University of Alberta

INTEGRATING EARLY INTERVENTION INTO THE DAILY ROUTINE OF FAMILY LIFE

By

Miriam Parakkal

A thesis submitted to the Faculty of Graduate Studies and Research
In partial fulfillment of the requirements for the degree of

Master of Science

In

Rehabilitation Science - Occupational Therapy

Faculty of Rehabilitation Medicine

Spring 2012
Edmonton, Alberta

To Papa and Mama for all the life lessons and teachable moments

And

To all the parents who shared their stories with me

ABSTRACT

Background: Striking a balance between work and family care is a challenge for families today. More than 200,000 families in Canada have the additional demands that come with caring for a child with disability including implementing therapist-recommended goals and home programs.

Aim: Underpinned by ecocultural theory, this study investigated 1) how parents juggle the demands of the daily routine, including early intervention (EI) and 2) the factors that influence the implementation of EI by parents

Method: This study employed a narrative approach. Data were collected through in-depth narrative interviews with 12 families and a narrative and thematic analysis was completed.

Results: Parents described accommodations, strategies, and trade-offs they made to fit intervention into their daily routines and to maneuver through the health and educational systems.

Conclusion: Implementing EI can have significant personal and family costs. Careful assessment and consideration of family routines and stories is necessary for successful interventions.

ACKNOWLEDGEMENTS

The process of writing this thesis has had its ups and downs for me. Through it all I have had the help and support of God and a lot of special people in my life.

I want to thank God for the gift of knowledge and education. Proverbs 2:6 of the Bible says, “For the Lord gives wisdom and from His mouth come knowledge and understanding.”

I want express my most heartfelt thanks to my supervisor Dr. David McConnell. From the beginning of my graduate studies and research work he has inspired me to go above and beyond what I thought was possible, challenged me to think differently, and encouraged me not to give up during setbacks. He has always taken a genuine interest in my personal and academic wellbeing. For that I am truly grateful to him.

I want to thank my parents Mathew and Alice, and my brother Sam; the three people who have stood by me, believed in me, and supported me all through my life.

My husband Alvin and I met when I was half way through my graduate studies. Ever since then, he has been a source of constant love, support, and encouragement. I want to thank him for keeping me calm through periods of stress, for being a sounding board for my ideas, and for being my best friend.

I want thank my family in Philadelphia for their love and prayers.

Special thanks to Dr. Gwen Rempel and Dr. Joannah Darrah, who served as members on my supervisory committee, for the all the valuable feedback and advice they gave me through this process.

I want to extend my deepest gratitude to all the parents who took part in this study. They took the time to share their stories with me and they opened their homes and lives to me. They have taught me so much.

Last but not least, I want to express how grateful I am for the love and friendship of my roommates and best friends in Canada; Justina Yoo, Nancy Liu, Yijia Zhu, Wei Lynn, and Hikari Ishimura. I also want to thank my colleagues and dear friends, Laura Pacheco and Amber Savage for all the insightful discussions, lessons on Canada, and their friendship.

Miriam Parakkal

Table of Contents

LIST OF TABLES

LIST OF FIGURES

LIST OF ABBREVIATIONS

ADHD	Attention Deficit/Hyperactive Disorder
COPM-P	Canadian Occupational Performance Measure-Performance Scores
COPM-S	Canadian Occupational Performance Measure-Satisfaction Scores
EI	Early Intervention
EIBI	Early Intensive Behavioural programs
FCP	Family Centred Practice
FSCD	Family Support for Children with Disability
HAP	Home Activity Program
IFSP	Individual Family Service Plan
NDT	Neuro-Developmental Treatement
NPC	Non-Parental Collaboration
OT	Occupational Therapist
OTHP	Occupational Therapy Home Program
PC	Parental Collaboration
PECS	Picture Exchange Communication System
PEP-R	Psychoeducational Profile-Revised score
PUF	Program Unit Funding
PT	Physical Therapist
SLP	Speech-Language Pathologist
TEACCH	Treatment and Education of Autistic and Related Communication Handicapped Children

CHAPTER 1

Background

1.0 Introduction

“No intervention will have an impact if it cannot find a slot in the daily routines of an organization, family or individual.” (Bernheimer & Weisner, 2007, p. 192)

Integrating earning and caring activities into a meaningful and sustainable routine of family life is a challenge for many families. More than 200,000 families in Canada face the added challenge of integrating the many out-of-the-ordinary activities associated with caring for a child with disabilities (Statistics Canada, 2008). Such activities may include, but are not limited to, implementing early intervention (EI) recommendations and/or home programs.

The potential benefits of EI for children with disabilities and their families, including parent-mediated EI activities, are well documented. However, recent research suggests that, in the face of many changing and competing demands, most families struggle to “find a slot” (Bernheimer & Weisner, 2007) in their daily routine for EI activities. Typically, families implement some but not all EI recommendations, and they implement these recommendations, some, but not all of the time (McConnell et al., 2008; Wiart, Ray, Darrah &Magill-Evans, 2010).

While many researchers have examined and documented the benefits of parental involvement (Kellegrew, 1998; Ketelaar, Vermeer, Helders & Hart, 1998; Ozonoff & Cathcart, 1998), few have explored how parents manage to juggle the demands of EI and other daily responsibilities within the routine. Likewise, few scholars have systematically investigated factors influencing parent implementation and non-implementation of EI recommendations and home programs. The limited available data suggests that the complexity and intensity of the therapy regimen is one influential factor (Brotherson & Goldstein, 1992; Hinojosa & Anderson, 1991; Segal & Beyer, 2006; Tetreault, Parrot & Trahan 2003). Another factor appears to be the adaptability of the therapy regimen to the family routine (Gajdosik & Campbell, 1991; Rone-Adams, Stern & Walker, 2004).

Building on this previous research, the aims of this study are to a) investigate how families juggle the often competing demands on their time and energy and integrate (or decide not to integrate) EI activities into their everyday routine and b) to explore the factors that influence how and to what extent families of young children implement the therapies recommended to them.

In sections 1.1 and 1.2, I discuss the challenge of juggling work and family and the out-of-the-ordinary demands of care-giving for a child with disability. This is followed by a review of the literature, in section 1.3, pertaining to the benefits and potential costs of implementing EI. The final discussion, in section 1.4, focuses on what is known about how parents implement EI for their children within the daily routine, and factors thought to influence the process of parental implementation of EI.

1.1 Work-family conflict and role overload

"Striking the balance between paid work and family … is ***the*** *topic of the 21st Century for families, employers and governments." (Human Rights and Equal Opportunity Commission, 2007, p. XI, emphasis added)*

Many families today are hard-pressed to integrate work and care-giving activities into a meaningful and sustainable routine of family life. Over the last four decades, trends in workforce participation have changed dramatically: the participation of women and mothers in the workforce has increased markedly (Campbell & Charlesworth, 2004; Duxbury & Higgins, 2001; La Rochelle-Cote & Dionne, 2009; Marshall, 2009); work hours are longer today than they were a few decades ago, and the nature of work is more intense (Allan, O'Donnell & Peetz, 1999; Vanier Family and Work Institute, 1997). These trends may explain, at least in part, the increased research interest and government concern about the work-family conflict. Parents, mothers in particular, are reporting high levels of work-family conflict and role overload in high income countries all around the world (Todd, 2004).

Striking a balance between paid work and family life is a major concern for approximately one in two working Canadians. A survey of 1500 Canadian workers conducted by the Conference Board of Canada (1999) found that 46.2% of the respondents reported stress over work-family conflict (MacBride-King & Bachmann, 1999). Consistent findings are reported by Duxbury and Higgins (2001), who surveyed

31,571 Canadian workers in 2001 and found that 58% of the respondents reported high levels of work-family conflict.

1.2 Work, family and care for families of children with disabilities

1.2.1 Responsibilities of care-giving

In addition to the normative challenge of balancing work and family demands, 200,000 plus families in Canada face the additional time- and strain-based demands that arise when caring for a child with disabilities (Statistics Canada, 2008). Such demands and tasks, include, but are not limited to, out-of-the-ordinary parenting/care-giving; negotiating and coordinating supports and services; and implementing interventions to promote or "normalise" their child's learning, development and/or behaviours (Freedman, Litchfield & Warfield, 1995; Green, 2007; Wiart et al., 2010).

Many of the activities involved in parenting a child with disabilities are the same as those involved in parenting any other dependent child. These activities include, but are not limited to, preparing meals, bathing, dressing, comforting, teaching, and transporting. However, for many parents who are raising children with disabilities, such "normative" activities may be more complex, greater in intensity and duration, and sometimes lifelong (Shearn & Todd, 1997, 2000; Ray, 2002). For example, all parents have to manage child behaviour problems, but the challenging behaviours of many children with disabilities (e.g., self-injurious behaviours) can be frequent and difficult to curb. A parent's day-to-day activities may revolve around the self-care and behavioural issues of their child with disability (DeGrace, 2004). In a similar manner, all parents have to ensure that their children are nourished and physically well, but many children with disabilities have special care needs. Parents are sometimes required to meet special nutritional and dietary requirements (Ray, 2002). Some children with disabilities may require special medications or equipment such as the use of a gastric feeding tube (Gannoni & Shute, 2009). In addition, the work of a parent of a child with disability may not always be publicly visible, for example activities such as monitoring the child's physical symptoms, anticipating the need for adaptive strategies; facilitating and monitoring the child's success in social situations; and working with health, education, and social service sectors (Ray, 2002).

Many parent-carers have reported that the everyday challenges associated with caring for their child with disabilities have resulted in significant career interruptions

(Freedman et al., 1995; Shearn & Todd, 2000). Shearn and Todd (2000), for example, explored how the employment participation of mothers was affected by the various daily demands of care giving. Eighteen working mothers of children between the ages of 5 and 15 were interviewed. The participants revealed that basic child care activities, including washing, feeding, toileting, supervising, transporting and organizing recreation, were time consuming and often difficult to balance with their work schedules. Mothers of children who had severe intellectual or physical disabilities and/or had challenging behaviours reported that the care work that they performed was particularly demanding. Mothers in this study deemed themselves to be “undesirable employees” because their schedules were highly dependent on their care-giving responsibilities and often inconsistent with the temporal discipline of the standard employment practices.

