrative personnel, etc.

The questions are based on what parents, like yourself, have told us about the way care is sometimes offered. We are interested in your personal thoughts and would appreciate your completing this questionnaire on your own without discussing it with anyone.

For each question, please indicate how much the event or situation happens to you. You are asked to respond by circling **one** number from 1 (Not at All) to 7 (To a Very Great Extent) that you feel best fits your experience. Please note that the zero value (0) is used only if the situation described does not apply to you.

When answering these questions, we would like you to think about the organization from which you first found out about this study.

PEOPLE: refers to those individuals who work directly with you or your child. These **may include** psychologists, therapists, social workers, doctors, teachers, etc.

In the past year, to what extent do the **PEOPLE** who work with your child….	Indicate **HOW MUCH** this event or situation happens to you							
	To a very great extent	To a great extent	To a fairly great extent	To a moder-ate extent	To a small extent	To a very small extent	Not at all	N/A
1….help you feel competent as a parent?	7	6	5	4	3	2	1	0
2….provide you with written information about what your child is doing in therapy?	7	6	5	4	3	2	1	0
3...provide a caring atmosphere rather than just give you information?	7	6	5	4	3	2	1	0
4. ...let you choose when to receive information and the type of information you want?	7	6	5	4	3	2	1	0
5. ...look at the needs of your whole@ child (e.g., at mental, emotional, and social needs) instead of just at physical needs?	7	6	5	4	3	2	1	0
6. ...make sure that at least one team member is someone who works with you and your family over a long period of time?	7	6	5	4	3	2	1	0
7. ...fully explain treatment choices to you?	7	6	5	4	3	2	1	0

8. ...provide opportunities for you to make decisions about treatment?	7	6	5	4	3	2	1	0
9. ...provide enough time to talk so you don’t feel rushed?	7	6	5	4	3	2	1	0
10. ...plan together so they are all working in the same direction?	7	6	5	4	3	2	1	0
11. ...treat you as an equal rather than just as the parent of a patient (e.g., by not referring to you as "Mom" or "Dad")?	7	6	5	4	3	2	1	0
12. ...give you information about your child that is consistent from person to person?	7	6	5	4	3	2	1	0
13. ...treat you as an individual rather than as a "typical" parent of a child with a disability?	7	6	5	4	3	2	1	0
14. ...provide you with written information about your child's progress?	7	6	5	4	3	2	1	0
15. ...tell you about the results from assessments?	7	6	5	4	3	2	1	0

ORGANIZATION: refers to all staff from the health care organization, whether involved directly with your child or not. In addition to health care people they **may include** support staff such as office staff, housekeepers, administrative personnel, etc.

In the past year, to what extent does the **ORGANIZATION** where you receive services….	Indicate **HOW MUCH** this event or situation happens to you							
	To a very great extent	To a great extent	To a fairly great extent	To a moder-ate extent	To a small extent	To a very small extent	Not at all	N/A
16. ...give you information about the types of services offered at the organization or in your community?	7	6	5	4	3	2	1	0
17. ...have information available about your child's disability (e.g., its causes, how it progresses, future outlook)?	7	6	5	4	3	2	1	0
18. ...provide opportunities for the entire family to obtain information?	7	6	5	4	3	2	1	0
19. ...have information available to you in various forms, such as a booklet, kit, video, etc.?	7	6	5	4	3	2	1	0
20. ...provide advice on how to get information or to contact other parents (e.g., organization's parent resource library)?	7	6	5	4	3	2	1	0

Appendices F: Informed Consent – Service Provider Questionnaire

yaldei
centre de développement
developmental center

First Canadian National Early Inventory
www.earlyinterventioncanada.com

Dear Colleagues,

The purpose of this survey is to identify Early Intervention (EI) centres across Canada that service young children with developmental delays/disabilities between the ages of 0 and 9 and their families. In gathering this information, our research team will be able to compare, analyze and evaluate the different approaches and models of service delivery prevalent in EI centres across Canada.

The *Early Intervention Canada Research team* has developed a brief survey that can be completed on-line (access www.earlyinterventioncanada.com). The information collected will enable us to better understand the state of affairs of Canadian early intervention efforts, which has a profound impact on the well-being and functioning of families and their children with delays.