In addition to the usual, though more intense, normative demands of parenting, parents raising children with disabilities may be cast into other multiple time and energy consuming roles, including, for example, the role of “case manager” and advocate for their child, and the proxy roles of nurse, therapist, and teacher. Parent-carers may spend substantial amounts of time delivering health care; completing paperwork and other administration; advocating or fighting for needed supports and services; transporting their child to and from various appointments; coordinating the activities of multiple professionals and other service providers who come in and out of the family home; and implementing EI and/or other professional recommendations including home therapy programs or regimens (Green, 2007; Shearn & Todd, 1997; Resch, et al., 2010). In an interpretive study, Ray (2002) described an example of the different responsibilities that parents take on. She interviewed 43 parents of 34 children, ranging in age from 15 months to 16 years, all with chronic disabilities. Parents reported that they often assumed the technical aspects of their child’s medical care and assumed responsibility for occupational and physical therapy. They also spent time teaching themselves and their children sign language and learning to operate assistive devices for communication.

1.2.2 Time spent on Early Intervention

Studies show that the time spent by parent carers implementing EI alone is substantial. Crowe (1993) looked at the differences in time use between 45 mothers of children with multiple disabilities, 45 mothers of children with Down syndrome, and 45 mothers of typically developing children, all between the ages of six months and five years. Results showed that mothers of children with multiple disabilities spent almost

38% of their time in child care activities that also included therapy (and therapy-related tasks), whereas the mothers of children in the other two groups spent 30% of their time in these activities. This amounted to six additional hours a week spent on child care activities by mothers of children with multiple disabilities.

Crowe and Florez (2006) undertook a similar study where the time use by mothers of school-aged children (aged 3 to 14) with disability was compared to the time use by mothers of typically developing children. The mothers in this study completed time diaries over seven 24-hour days. Results showed that mothers of school-age children with disabilities spent, on average, 13.1 hours more a week (1.9 hours more per day) on child care activities in comparison to mothers of typically developing children. These child care activities included therapy sessions, transport to therapy sessions, medical appointments, and preparing and participating in any child activity or event.

Leiter, Krauss, Anderson, and Wells (2004) surveyed 1,954 mothers of children with disabilities in the United States and found that 18% of these mothers were providing 20 or more hours of in-home health care to their children each week. The authors noted that the intensity of in-home health care may stretch the role of parent into the role of caregiver. In this study, 56% of the 984 employed mother-respondents reported cutting down their hours of employment, and 56% of the 888 full-time stay-at-home moms reported that they had stopped working because of their child's health needs. Likewise, mothers in Shearn and Todd's study (2000) felt that they spent considerable amounts of time looking for and organizing services for their children.

In Alberta, Canada, McConnell et al. (2008) investigated the work-family-care integration in a stratified (by child age group) random sample of more than 500 families raising children with disabilities. Of the 125 families with preschool-age children with developmental disabilities, 118 (94.4%) indicated that they were expected to carry out a home EI program. On average, these parents spent almost 8 hours a week implementing home therapy, and an additional 2 hours and 30 minutes a week attending therapy appointments.

1.3 Early Intervention

Early intervention has been shown to be beneficial in helping children with developmental disabilities to reach milestones. Furthermore, parental involvement in implementing EI has been shown to help children to meet therapeutic goals. However, pursuing and implementing EI may entail significant costs for a family whose child has a disability.

The general purpose of EI is to reduce developmental risk and optimize child and family functioning (Guralnick, 2005; Majnemer, 1998). Broadly defined, EI may include parent consultation with health care professionals including but not limited to occupational and physical therapists and speech/language pathologists; school, centre, and home-based implementation of therapeutic programs by therapists and/or aides, and parent-mediated interventions implemented at home and/or in the community. Parent-mediated interventions, including implementation of home programs, may be used in combination with or as an alternative to hands-on intervention by a therapist or aide (Kruskal, Thomasgard & Shonkoff, 1989; Majnemer, 1998).

1.3.1 Benefits of Early Intervention

The rationale behind EI comes from recent advances in the scientific understanding of early childhood development, which suggests that the early years may constitute a unique window of opportunity to modify children’s developmental trajectories (Guralnick, 1998, 2005; Nelson, 2000). There is broad agreement in the literature that EI has positive effects on the developmental achievements of children with or at risk for developmental disability, and may benefit the families of these children (Hines & Bennett, 1996; Majnemer, 1998). After reviewing the extant literature several authors have concluded that EI has the potential to positively impact the social, cognitive, behavioural, and physical development of children with a broad range of impairments or diagnoses including but not limited to Down syndrome, intellectual disability, autism, and attention deficit hyperactivity disorder (Guralnick, 2005; Hines & Bennett, 1996; Sallows & Graupner, 2005; Smith, Groen & Wynn, 2000; Trudgeon & Carr, 2007).

Guralnick (2005) reviewed studies on the advances in, benefits of, and basis for EI for children with intellectual disabilities. Based on the results of various clinical trials, he concluded that EI achieves positive outcomes. In particular, positive outcomes have been documented in prevention-focused studies for children at environmental and biological risk (e.g., Campbell & Ramey 1994; Infant Health and Development Program 1990; Rauh et al. 1988), behavioural intervention studies for children with autism (e.g., Lovaas, 1987), and comprehensive early intervention programs for children with Down syndrome and children at risk of cognitive decline (e.g., Berry et al. 1984; Woods et al. 1984; Sharav & Shlomo 1986).

Home programs have also been shown to have a positive impact on children with various developmental disabilities (Ozonoff & Cathcart, 1998; Trudgeon & Carr, 2007). For example, Novak, Cusik and Lannin (2009) assessed the effectiveness of an Occupational Therapy Home Program (OTHP) compared with no OTHP for upper limb skill improvement in children diagnosed with cerebral palsy, aged 4 to12. In addition to this, there was an evaluation of parent satisfaction with child function, participation, and goal attainment. A double-blind, randomized, controlled trial was performed. Participants were divided into three groups: no OTHP, OTHP for four weeks, and OTHP for eight weeks. OTHPs were developed in collaboration with families and were comprised of activities that were based on family goals and best evidence. The activities selected were parent-directed and in keeping with family-centered practice. Parents drew from a resource that explained and demonstrated how to achieve particular goal types. The programs included a) child-executed activities, such as structured practice of tasks, b) environmental adaptations to promote success, and c) parent education to enhance the way in which the child learned. Parents implemented the chosen activities by using principles identified by the therapist but applied them based on their own expert knowledge of the child. The effects of the OTHP were measured at the end of eight weeks using the Canadian Occupational Performance Measure's (COPM) performance and satisfaction scores (COPM-P and COPM-S).The authors found positive, statistically significant effects of the OTHP on parent satisfaction and child skill attainment in the OTHP-at-four-weeks and OTHP-at-eight-weeks groups as compared to the group with no OTHP. The authors concluded that OTHPs may be used as an effective alternative to regular hands-on therapy.

The benefits of EI are said to be greater when parents are actively involved in its implementation. Ketelaar et al. (1998) reviewed a number of studies, undertaken between 1980 and 1996, that focused on interventions mediated by parental involvement. The participants in these studies were parents of young children diagnosed with cerebral palsy. These studies showed that greater degrees of parent involvement in implementing an intervention resulted in faster and more positive child outcomes than when therapists worked alone with the children. In studies where parents were trained to carry out specific interventions with their children, greater gains and improvements in child outcomes were observed when compared to baseline measurements of function.

Ozonoff and Cathcart's (1998) study evaluated the effectiveness of a home program that was based on the treatment and education of autistic and related communication handicapped children model (TEACCH).To evaluate the efficacy of the program, 22 children diagnosed with autism were divided into a treatment group and a non-treatment control group. The groups were matched on age, severity of autism, initial Psychoeducational Profile-Revised score (PEP-R), and time interval between pre- and post-testing. Parents of these children were trained to conduct the intervention for their child at home for about half an hour a day. The program included weekly visits to the therapist as well as home visits from the therapist to observe parent implementation. The treatment group was provided with approximately four months of home programming and was tested before and after the intervention with the PEP-R. The control group did not receive the treatment but was tested at the same four-month interval. Results showed that parent implementation was effective; compared to the non-treatment group, children in the treatment group had more positive outcomes in the areas of fine, gross motor, and social skills.

1.3.2 The struggle to implement EI

Various forms of EI have been shown to have positive effects on the development of at-risk children, and on the well-being of parents and families. However, there is also the evidence of struggle for families with the implementation of EI. First, accessing and implementing EI has been associated with certain costs for families of a child with disability; namely stress and trade-offs. Second, numerous studies report that even when parents are involved in developing the program, parents only partially implement or follow through on EI recommendations and regimens (Mackean, Thurston & Scott, 2005; Schreiber et al., 1995; Thompson, 1998).

Potential costs. Stress has long been studied in the field of rehabilitation and shown to be associated with the presence of disability in a family. However, in more recent times, stress has been shown to be related to the demands associated with disability rather than the disability per se, namely, demands associated with implementing intervention (Trudgeon & Carr, 2007; Neely-Barnes & Marcenko, 2004).

Plant and Sanders (2007) examined predictors, mediators, and moderators of parent stress in 105 mothers of preschool-age children with developmental disability in Queensland, Australia. The findings showed that therapy-related tasks such as therapy programs, educational activities, advocating on behalf of the child, transportation to appointments, and attending therapy and medical appointments ranked among the top ten most stressful and difficult on a list of 22 care-giving tasks. Engaging in therapy and intervention-related tasks ranked high among the tasks that caused the highest amounts of perceived stress. Parents of children with more severe disabilities reported higher levels of stress. It is possible that parents of children with more severe disabilities also had to engage in more intervention-related tasks.

Likewise, parents in a study by Trudgeon and Carr (2007) reported feeling sometimes stressed or burdened by the demands of implementing EI for their children. Trudgeon and Carr (2007) investigated the impact of Early Intensive Behavioural Intervention programs (EIBI) on families with young children with autism in the United Kingdom. The EIBI program ran for approximately 30 hours per week in the family home. Semi-structured interviews were conducted with 16 parents (nine families), exploring both the positive and negative impacts. While parents reported benefits such as practical, emotional, and social support from the EIBI tutors, they also reported stress caused by the demands of the program such as the constant presence of tutors in the home. Some examples of these demands were changes being made in the home environment to accommodate the program, less time for their other children, strains on the marital relationship, concerns about reaching target hours each week, giving up career (reported only by mothers), and curbing social life in order to fit the demands of intervention into the family life. A notable finding of this study was that families were able to differentiate between the stressors that they faced from their child’s autism and those from trying to implement the program. The authors concluded that home-based EIBI programs place high levels of demand on families’ personal and material resources and are a source of stress for parents who implement these programs.

Studies have consistently reported trade-offs that parents make to accommodate the special needs of their child, but the demands of EI alone may cause families to compromise or forgo certain aspects of daily life. Breen (2011) contends that in today’s family-centered practice, responsibilities of care and service coordination have been imposed upon parents, causing them to make trade-offs in various aspects of their lives:

everything from work and leisure to managing demands from the services. Therapy services and services from the special education system have been shown to be significantly related to altered sleep, changed work schedules and financial strain for parents of a child with disability (Neely-Barnes & Marcenko, 2004; Thompson, 1998). Efforts to pursue, advocate for, and negotiate services for a child take time and energy (Brown, 2004; Resch et al., 2010) and therefore may require parents to adjust their work hours or forgo advancements in their careers or give up careers altogether (Freedman et al., 1995; Green, 2007; Thompson, 1998; Trudgeon & Carr, 2007).

Parents have reported making trade-offs in their social and recreational lives by sacrificing leisure activities to fit in the demands of EI activities like home programs (Tetreault et al., 2003; Trudgeon & Carr, 2007). Another trade-off that has been often reported is time spent with family and the marital relationship. Parents have reported a strain in the marital relationship and lack of time for their other children (Trudgeon & Carr, 2007). Parents in the study by Trudgeon and Carr (2007) reported that a rigorous behavioural program for their child with autism had mixed effects on their marital relationship. While a few families felt that working on the program with their child brought the spouses together, others reported that it was a factor in their marriage breakdown. Some parents in the same study also felt that they had less time available for the siblings of their child with autism because of the demands of the program. In summary, families seem to make adjustments and trade-offs in order to “fit” EI into their routine of family life.

Partial implementation and reports of difficulty with EI. Incomplete implementation of a therapy program or “non-compliance” with a medication regime has puzzled practitioners and researchers alike for decades. Becker and Maiman (1975) stated, “It seems fair to assert, after an extensive survey of the literature, that patient noncompliance has become the best documented, but least understood, health-related behavior” (pg.11).

Research from the last four decades provides evidence that families have often struggled to access, implement, and follow through with early intervention activities and home programs. Studies that were carried out during the 1980s and 90s consistently document incomplete parent implementation of EI recommendations and regimens. During that period, before family centered practice (FCP) had taken root, research on parental implementation of EI was reported in terms of *compliance* or *adherence*. The results from these studies showed significant variations in how adherent or compliant families were to EI recommendations (Gajdosik & Campbell, 1991; Law & King, 1993; Mayo, 1981). Moreover, findings from these studies indicated that interventions designed to promote parent compliance typically had only modest effects.

Mayo (1981) investigated the compliance of mothers with a physical therapy home program for children with developmental delays. Eighteen mothers and their infants participated in the study and were randomly assigned to an experimental or control group. The participants were given a prescription for a physical therapy treatment program and a demonstration of the program. In addition to this, the experimental group received a home visit from a therapist. Participants also received a journal to record daily activities and necessary supplies to conduct the treatment program at home. The mothers were then asked to return to the clinic after one month for evaluation of compliance and child outcomes. Results showed that the mean compliance rates of mothers in the experimental group were not significantly different from the mean compliance rates of mothers of the members in the control group. Also, the effect of a home visit by the therapist showed no significance difference in compliance between groups. Mayo (1981) also found that none of the mothers complied all of the time.

A decade later, Gajdosik and Campbell (1991) investigated the effect of a weekly review and parent logs on parent carers' compliance with a prescribed home program. A total of 18 caregivers of young children with developmental delays was allocated to experimental (weekly review) and control (no weekly review) conditions. The effect of socioeconomic status on compliance was also examined. The study found a decrease in caregiver compliance over time. Although the decrease was less marked in the experimental group, the study documented a decrease in caregiver compliance over a four-week period in both groups. No association was found between parent compliance and socioeconomic status.

Another early study assessed parent compliance in a clinical trial comparing the effects of intensive Neuro-Developmental Treatment (NDT) with upper extremity inhibitive casting (Law & King, 1993). The sample included a total of 72 children between the ages of 18 months and 8 years. Over the six-month trial period, parents of children receiving NDT were required to implement specific NDT activities on a daily basis. Parents of children assigned to the casting group were required to ensure that the cast was worn for at least four hours per day. Parents kept a record of home program completion and times of cast wear in a booklet and were encouraged to make observations at home and discuss these with the therapists. The results of the study indicated that 66 percent of the parents were able to complete all or some of the home program about 75 percent of the time. The authors speculated that what they viewed as a moderately high rate of compliance by parents may have been by virtue of participation in the study.

In addition to quantitative studies that reported the variations on compliance to intervention programs, a few qualitative studies that were conducted during this time provided some much-needed insight into the experiences of parents who were implementing an early intervention program. Hinojosa and Anderson were among the few researchers who recognized, early on, family struggles with the expectation to comply with therapist-recommended goals. They explored parent perceptions and experiences of implementing EI home programs at home on an everyday basis. Hinojosa (1990) used a qualitative case study approach to explore how eight mothers of children with cerebral palsy perceived therapists and the influence of EI on their family lives. In a follow-up study, Hinojosa and Anderson (1991) analyzed the same qualitative data from Hinojosa’s 1990 study to evaluate mothers’ perceptions of home programs for their children. The combined findings of the two studies showed that mothers reported that they often did not have the time or energy needed to implement interventions as prescribed by the therapists. Also, all the participants had ceased to participate in the home programs because they reported struggling with balancing responsibilities related to the running of their homes and the care of their other children, or because they found the program too difficult or frustrating.

Brotherson and Goldstein (1992) also interviewed parent-carers (n = 21) and similarly found that many were overwhelmed by the demands of implementing EI recommendations. Participants reported that implementing EI sometimes left them with little or no time to fulfill other responsibilities. Notably Brotherson and Goldstein (1992) found that most of the parents believed that their time was used more effectively when (a) therapists respected their knowledge and expertise with respect to their children, and (b) when EI activities could be integrated seamlessly into the family's daily routines and home environment.

The move away from expert-driven and child-focused models of EI toward collaborative, family-centered models of EI gathered momentum through the 1980s and 90s. Parents were encouraged to be involved in intervention programs for their children with disabilities as equal partners with professionals on all levels of care (Dunst, 1997; Ketelaar et al., 1998). Fundamental to the new FCP philosophy was the belief that parent participation in all aspects of EI optimized outcomes for their children (Ketelaar, Vermeer, Helders, and Hart, 1998; Majnemer, 1998; Shonkoff and Hauser-Cram, 1987; Zeanah and McDonough, 1989). Bazyk (1989), among others, further argued that engaging parents as partners and collaborators in EI would build their internal locus of control and increase their feelings of competence in helping with their child's development. The core elements of FCP philosophy were summarized by Dunst (1997). These are a) family-practitioner collaboration on every level of care, that is, hospital, home, and community; b) therapist sensitivity to family priorities, needs, and choices with respect to decision-making; c) honouring cultural, ethnic, educational, and economic diversity in policy and practice, and d) providing supports, resources, and services in a flexible and responsive manner.

Although a number of positive outcomes are attributed to the emergence of FCP philosophy and practice (Novak, 2011; Wiart et al., 2010), there is evidence that many families continue to struggle to balance work and family, and to integrate early intervention into their daily routines. Though intended to empower parents and optimize their involvement, recent studies suggest that FCP may have had little impact on parent-implementation, or rather non-implementation of EI in a family's daily routine. Despite parent-therapist collaboration, many families may still struggle to keep up with the demands of accessing and implementing EI or to "comply" (MacKean et al., 2005; Schreiber et al., 1995; Thompson, 1998).

Schreiber, Effgen and Palisano (1995) investigated the effect of parental collaboration on parent compliance with EI recommendations. Eighteen children with developmental delays and their families were randomly assigned to two groups: Parental Collaboration (PC) and Non-Parental Collaboration (NPC). Parents in the PC arm of the trial were involved in developing programs that fit with their goals, and were not too complex. The results indicated that the PC group had a mean compliance of 80.3% and the NPC group, a mean of 77.5%. The difference between the groups was not statistically significant and compliance in both groups decreased over time.

In Australia, Thompson (1998) employed ecocultural theory to explore parents' perceptions of occupational therapy services and the impact of these services in their daily family life. Ten mothers of children with disabilities (aged 0-6 years) completed questionnaires and semi-structured interviews. All 10 families were recipients of occupational therapy services and represented diverse socioeconomic strata and geographic locations. The interview covered five basic areas. These were a) the focus of the services; b) the fit of services into family routines; c) the values and attitudes of the therapists working with families; d) the coordination between services and different occupational therapists; and, e) parents' descriptions of occupational therapy. There was an analysis of the resources, constraints, values, beliefs, concerns, priorities, and adjustments that affected the families as a result of their contact with early intervention services. Results revealed that mothers found it difficult to incorporate interventions into their daily routines because their family routines clashed with the therapists' schedules. Thompson (1998) concluded that there is a need for a collaborative effort from therapists and families to develop common functional goals that support family members as individuals as well as the child with a disability.