The benefits of completing this survey include:

* Providing a comprehensive snapshot of the Early Intervention system in Canada;

* Developing an up-to-date, Canada-wide database that will play an instrumental role in improving our knowledge of existing EI service models;

* Playing a role in developing a province-by province breakdown and evaluation of EI centres across Canada;

* Helping to improve our knowledge of current EI services and identification of gaps and critical issues in EI services;

* Sensitizing EI centers to best practices, success factors, and alternative EI models;

* Motivating EI centers to re-examine practices in light of inventory of other models;

* Encouraging EI centers to add new elements in their intervention approaches;

* Evaluating your own EI centre in comparison to other similar sites.

These results will be published online for public access, however, please note that information concerning specific EI centres will not be provided. The EI research team will ensure confidentiality with respect to specific information concerning your centre and will only publish aggregate data. Your information will be used for research purposes only and adheres to ethical standards set out in the tri-council ethics protocol.

If you are the executive director, program director or manager/coordinator of your centre please support our research goals by filling out this short online questionnaire. The results of the online survey concerning EI services, models, treatment approaches, best practices, critical success factors, and practice and policy recommendations for optimal service delivery will be disseminated to you personally in a timely fashion. It is agreed that you understand the purpose of this study and you agree to participate in our study.

Thank you for your contributions in this important effort to support early intervention in Canada! If you have any questions concerning this survey, please contact the investigators listed below.

To complete the survey please click here
http://www.zapsurvey.com/Survey.aspx?id=54dfbfc5-8269-40eb-901a-0978a2d7ff75

Sincerely,

Primary Investigator	***Co- Investigator***
Ingrid E. Sladeczek, PhD Associate Professor School/Applied Child Psychology Program McGill University Telephone (514) 398-3450 Fax Number (514) 398-6968 Email: ingrid.sladeczek@mcgill.ca www.earlyinterventioncanada.com	Daniel Amar, MBA, Research Director Yaldei Developmental Centre Telephone (514) 279-3666 ext. 236 Fax Number (514) 278-3666 Email: amardaniel@sympatico.ca

A Dynamic Assessment of Early Intervention Models in Children with Developmental Delays
Creating a Paradigm Shift in Early Intervention Policy and Practice
Funded by the Max Bell Foundation

Appendices G: Informed Consent – Parent Questionnaire

McGill

yaldei
centre de développement
developmental center

First Canadian National Early Inventory
www.earlyinterventioncanada.com

Dear Parents,

We would like to request your participation in a National study of Early Intervention for children with developmental delays. The purpose of this questionnaire is to survey parents of children with developmental delays from across Canada to determine what they believe to be the critical success factors and current gaps in service delivery. Responses will be used to make cross-province/territory comparisons in an effort to facilitate a national paradigm shift toward effective Early Intervention (EI) across Canada.

The service providers at your center have already participated in our national study by completing a questionnaire to help us understand the state of affairs of Canadian EI efforts. We believe that is critically important to assess the perceptions and experiences of families as well as service providers.

Parents are being asked complete a brief questionnaire used to assess their experiences with EI in their respective province. In addition, there is a 20-item standardized self-report measure (the Measure of Processes of Care-20) to determine the extent to which parents perceive services at children rehabilitation treatment centers as being family-centered. Participation shouldn't take longer than 20 minutes in total for both questionnaires.

The benefits of completing this survey include:

- → Providing a comprehensive snapshot of parent and family experiences with the Early Intervention system in Canada;
- → Developing an up-to-date, Canada-wide database that will play an instrumental role in improving our knowledge of existing EI service models;
- → Playing a role in developing a province-by province breakdown and evaluation of family experiences with EI centres across Canada
- → Helping to improve our knowledge of current EI services and identification of gaps and critical issues in EI services;
- → Sensitizing EI centers to best practices, success factors, and alternative EI models;
- → Motivating EI centers to re-examine practices in light of inventory of other models;
- → Encouraging EI centers to add new elements in their intervention approaches;
- → Evaluating the center/program your child attends in comparison to other services;

These results will be published online for public access, however, please note that any personal or identifying information will not be provided. The EI research team will ensure confidentiality with respect to specific information concerning your experience and will only publish aggregate data. Your information will be used for research purposes only and adheres to ethical standards set out in the tri-council ethics protocol.

If you are a parent of a child between 0 and 9 years of age with a developmental delay, please support our research goals by filling out these short questionnaires. The results of the parent and service provider questionnaires will be disseminated to you personally in a timely fashion. It is agreed that you understand the purpose of this study and you agree to participate in our study.

Thank you for your contributions in this important effort to support early intervention in Canada! If you have any questions concerning this survey, please contact the investigators listed below.

To complete the survey please click here
[insert survey link here]

Sincerely,

Primary Investigator	***Co- Investigator***
Ingrid E. Sladeczek, PhD Associate Professor School/Applied Child Psychology Program McGill University Telephone (514) 398-3450 Fax Number (514) 398-6968 Email: ingrid.sladeczek@mcgill.ca www.earlyinterventioncanada.com	Daniel Amar, MBA, Research Director Yaldei Developmental Centre Telephone (514) 279-3666 ext. 236 Fax Number (514) 278-3666 Email: amardaniel@sympatico.ca

A Dynamic Assessment of Early Intervention Models in Children with Developmental Delays

Creating a Paradigm Shift in Early Intervention Policy and Practice

Funded by the Max Bell Foundation

Appendices H: Debriefing Sheet – Service Providers

Dear Colleagues,

Thank you for participating in our Early Intervention Inventory. The information you have provided us with has enabled us to better understand the state of Early Intervention efforts in Canada. The closing date for this survey is expected to be in January 2009, however, conference presentations with interim data will be made available to you and on our website at www.earlyinterventioncanada.com. When the exact date is finalized, you will be sent an email with instructions on where to view the final results. Again, your individual centre will not be identified and only aggregate data will be provided.

Thank you again for your contributions in this important effort to support Early Intervention in Canada! If you have any questions concerning this survey, please contact the investigators listed below.

Sincerely,

Primary Investigator
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Associate Professor
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Appendices I: Debriefing Sheet – Parents

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centre de développement
developmental center

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Dear Parents,

Thank you for participating in our Early Intervention study. The information you have provided us with has enabled us to better understand the perceptions and experiences of parents with children in Early Intervention programs across Canada. The closing date for this survey is expected to be in January 2009, however, conference presentations with interim data will be made available to you and on our website at www.earlyinterventioncanada.com. When the exact date is finalized, you will be sent an email with instructions on where to view the final results of the study. Again, the data you provided will not be identified and only aggregate data by province or territory will be provided.

Thank you again for your contributions in this important effort to support Early Intervention in Canada! If you have any questions concerning this survey, please contact the investigators listed below.

Sincerely,

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Associate Professor
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Appendices J: Parent Recruitment Letter and Pamphlet

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developmental center

Dear Colleagues,

For the first phase of our Canadian Early Intervention Research Project, you completed an inventory regarding the services offered through your program. In an effort to expand on the research in the field, we are now surveying parents from EI programs across Canada to determine their experiences and perceptions of services for families and children with developmental delays.

In order to recruit an optimal number of participants we are asking service providers to post or distribute a pamphlet to recruit parents at the center to participate in this study. Enclosed you will find a copy of the pamphlet with information for parents about the study as well as contact information and a website link to the survey. The parent survey was designed to investigate parent perceptions of Early Intervention as well as parental coping and family-centered experiences.

Please distribute or post the parent pamphlet through your program. If you have any questions or concerns, please don't hesitate to contact us beforehand. We greatly appreciate your participation in this crucial national project.

Aggregate results from the parent and service provider questionnaires will be provided to you upon completion of the study and interim findings will also be distributed along the way. You can also find out more about the project at www.earlyinterventioncanada.com

Thank you again for your contributions in this important effort to support Early Intervention in Canada! If you have any questions, please contact the investigators listed below.

Sincerely,

Primary Investigator
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Associate Professor
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yaldei
centre de développement
developmental center

Dear Parents,

The Canadian Early Intervention Research Team needs your HELP!!

We are conducting a national study on the experiences and perceptions of parents of children with developmental delays in Early Intervention across Canada. We have constructed a survey that is being distributed to parents from across the country to determine how parents perceive services and supports in each respective province or territory.

The survey takes approximately 25-45 minutes to complete and is available online for your convenience at:
http://www.zapsurvey.com/Survey.aspx?id=e09fe4d1-7ff6-4926-b55a-1c88deb7a4f0

Alternatively, the survey can be emailed to you or administered over the telephone by contacting the primary research associate, Jennifer Saracino at jennifer.saracino@mail.mcgill.ca or (514) 469-0806.

Sincerely,

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