Tetreault et al. (2003) have also documented the challenges that families have had with adhering to a home program. In a study conducted in Quebec, Canada, Tetreault et al. (2003) evaluated family compliance with a home program and parental perceptions about the use of a Home Activity Program (HAP) for their children presenting with Global Developmental Delay. Of the 41 participating families, 31 reported that they were using a home activity program up to 7 or 8 months after they had first received the program recommendations. Even so, 42% of the sample reported that they had to make time to integrate the HAP into their lives. About 45.2% reported having trouble integrating the exercises into their daily activities. Families also reported feeling burdened by having to use a HAP and often experienced guilt because they felt as though they were unable to fulfill all the HAP tasks as prescribed. Some parents reported that they did not always enjoy doing HAP tasks but nevertheless performed the tasks out of a sense of duty to their children. The authors noted that despite the trade-offs and difficulties, many participants persisted in the program. Tetreault et al. (2003) concluded that HAP's may indeed be a burden on families and that therapy must be designed to fit the families' routine and the child's specific needs.

McConnell et al. (2008) reported that of the 125 families with preschool age children with disabilities, the majority of families indicated that they were expected to carry out a home program. Of these families, 76% reported moderate-to-great difficulty in carrying out prescribed programs at home, and a total of 63 % indicated that they either did not carry out every activity that had been prescribed or did not carry out the prescribed activities as often as they should.

More recently, parents who participated in a qualitative study by Wiart et al. (2010) reported that they felt that they sometimes “couldn’t do it all” and found it difficult to balance therapy with the demands of daily life. Parents revealed that they would sometimes forgo therapist recommendations to enjoy life as a family and meet the other demands of their daily routine. These activities and demands included homework, playtime, and developing social relationships with others, or reserving time for their children to play. Based on the study findings, Wiart et al. (2010) emphasized the importance of considering the broader context of the families, respecting the different perspectives and the uniqueness of families, and discussing how interventions might fit with family values, goals, priorities and lifestyles. The authors suggested that these discussions will help families find the best fit between interventions and their goals, as well as help avoid the guilt that they often feel when they are unable to follow through with recommendations from their therapists.

With the shift to family-centered care, there has been some speculation that parents are given more responsibility than many can handle. Parents may spend substantial amounts of time on administrative paperwork, accessing information, fighting to access services, coordinating services, and carrying out therapy (Green, 2007; Resch et al., 2010; Shearn & Todd, 1997; Wiart et al., 2010). According to Wiart et al. (2010), there is a risk of downloading too much responsibility on parents without understanding their preferences for involvement in their child’s therapy.

MacKean et al. (2005) undertook a grounded theory study of family and health-care provider experiences of family-centered care in child developmental services in Alberta, Canada. Thirty-seven parents of children with developmental disabilities participated in focus groups and individual interviews. The families that participated in this study felt that the concepts of family empowerment and autonomy had been taken to an extreme and, as a result, all the responsibility of care and therapy had been placed upon the parent. Participants also felt that service providers expected parents to provide specialized care and therapies for their child at home, obtain needed information about their child's condition and specialized services, find the appropriate services for their child, and transfer important medical information about their child to the health care providers. While parents greatly valued practitioner knowledge, they strongly expressed their need for help in advocating for their child in complex medical and human service systems.

Novak (2011) documented the positive experiences reported by parents who participated in a partnership-based home program and their contrasting experiences of implementing their usual therapist-prescribed home programs. Novak aimed to describe the experiences and views of 10 parents of children with cerebral palsy who participated in an earlier randomized controlled trial study of partnership-based home programs (Novak et al., 2009).The partnership-based home program comprised elements such as establishing a collaborative partnership between parent, child and therapist; and supporting parents to implement the program through education, home visiting, and progress updates to sustain motivation for program use. Semi-structured interviews were conducted with the parents. Participants reported that the benefits they received from a program of this nature were the support from the therapists, flexibility rather than a list of activities that they had to do for their child, active involvement in setting goals that were tailored to parenting needs and styles, and not having to take on the role of the therapist. In contrast, when speaking of their usual experience of home programs, parents described feeling overwhelmed by the burden of responsibility because they felt they were left alone during the follow-through period after therapy goals had been set. Parents expressed their need for constant and accessible support from therapists to avoid feeling burdened. Another challenge that parents faced with using a therapist-prescribed home program was the lack of coordination between services, which often led them to feeling confused about the goals set with various therapists or practitioners.

1.4 EI in daily life

Recent research suggests that families may struggle with the implementation of EI today, just as they did in earlier decades, despite the move to a family-centred philosophy. However, little research has explored how families go about implementing EI in the context of their daily routine and the factors that influence their decision to participate in and implement EI. Literature related to this topic is presented in the following sections.

1.4.1 "Fitting" EI into a routine

Research that focuses on the construction and sustenance of routines has been carried out mainly by scholars who have approached their studies from an ecocultural perspective. Few authors have looked specifically at how families balance the demands of EI within their routine. However some have explored how parents can construct routines to support their child's skills and therapeutic goals. For example**,** Kellegrew (2000) explored how mothers constructed routines in response to their children's emerging skills. Six mothers of children with disabilities, and their families, participated in in-depth interviews that delved into the daily routines, as well as ecological constraints and resources that affected their routines. The main findings of this study were that mothers made adjustments or accommodations to their daily routine to fit their child's emerging self-care skills. Some of these self-care skills were also part of the goals in the family's Individual Family Service Plan (IFSP). Mothers also developed activity settings and routines based on what they anticipated would be their child's future needs and what was necessary for their child's future success. Mothers constructed routines based on their own personal goals for their children. Kellegrew (2000) also found that routines were built based on the motives and meanings that mothers attributed to everyday events. The mother's child-rearing style and perspective also seemed to contribute to the meanings and motives she attributed to everyday events and the resulting construction of the daily routine. This study addressed the way mothers constructed a daily routine to encourage their children's self-care skills. The experience of parents in implementing other aspects of intervention and the accommodations they made in areas outside of their children's self-care routine were not explored.

Parents have been shown to use routine tasks to try and integrate therapy goals (Hinojosa & Anderson, 1991; Segal & Beyer, 2006). For example, the mothers in Hinojosa and Anderson's study (1991) used everyday tasks such as bath time, meal time, and dressing as opportunities for therapy for their children. A mother would adapt a prescribed activity to achieve a therapy goal in a way that was enjoyable for her child and herself. The authors found that mothers did not consider their adaptations to be therapy because it did not necessarily replicate what the therapists had taught them.

Parents in Segal and Beyer's study (2006) described integrating into their daily routine a brushing and compression program for their children with autism. Parents reported that the prescribed frequency of the program (every two hours) was hard to keep up with. Some parents made a conscious effort to follow the program, although not as frequently as prescribed. Parents used different opportunities to integrate the program: some used the time they had during outings such as to the bookshop or the museum. Some parents used the time just after waking or just before bedtime to do the program and some parents deliberately adjusted their own routines to accommodate the program. Other parents used the help of family members and friends to carry out the program.

Segal (2000) explored, in depth, the daily time-use strategies of mothers of children with Attention Deficit/Hyperactive Disorder (ADHD). Seventeen families of children with ADHD participated in in-depth interviews. Parents were asked to give a detailed account of their routine from the time they got up in the morning until the last person in the house went to sleep. They were also asked to describe how each occupation was performed and by whom they were performed. The author found that mothers managed their routine responsibilities within the time frame of their day and around the challenging routines of their children with ADHD. Mothers used two main adaptive time-use strategies, namely, *enfolding occupations* and *unfolding occupations*. Enfolding occupations involved doing more than one activity at a time. For example, a mother enfolded the occupation of reading while supervising her child's play activity. Parents used this adaptive strategy most commonly when they found they had no other alternative, typically when there was no one else to help or at busy periods of time, as in the morning. Unfolding consisted of "chunks" or components of activity from previously established sequences of enfolded activity. Parents either chose to perform those activities at another time (temporal unfolding) or assigned the activity to another person at the original time of the activity (unfolding by inclusion).Temporal unfolding occurred when mothers wanted to focus their time on one activity, typically with their child with ADHD. Maternal needs were not considered when mothers used temporal unfolding. This adaptive strategy was common among families with limited financial resources and support systems. For example, a mother may have decided to perform homemaking occupations after the children went to sleep, often leaving herself limited time to sleep. Unfolding by inclusion was an adaptive strategy where the mothers decreased the number of maternal occupations and delegated tasks to another family member or hired help. This strategy was used by families who had financial resources and support from friends or family members. This often eliminated the stress or burden for the primary caregiver. These strategies are examples of how mothers went about balancing their routines and the demands of their child with disability. In this particular study, mothers organized occupations around the needs and behaviours of the child with ADHD

In summary, a few scholars have explored how parents use activities that are part of their daily routine to integrate certain therapeutic goals and encourage their child's developmental skills. Parents are also known to use innovative strategies to manage time and responsibilities in the daily routine. The accommodations and strategies that parents use to balance early intervention and other responsibilities within the daily routine have yet to be explored.

1.4.2 Factors that influence the implementation of EI by parents

Throughout the literature of the last four decades researchers have documented some common findings or patterns that seem to influence how or to what extent parents implement or integrate EI into their routines. These factors include the program's intensity or complexity (Gajdosik & Campbell., 1991; Tetreault et al., 2003; Thompson, 1998), how beneficial parents perceive the intervention program to be, how easy it is for the family to adapt the program to their routine and lifestyle, how congruent the program is with family goals, and how parents want society to perceive them and their children.

Complexity of regimen. The literature suggests that parents of disabled children are less likely to implement EI recommendations and activities that are complex or require an extensive amount of time (Hinojosa & Anderson, 1991; Wiart et al., 2010). The level of compliance of caregivers has been shown to be determined, in part, by the frequency prescribed for a therapy program (Rone-Adams et al., 2004). The frequency and intensity of a home program or exercise protocol may make it tough for parents to integrate it into their daily activities (Segal & Beyer, 2006). This is a known factor of non-compliance (Gajdosik, 1991; Rone-Adams et al., 2004; Schreiber et al, 1995). Complex programs can be frustrating for parents to implement, especially if they have not received adequate training and support. Parents are more likely to adhere to an EI regimen when they are confident in their ability to implement it (Hinojosa & Anderson, 1991; Tetreault et al., 2003). Lengthy programs may simply be too time-consuming for parents, particularly working parents, to integrate into their everyday routine (Gajdosik &

Campbell, 1991; Hinojosa & Anderson, 1991; Schreiber et al, 1995; Segal & Beyer, 2006; Tetreault et al., 2003; Thompson, 1998).

Efficacy of interventions. Another influential factor appears to be whether parents perceive benefits of early intervention and home programs. Put simply, parents are more likely to implement or continue implementing professional recommendations if they can see positive results (Gajdosik & Campbell, 1991; Hinojosa & Anderson, 1991; Schreiber et al., 1995; Segal & Beyer, 2006). For example, in Segal and Beyer's (2006) study on hindrances and facilitators of parent compliance to a brushing and compression program (Walberger's protocol), parents perceived the program to be effective when their children responded positively. Children's positive responses motivated parents to adhere to the program.

Adaptability**.** Adaptability appears to be a third factor influencing whether a parent will implement EI (Hinojosa & Anderson, 1991; Thompson, 1998). That is, parents are more likely to implement EI recommendations that fit naturally or otherwise can be adapted to fit within their daily routine (Segal & Beyer, 2006).

Hinojosa and Anderson (1991) found that mothers tried to adapt or select certain aspects of the interventions for use within their everyday routine so long as they did not cause stress to the mother or the family at large. They also found that these self-selected interventions by mothers had four main characteristics: a) mothers found the program "doable" within their everyday routine, b) the interventions did not interrupt family life, c) they were perceived as beneficial for the child, and d) they could be done within the context of other home activities. In her concluding remarks, Hinojosa (1990) recommended that therapists should assist mothers in adapting interventions to suit their chosen lifestyles rather than expecting compliance with a strict program with which they would struggle to keep up. Hinojosa and Anderson (1991) concluded from their study that therapist-prescribed parent-mediated intervention regimes were a constraint on families. The authors also found mothers in their study to be problem-solvers and innovative in coming up with strategies, so they suggested choosing activities collaboratively with parents and based on a sensitive understanding of family needs, goals, and the daily routine.

Likewise, parents in the study by Novak (2011) reported positive experiences from a partnership-based program because it allowed for flexibility rather than a list of activities that they had to do for their child. The parents also appreciated having active involvement in setting goals that were tailored to their needs and styles. Parents observed that the kinds of home programs they were most likely to implement were those that that could become part of the family routine and that the child enjoyed.

***Incongruence with family goals*.** Another factor that seems to affect parent implementation of EI is when there is incongruence between their hopes and expectations and those of the therapists involved in their child's life (Cohn, Miller & TickleDegen. 2000; Thompson, 1998). For example, in a study of parental hopes for occupational therapy outcomes for children with sensory modulation disorders, Cohn et al. (2000) found that the parents' hopes, concerns and goals often differed from those of their child's therapists. Parents reported that practitioners had focused on child outcomes, in terms of improvements in the child's physical, cognitive, and functional abilities while parents articulated goals for their children in terms of social participation, self-regulation, and perceived competence.

Studies by Thompson (1998) and Wiart et al. (2010) also found that there was a disconnect between therapist priorities and family priorities. Wiart et al. (2010) found that what parents wanted for their child was not necessarily what their therapist had suggested as appropriate goals. For example, though skill and attainment of functional goals were important, most parents expressed that their desire was for their children to lead happy, fulfilling lives without societal barriers. This disconnect has the potential to affect how often and to what extent parents decide to implement interventions for their children.

***Societal and cultural perceptions*.** The question has risen as to whether parents choose to implement EI for their children because they are driven by norms in society and the medical system which allude to the notion that they have to somehow "fix" their child (Landsman, 2005). According to Landsman (2005), mothers may not necessarily agree to the accuracy of the medical judgment of the practitioner who diagnoses their child. However, a mother may still choose to accept the medical expert's determination of her child's disability in order to seek the tools that will assist her in moving her child out of the category of "disabled." Some of these tools are the various services (including EI) that she chooses to use.

Societal acceptance is sometimes a concern for families. A few parents from the study by Wiart et al. (2010) who had children with milder disabilities seemed concerned that their children should attain typical movements to gain acceptance in society. Likewise, the mothers of children with more severe disabilities in studies by Mayo (1981) and Tetreault et al. (2003) seemed to be more likely to adhere to interventions despite the burdens placed on them. This suggests that perhaps families want to help their children progress faster so that they can more quickly remove the disability-associated labels that society has placed on their child. It can be speculated that achieving social acceptance for one's child is one of the driving factors to seeking and implementing EI.

Stress. The presence of stress due to the various demands of EI can well influence whether a family decides to pursue therapy or implement a home program. This is illustrated by a study conducted by Rone-Adams et al. (2004) to determine the relationship between the level of caregiver stress and the rate of compliance with a home exercise program. Sixty-six caregivers of children with disabilities participated in a survey where 66% of the sample reported non-compliance at some level. The authors found a relationship between the level of stress in caregivers and the compliance rate, indicating that the compliance rate could be predicted based on the parent's stress level. This suggests that increased stress levels were related to decreased compliance. The authors concluded that alleviating stress could increase the compliance with a home program, but did not explore whether the cause of stress could have been the expectation to comply with the home program. Nevertheless, in their concluding remarks, the authors suggested that encouraging families to incorporate home programs into their regular routines and activities may lead to a decrease in stress and an increase in compliance.

1.5 Summary

Striking a balance between work and family life is a challenge for all families. When a family has a young child with disability there is an added demand of dealing with the many tasks involved in care. One of these demands may be the expectation to implement EI recommendations and home programs. The benefits and challenges for parents implementing EI have been documented widely over the last four decades, but except for a few studies in the late 1980s and 1990s, not much recent research has been done to explore, in depth, the experiences of parents in implementing EI in the everyday routine after a therapy or home program has been prescribed. However, there is evidence that families are struggling to manage EI in their daily routine and that its demands may entail certain costs for family members, particularly caregivers.

Building on the existing literature on the process of parental implementation of EI, the overall aim of this study is to explore how parents of young children with disabilities are currently juggling EI's demands, along with their other daily responsibilities. The specific objectives of this study are to:

1) Investigate the accommodations that families make to "fit" EI into their daily routines.

2) Investigate the factors (including family beliefs, values, goals, expectations, and resources and constraints) that influence how and to what extent families implement EI recommendations, including home programs.

CHAPTER 2

Methods

2.0 Overview

Two theoretical propositions underpin the methods used in this study. The first proposition is that human beings live storied lives and use stories to bring meaning to their life experiences (Clandinin & Connelly, 2000).The second proposition is that family life (i.e., daily routines**)** is shaped by cultural factors (e.g. family beliefs, values, goals, expectations), as well as material resources and constraints (Weisner, Matheson, Coots & Bernheimer, 2005). Through stories, therefore, I sought to (a) understand how families juggle the often competing demands on their time and energy, and integrate (or decide not to integrate) early intervention (EI) activities into their daily routines; and (b) explore the cultural and material influences on family implementation *and non-implementation* of EI recommendations.

A purposive sample of 12 families with pre-school-age children with disabilities took part in the study. I conducted in-depth interviews and communicated regularly with each family over a two-year period. Interviews were digitally recorded and then fully transcribed, and detailed field notes were kept throughout. The analysis of transcript and field note data was undertaken in three steps. The first step involved the narrative analysis and write-up of each participant's individual story. The second step involved narrative analysis to identify common narrative themes and *plot.* Step three was a theory-informed thematic analysis exploring how family routines, including implementation or non-implementation of EI recommendations, were shaped by family culture, resources, and constraints.

2.1 Narrative Approach

The narrative approach that I used in this study is informed by narrative inquiry. Narrative inquiry is underpinned by the premise that human beings individually and socially lead storied lives and tell stories of those lives (Clandinin & Connelly, 2000) and, in doing so, give meaning to their experiences (Polkinghorne, 1988). According to Bruner (1991), *narrative* or the telling of stories is used by human beings to organize their experiences and their memory of happenings. Polkinghorne (1988), on the other hand, describes narratives as being organised in the mind before they are actually told.

The basic premise that humans live storied lives also underpins various narrative approaches and methods of different scholars in the field. For example, narrative inquirers may collect data using photographs and field notes as observations of people's experiences. Interview transcripts may be used in the analysis of stories that people tell (Clandinin, 2006). Bleakley (2005) explains how the analysis of narratives or stories can be undertaken in two ways. The first one is *thinking about stories*, where a researcher is required to derive categories inductively from raw data and/or apply categories back to the narratives for explanation and illumination. The second way to conduct narrative analysis is to *think with stories*. Here, the researcher enters empathically into a given narrative or creates a story as a way of capturing all the elements which might otherwise be lost in a structural analysis. This method, according to Bleakley (2005), seeks a more holistic and integrative understanding of storied accounts.

The narrative approach that I used in this research was informed by the ideas of different scholars in the narrative tradition. For example, I used Polkinghorne's (1988) concept of a narrative plot or scheme to organize the narratives and vignettes as well as the overall narrative analysis of the families' stories. I also employed Bleakley's (2005) concept of thinking with stories to write the narratives and vignettes that represent each family in this study. Another narrative method that informed my approach was the narrative analysis structure described by Riley and Hawe (2005). This is further elaborated in the data analysis section of this chapter.

2.2 Ecocultural Theory

2.2.1 History and applications of ecocultural theory

Ecocultural theory was derived from the psycho-cultural model developed by Whiting and Whiting, their associates, and students (Bernheimer et al., 1990). Ecocultural theorists engage in research that explores how families construct and sustain their lives and routines in both unremarkable times and remarkable times. Unremarkable times are the times between crisis episodes where there is an established routine, balance, and equilibrium (Gallimore, Weisner, Kaufman & Bernheimer, 1989). Remarkable times are times of change in the routine of family life and periods of adjustment to that change.

Ecocultural theory has been applied in different areas of research. It has been used:

- to better understand child development and learning (Weisner, 1984; Weisner, 2002; Super & Harkness, 1986),
- in the development of culturally appropriate classroom instruction for children with disabilities (Keogh, Gallimore & Weisner, 1997)
- to explore how interventions can be woven into the daily routine (Bernheimer & Keogh, 1995)
- to understand the impact of culture and society on the construction of daily routines of families who have a member with disability and their perceptions of disability (Lalvani, 2008; Skinner & Weisner, 2007)
- to understand how routines can be used as a context for therapeutic goals (Kellegrew, 1998, 2000).

2.2.2 Central premise and core concepts

The central premise of ecocultural theory is that all families face the adaptive challenge of creating and sustaining a routine (Weisner et al., 2005). It also explicitly includes how families construct meanings about their circumstances and their proactive responses and adaptations or accommodations to those circumstances (Bernheimer & Weisner, 2007). The assumptions and core concepts of ecocultural theory underpinned this study’s research aims, data collection, and data analysis. These assumptions are explained first:

1. *Families are proactive and mediate ecological influences.* All families proactively respond to changes in their environment and their routine. Families are said to adapt, counterbalance, exploit, and react to the many competing and sometimes contradictory forces in their proximal and distal ecologies through the process of *accommodation*. Therefore, unlike past theories of anticipated pathology in a family of a child with disability (Olshanksy, 1962; Solnit & Stark, 1961), ecocultural theory assumes families of a child with disability to be agents of change, innovative, and adjusting, rather than hapless victims of social and economic forces or of disability (Gallimore et al, 1989).

2. *Families are influenced by their social, cultural and material ecologies.* Families are influenced by the mix of social and economic forces in their distal (the broader social, political, and economic ecology) environment. Families also create a more proximal environment called the *econiche*, which is reflective of their material and cultural ecologies (Super & Harkness, 1986).

In the section below, I briefly explain the main core concepts of ecocultural theory that I used to understand and analyse my data. The concepts have been further elaborated in the glossary.

1. *Ecocultural Niche*. The ecocultural niche describes the sociocultural environment surrounding the child and the family (Gallimore et al., 1989). This econiche is dynamic and changes at two levels: firstly, at the level of the broader socioeconomic and cultural-historical levels that are beyond the control of an individual household and secondly, at the household level through the process of family accommodation. Knowing a family's material ecology and cultural beliefs helped me to analyze the factors that influenced them to make decisions about their routine and early intervention.
2. *Accommodations.* Accommodations are proactive actions that families take to adapt, counterbalance, exploit, and react to the competing forces in their broader social and economic ecologies (Weisner et al., 2005). The process of accommodation is often unconscious and involves strategies, tradeoffs, and compromises that families make (Gallimore et al., 1989). I analysed the data for accommodations made by parents to understand how each family created a routine that fit with the demands of their roles and responsibilities, including the demands of early intervention. Areas in which parents make accommodations are called *accommodation domains* and have been identified by Gallimore et al. (1993). Descriptions of these domains are presented in Table 1, with examples of each.
3. *Activity settings as the unit of analysis*. The activity settings or the specific activities in the daily routine are the unit of analysis in ecocultural theory (Bernheimer & Keogh, 1995).The daily routine provides a picture of the ways in which families organize their lives:

who does what and how family members spend their time. The interviews that I conducted with the participants mainly dealt with their daily routines. I asked parents to describe a typical day from start to finish. This information about their routine served to give me an in-depth understanding of how they organized their routine to integrate EI and other activities.

2.2.3 Ecocultural theory in my study

Ecocultural assumptions and concepts guided the formation of the research aims and objectives for this study. For example, the aim of investigating how families managed to juggle the demands of their daily routine was underpinned by the concept of accommodation and the assumption that families sustain a routine during remarkable and unremarkable times. Ecocultural theory also guided my analysis of my interview conversations with the families in order to meet the objectives of my study and to create narratives. I asked the participants to tell me about their everyday routines. These accounts were used as the unit of analysis from which I identified themes related to accommodations that families made to fit the demands of EI into their routines. I then explored themes related to values, goals and beliefs, and resources and constraints that determined how and to what extent parent-carers implement EI recommendations.

Table 1 Accommodation Domains

Accommodation domains (Adapted from, Bernheimer and Weisner, 2007)	**Description with example**
Family subsistence	Hours worked, flexibility of work schedule, adequacy of and satisfaction with financial resources, career vs. job orientation. *Mother works part time from home so she can supervise her child's home activity programs and home visits from therapists.*
Access to health and educational services	Availability of and eligibility for services, sources of transportation, amount of parent involvement required. *Parents each take time from work to make trips to speech therapy and doctors' appointments.*
Home and neighbourhood safety	Safety of locks and accessibility of play area, alterations in home (Installation of locks, fences for safety, choice of specific

	neighbourhood). *Parents install locks on doors and build higher fences around the house to prevent child with autistic behaviours from wandering out or jumping over.*
Domestic workload	Amount of work and persons available to do it, amount of time spent by different family members. *Mother pushes back routine household tasks to make time to supervise and involve herself with home visits from aides and therapeutic activities for her child.*
Childcare tasks	Complexity of childcare tasks, extraordinary childcare demands (medical or behavioural problems), number and availability of caregivers. *Dealing with special equipment like gastric pegs and nutritional supplements. Child's older brother assists in child-care activities, household tasks and therapy*
Play groups and peers	Children with disabilities vs. typically developing children, amount of parent supervision, role of siblings as playmates. *Mother takes child to neighbourhood and community events to encourage child to develop friendships with his typical peers and/or peers with disability.*
Marital role relationships	Amount of shared decision-making regarding child with delays, degree to which childcare and household tasks shared. *Parents take shifts in the night to supervise child who tends to have disturbed sleep.*
Social support	Availability and use of formal (church, parent groups) and informal (friend, relatives) sources of support, costs of using support. *Mother seeks support from grandparents to supervise child while she goes to work.*
Father’s role	Amount of involvement with child with disability, amount of emotional support provided. *Father takes over from stay at home mom the minute he gets home, father cooks dinner on the weekend.*
Sources of parental information	Reliance on professional vs. nonprofessional sources, amount of time and effort spent accessing information. *Family friend who is a physical therapist provides valuable information about accessing services, as well as free consultations*

	at home for child.

2.2.4 Narrative Approach with ecocultural theory

There are two main reasons that the narrative approach fits well with ecocultural theory as the theoretical approach of this study. First, the narrative approach is based on the premise that the experiences of an individual are embedded and shaped by context. One cannot be understood as an individual alone but only in relation to a social context because one is situated in a social context (Clandinin & Connelly, 2000). As a result, an individual as the narrator also situates his or her story in a particular social, cultural, or political context. Second, in a narrative approach, the question “How do we come to endow experience with meaning?” is posed. As a method, it aids to determine the meaning of a particular experience or event for the person who had the experience and is telling about it in a story. The context or setting assists the researcher to interpret the story and understand its meaning (Kramp, 2004). Therefore, a narrative approach helped me to understand the meanings and themes that families attach to their experience in the routines they construct within the social context in which they live (Clandinin & Connelly, 2000).

2.3 Thematic Analysis

Thematic analysis involves the identification, analysis, and reporting of patterns or themes within data. It is used as a way to organize or describe a data set (parts of the overall data) in rich detail (Braun & Clarke, 2006). The themes or patterns are identified because they capture the essence of data in a way that it relates to the research aim. Moreover, themes represent some level of a patterned response or meaning within the data. The number of times a word or phrase occurs may not reflect a theme so much as how the words and phrases serve to capture an important element that speaks to the research focus. Thematic analysis, as used in this study, is based on the method defined by Braun and Clarke (2006). The analysis itself, including coding and categorizing, was carried out in the structure described in Rubin and Rubin (2005). This structure is elaborated in a following section on data analysis.

According to Braun and Clarke (2006), thematic analysis can be used within many but not all theoretical frameworks because thematic analysis itself does not adhere to a pre-existing framework. For this reason it is an accessible form of analysis and can be combined with other methods [see for example, Floersch, Longhofer, Kranke, and Townsend (2010) and Bernard, Malone, Kman, Caterino, and Khandelwal (2011)]. In this study, I combined narrative analysis with thematic analysis for a deeper understanding of the topic of focus. Thematic analysis can be carried out in a number of ways. For the purpose of this study I chose to use a theoretical thematic analysis (Braun & Clarke, 2006) which is more deductive in nature. This was ideal for the purposes of my project as I approached the data with an ecocultural lens. Concepts from ecocultural theory were used as a guideline to code the raw data and find themes or patterned responses that were related to the specific research questions in this study.

The analysis of data for this study was done at the *latent* or interpretive level rather than at a *semantic* level, which is more descriptive and looks only at surface meanings without going beyond what the participant has said or what is written. Analysis at the latent level seeks to examine the underlying ideas, assumptions, and conceptualizations of what is said. The analysis that is finally produced is interpretive but is already theorised (Braun & Clarke, 2006). In the case of this study, the data were analysed and interpreted based on the tenets already theorised within the ecocultural framework.

2.4 Overview of sample

2.4.1 The Sustainable Family Care Project

This study was part of the larger Sustainable Family Care for Children with Disabilities project (McConnell et al., 2008) conducted in Alberta, Canada. The Sustainable Family Care project is a three-year, mixed-methods study of work-family-care integration involving a stratified (by child age group) random sample of more than 500 families. The study is supported by grants from the Alberta Centre for Child, Family and Community Research and the Social Sciences and Humanities Research Council of Canada.

2.4.2 Sampling and recruitment

Of the 538 participants in the Sustainable Family Care project, 125 have a child under the age of six with developmental disabilities. Of these, 118 indicated that they were expected to carry out therapist-prescribed activities/home programs. From this sample, I purposively selected 30 potential interview participants. Potential participants were selected to ensure representation of single-parent and two-parent households, lower and higher socioeconomic groups, and immigrant and non-immigrant families.

I contacted the primary parent-carer by phone and invited them to participate in my study. I explained briefly what the interview would entail and answered any questions they had about the study. A total of 14 families agreed to participate. Data collection was completed with 10 of these 14 families. Two families withdrew before the first round of interviews. Another family withdrew before the second round of interviews was completed due to the death of their child. A fourth family could not be located for the second round of interviews. Table 2 summarizes how much time each family spent on EI and the components of the programs in which they were involved. The families provided this information in the Family Life Survey and in the in-depth interviews.

Table 2 Program components and time spent on EI

Name of participant (names are pseudonyms)	**Name of child**	**Diagnosis**	**Total number of hours spent on EI per week**	**Components involved in accessing and implementing programs**
Leigh	Sierra	Autism	21	Consultations with speech and occupational therapists Multidisciplinary team meetings Home visits from aides Working on therapy goals on a daily basis
Asha	Anil	Autism	3	Consultations with speech and occupational therapists Multidisciplinary team meetings Home visits from aides PECS (Picture Exchange Communication) Working on therapy goals on

				a daily basis Private speech therapy
Eva	Aura	Autism	2	Consultations with service providers Seeking to find services Advised to use PECS and sensory strategies, including use of sensory equipment at home
Luana	Anya	Prader-Willi syndrome	11	Consultations with occupational, physical, and speech therapists Multidisciplinary team meetings Coordinating services between consultants Home visits from aides 3 days a week Private speech therapy Implementing therapy goals and strategies at home.
Lydia	Evan	Spina-Bifida	13	Consultations with occupational, physical, and speech therapists Multidisciplinary team meetings Seeking and negotiating services Coordinating services between consultants Home visits from aides Exercise machines for lower limb strengthening Implementing therapy goals and strategies at home. Private therapies including massage and essential oils

Ruth and Jason	Ian	Phelan-McDermid Syndrome (22 Q 13.3 deletion)	3	Consultations with therapists Coordinating services and negotiating with service providers and school board Implementing physical and occupational therapy goals Walking with walker at home Occupational therapy adaptations at home
Maleah	Jonathan	Profound development delays	10	Appointments with consultants Negotiating services Physical, occupational, and speech therapy goals 3-5 times a day. Range-of-motion and cheek-and-tongue manipulations, tone stretches
Etana	Tomas	Attention deficit/ hyperactivity disorder and mild speech delays	8	Appointments with consultants Seeking and negotiating services with service providers and school board Speech therapy goals implemented at home
Carissa	Gavin	Acquired Brain Injury	20	Speech, occupational, and physiotherapy goals Seeking services and negotiating with service providers and school boards. Gymboree and other activities to work toward therapeutic goals
Gareth and Vivenne	Avigail	Down's Syndrome	7	Consultations with speech, physical, and occupational therapists Multidisciplinary team meetings Home visits from aides Working on therapy goals on a daily basis

Alessa	Zeph	Autism	4	Consultations with speech and occupational therapists Negotiating and coordinating services Multidisciplinary team meetings Home visits from aides PECS Working on therapy goals on a daily basis Speech and anxiety therapy groups Implementing therapy strategies and adaptations at home
Sabah	Andrew	Acquired Brain Injury	9	Consultations with speech, physical, and occupational therapists Negotiating and coordinating services Multidisciplinary team meetings Working on therapy goals on a daily basis, gross and fine motor activities and exercises Implementing therapy strategies and adaptations at home

2.5 Data Collection

The data for this study were collected primarily through semi-structured responsive interviews with each participant. Other forms of data that contributed to the study were the field notes and reflections I recorded before and after each interview and information provided to me by families through periodic telephone conversations and e-mail correspondence.

2.5.1 Initial and ongoing contact with participants

I contacted each of the families a few days before the agreed-upon date of the interview to confirm their participation. At the time of the first interview I gave the participant an information sheet about the study and went through it with them before obtaining their written informed consent. Following the first interview, contact was maintained with families periodically through telephone calls, email correspondence, and through letters which were mailed along with transcripts to each family for review. A list of the frequency and medium of contact with each participant is presented below in Table 3.

Table 3 Ongoing contact with participants

	Phone conversations		**In-depth Interviews**		**Emails**		**Thank you cards/letters and transcripts**		**Total contacts**
Year(Y)	**Y1**	**Y2**	**Y1**	**Y2**	**Y1**	**Y2**	**Y1**	**Y2**	
Alessa	2	1	1	1	0	0	2	1	8
Sabah	1	1	1	1	2	0	2	1	9
Gareth and Vivenne	1	1	1	1	1	0	2	1	8
Luana	1	1	1	1	1	0	2	1	8
Etana	1	1	1	1	2	0	2	1	9
Leigh	1	1	1	1	2	0	2	1	9
Anna	1	1	1	1	2	0	2	1	9
Ruth and Jason	1	1	1	1	1	0	2	1	8
Asha	1	1	1	1	1	3	2	1	11
Lydia	2	1	1	1	0	2	2	1	10
Maleah	2	1	1	0	0	0	1	0	5
Eva	1	0	1	0	2	0	2	0	6
									100

2.5.2 Interviews

All but one interview was conducted in the participants' homes. One interview was conducted on the University of Alberta campus. Each interview lasted anywhere from 45 minutes to two hours. I started the interview by asking the participant to describe what a typical day was like for them. The interview was open-ended but an interview protocol (outlined in Appendix C) was used to guide the conversation. The data-gathering technique for this study draws heavily from Rubin and Rubin's (2005) responsive interviewing model. The responsive interviewing model gives great importance to the interview process as it seeks more depth than breadth in understanding. Further, the model emphasizes the relationship between the interviewer and the interviewee where both influence and interact with each other. The interviews explored the following topics:

1. A typical day in their lives (I usually asked them to start by describing "yesterday").

2. Their family: what each member is like and how each is involved in family responsibilities.

3. Juggling routines, roles and responsibilities.

4. Trade-offs and compromises they've made.

5. Involvement with EI services.

The second round of interviews was conducted using similar guidelines but certain areas were explored in greater depth, based on the information shared by the participants during the first interviews.

2.5.3 Data recording

Data were recorded for this study using three methods: audio taping, field notes, and journaling reflections.

Audio taping. After obtaining consent from each participant, interviews were digitally recorded. I kept a note pad on the side in case I had questions or comments I wanted to clarify later so as to avoid interrupting the interviewee. Taping the interviews allowed me as the interviewer to be completely attentive. In most cases the presence of the recorder seemed to be forgotten over the course of the interview. The recorded interviews were later transcribed in full.

Field notes. Pre- and post-interview field notes were documented for each interview. The field notes that I wrote included details such as a description of the environment, people present, and participant non-verbal behaviours and reactions that I observed during the time I spent with the families. I also recorded a brief summary and noted difficulties that I might have had so that I would be able to address them in the next interview. For example, I had to make the conscious effort not to fill every pause or silence even when I felt it to be awkward. Some of my impressions and reflections of the interview were also written in my field notes.

Journaling reflections. The responsive interviewing model (Rubin & Rubin, 2005) encourages self-reflection and necessitates that researchers come to the situation after sifting through their own experiences and cultural expectations in order to be open and willing to hear and understand what their conversational partner is saying. This was very helpful to me during my preparation for each interview. Being in Canada where there is a different culture and health care system than what I have known in my home country, I had to make myself aware that my culture, religious beliefs, expectations of family dynamics, and reactions to the disability and the health care systems may have created certain biases in my mind. Reflecting on some of my expectations helped me develop a greater sensitivity and openness to each participant during the course of the interviews (Rubin & Rubin, 2005). Before and after each interview I made brief field notes. After each interview I added other reflections or impressions from the session. I was able to note any biases or impressions that I might have had that might affect the process.

2.5.4 Rigor

In order to ensure trustworthiness and rigor during the course of this study, strategies were employed based on the recommendations of Fossey, Harvey, McDermott, and Davidson (2002), Lincoln and Guba (1985), and Stiles (1999). These strategies are listed below in Table 4, according to their primary purpose.

Table 4 Strategies to ensure rigor

Primary Purpose	Method	Description of Methods in this study

To collect high quality data	Purposive Sampling (Coyne,1997)	Sampling information-rich cases that are selected purposefully to fit the study.
	Engagement with material	Through in-depth interviews in two waves, ongoing communication with participants throughout the duration of the study, thorough analysis of the data and the creation of narratives from the interview transcripts which were thereafter sent to participants for clarification, and discussion of the resulting interpretations and themes with research team and supervisor.
	Persistent observation	Teasing out the irrelevant information during the analytical process by recognizing that sometimes what seems interesting but may have no connection with the topic of study and, likewise, that even atypical findings may have importance in light of the topic of study (Lincoln & Guba, 1985). Engaging in tentative labelling of the salient features in each transcript.
To establish permeability (the capacity for understanding to be changed by observations) and coherence (the findings fit the data from which they are derived) (Stiles, 1999)	Critical reflection	By presenting narratives and interpretations to fellow researchers and supervisor. The team acted as a sounding board that gave feedback and their take on the interpretation. Biases were probed, meanings were explored and the basis of the interpretations was clarified.

	Vivid/thick description	Providing a detailed description of the context/circumstances surrounding the experiences of the study participants so as to gain an understanding of the meaning ascribed to their routines and decisions regarding EI implementation.
To establish authenticity (Fossey et al., 2002) and to test, revise, elaborate, and verify understanding	Member/checks/reciprocity	The transcripts and narratives were sent back to the participants for clarification, comments, and feedback as to whether the narrative represented their situation accurately. Each transcript was analysed for themes. Interpretations were made accordingly and represented in the narrative through first-person accounts.
	Iteration	Through the cyclical back and forth process of moving from observations to interpretations and back to revise and reformulate interpretations.
	Participant representation in narratives	Data were presented in the form of first person narratives. The narratives were written using the participants' words, but were rearranged by the investigator to give the narratives flow. Quote marks were placed around any quotes used verbatim.

2.6 Data Analysis

2.6.1 Overview

The data were analysed using a combination of narrative and thematic analysis. Narrative analysis was used to explore how parents understood the experience of EI in the context of their daily routines. Thematic analysis was used to identify accommodations that families made, as well as values, goals, beliefs, resources, and constraints that influenced how and to what extent families implemented EI. Narrative analysis led to the identification of common *narrative threads* which were narrative plots or organizing themes that families used in the telling their stories. Thematic analysis led to the identification of a number of common themes across all 12 families' stories. The results of narrative analysis and thematic analysis are presented in Chapters 3 and 4 respectively. In addition, three extended narratives and nine short vignettes were also created as a way of thinking with stories. The methods used to develop each are outlined and described in the following sub-sections.

2.6.2 Narrative Analysis

The narrative analysis method for this study was adapted from the structure used by Riley and Hawe (2005). Short *narrative segments* or short descriptive pieces taken from each participant interview were analyzed. Common narrative threads from across the 12 participant families were identified. These narrative threads speak to the overall experience of families in implementing EI in the context of their daily routines. Common narrative threads are presented in Chapter 3. Narrative threads and narrative segments were also used to create family narratives and vignettes.

Table 5 contains an example that illustrates how narrative analysis was performed on narrative segments. The background on the segment is presented first.

The 'Bouncy House' story

This story comes from Alessa, who is the mother of a young boy named Zeph, who has been diagnosed with autism. Just before she narrated this story, Alessa had been talking about how Zeph could not appreciate or tolerate certain things that his typical peers could, for example colourful classrooms or posters in his bedroom. Then she related to me the story of "the bouncy house." Here she talks about how her son wanted to go into an inflatable castle at the local farmer's market, but he was too overwhelmed and scared to go in through the small opening.

> *He can't get in and he couldn't just do the threshold. He couldn't and you couldn't force him, cause' he'd scream and yell and have a temper tantrum. But he'd also scream and yell and have a temper tantrum cause' he wanted to go in! And the people who are doing it don't understand what's going on and in the end, I'm hugely upset and it's like 'Well why I am so upset? Who cares if he goes in a bouncy house or not? Cause really is that the measure of my mothering skills-whether he will go in a bouncy house and have fun?' But it is upsetting because it is something you feel a child should be able to do. And they should be able to enjoy and he couldn't and I used to find that really upsetting and this year we went to the Autism walk and he was able to go in a bouncy house and bounce. (I2, pg.1)*

Table 5 Example of narrative analysis of a narrative segment.

Story	Where does the storyteller situate the story How does the parent relate the story? Types of phrases, sentences used. Why the story is told in the way that it is? What is the tone?	What are the meanings the story teller attributes to the situation and organizing theme
"The Bouncy House" story	Alessa situates the story in the past but relates her thoughts from that time in present tense as though she is reliving that moment. She uses words like "can't", "don't", "upset", which denotes that the experience was largely negative. Alessa uses a tone of building frustration about her son's frustration as well as the reactions of the people around her. She pauses to wonder why she is upset and frustrated. She reflects on whether the success of her motherhood depends on whether her son enters the bouncy house. Toward the end of the story, the tone changes to one of relief, a sense of achievement and joy.	Alessa negotiates a number of different thoughts at this one moment. As a mother she feels upset that her son is unable to enjoy activities that he wants to do but struggles with. At the same time, she is worried about what others think because of Zeph's reactions. She also feels that her son "should be able" to do this activity like any other child, which denotes she is influenced by norms set by society. Alessa also questions the meanings of success and whether her ability as a mother is measured by her son's success. This also alludes to the fact that societal norms tend to

		dictate her ability as a mother based on her son's achievements. The end of the story is a marked with a sense of triumph and relief. The narrative threads that came from this story were, "The meanings of success," "The source of motivation."

2.6.3 Creation and development of stories

Three narratives and nine vignettes were created for the families that participated in this study. Vignettes gave a brief account of each family and an overall view of how they manage to juggle the various demands of their routines, including EI, and a brief look the meanings they attribute to life events and disability. The narratives were created to give the reader an in-depth view of the EI experience in the context of the lives of three different families: that is, a richer, deeper, understanding of the values, beliefs, goals, resources, and constraints that help a family balance work, family, and EI.

While going through each transcript for the purpose of creating narratives, I first identified narrative segments (Riley & Hawe, 2005) that were relevant to the overall topic. I identified elements that were integral to the participant's story, such as characters, times, settings, events, and organizing themes that parents used in telling their stories (Table 6). These elements and narrative segments were then restructured and reorganized to compose a narrative to help give the reader an understanding, from the participant's point of view, of daily experiences of families with EI and disability. In other words, to achieve an "inside" understanding, I used the participant's words from the transcript to create a story but rearranged certain sentences in order to give the narrative flow in terms of language and timing of events.

Narrative segments and elements were brought together using the organizing themes or *plot lines* that I had identified from families' accounts of events that had occurred in their lives. The plot or the organizing scheme of the narrative "serves to transform a list of events into a schematic whole by highlighting and recognizing the contribution that certain events make to the development and outcome of the story"

(Polkinghorne, 1988, p.19). Without the plot, a story would remain merely a list of events, where each event would seem separate from each other and disconnected. The meaning of each event would be confined to its location in space and time.

Vignettes were created for the other nine families. These were smaller stories that briefly described each family and their situation. The vignettes also touched on details such as a defining characteristic or event which families recounted to me that had a significant effect on their lives, their experience of early intervention, and their daily routine.

Table 6 Description of elements used to create a narrative

Name	**Description**
Narrative segments	Sentences and paragraphs that contain stories or information related in any way to the topic of focus. These segments were analysed for the way in which the story was told, the context, tone, descriptions and meanings that the story teller ascribed to the event. The segments were also analysed for why they were told and how the telling interacted with the broader forces of society and culture.
Characters	The characters in the story: the story teller, and the supporting cast. For example, family members, friends, the social worker, the therapists, etc.
Events	Significant dates, defining moments, e.g., births, deaths, illnesses, significant moves, marriages..
Setting	In terms of time, e.g., past, present, or future. In terms of place: countries they've immigrated from, urban or rural settings, community, and culture.
Plot/organizing schemes	Themes that run through the telling of the story, e.g., themes of hope, despair, triumph, struggle, conquest.

2.6.4 Naming participants

An important part of the narrative process was naming each participant. I looked for names whose meanings reflected either a strong personality trait possessed by the participant that I had recognized from my conversations with them, or a character that they identified themselves to be within their own stories. The naming process happened toward the end of the creation of each vignette or narrative. The name, in itself, acted as an organizing theme or plot that brought the story together.

2.6.5 Thematic Analysis

The data were analysed for themes, in two steps, while keeping in mind the following (terms used in the following section are presented in Table 7):

a) The overall aims of this study: a) to investigate how families juggle the often competing demands on their time and energy and integrate (or otherwise) EI activities into their everyday routine, and b) to explore the factors that influence how and to what extent families of young children implement the therapies recommended to them.
b) The tenets or concepts of ecocultural theory which informed the data collection and analysis, namely, accommodations, values and goals, and resources and constraints for each family.

The first step of analysis involved going through each transcript line by line and looking for data units related to:

1. Early intervention: for example, strategies, implementation, relationship with services.
2. Maintaining a routine.

I also highlighted topical markers, concepts, and themes as I went along. This process also helped to provide relevant information that could be used in creating a narrative or a vignette.

Data units were further coded for:

1. Concepts that fit the ecocultural concepts of accommodations, family values and goals, resources and constraints
2. Themes such as culture, attitudes, meanings that families attribute to disability, and early intervention services

Table 7 Definition of terms

Name	**Definition**	**I looked for ‘Data units’ that contained information about:**
Topical Markers	Names of people, places, numbers, organisations, etc., that are not important by themselves but are important to the overall story that is told	Family members, background, where they’ve come from, places they’ve lived, important dates
Concepts	A word or term that represents an idea important to the research aim	Accommodations, family and personal values and goals, cultural values, resources and constraints, everyday routine
Themes	Summary statements and phrases	Words, statements or phrases that are used by participants throughout their interview conversation
Data Units	Blocks of information that contain comments made in the interview that are examined and analysed depending on the research aim	EI services, the participants’ experience with EI, e.g., their relationship with the services and their implementation of EI in the daily routine

In the second step, I reflected on and analysed the first codes for their meanings, coded them further, and regrouped them into sub-categories which were then finally categorized under the three main headings:

1. What am I juggling?
2. How am I juggling these things?
3. What influences my implementation of EI? These three headings corresponded to the research aims and objectives.

Three examples of how the transcript was coded and analysed are presented in Table 8.

Table 8 Examples of thematic analysis of data

Transcript/ data unit	**Concept**	**Reflection on meaning/comments**	**Coded as**	**Categorized under**	**Grouped under main heading**
"I just take each day as it comes, that's what keeps us strong"	Strategies	Sabah's positive attitude helps her find strength to juggle her family's routine.	*"My attitude towards life"*	*Accommodations/strategies-*	*"How am I juggling these things?"*
"I mean, that's also how I get respect from people at the hospital, right? If I look like I'm put together, then they'll listen to me right?	Strategies	Maleah tries to manage the professionals' perceptions by keeping up a healthy physical appearance	*Managing perceptions in health care services*	*Accommodations/ Strategies-*	*"How am I juggling these things?"*
"It's more the experts looking at him and deciding this is the best stuff for him, rather than me. I mean I'm an expert on him, too...."	Beliefs	Alessa feels that she is the expert on her child and also knows what's best for him	*"Knowing what's best for my child"*	*Values and goals*	*"What affects my implementation of EI?"*

2.6.6 Participant Feedback

All of the transcripts, narratives, and vignettes were sent back to the participants to obtain feedback, giving each an opportunity to discuss the findings and make comments or clarifications. This was done so as to maintain authenticity and accuracy, and to test, verify, revise, and elaborate researcher understanding. Parents responded with feedback and comments from via email.

2.7 Summary

The aim of this study was to explore and understand the process of how families juggle the demands of work and family life and early intervention/home programs, as well as the resources, constraints, beliefs, values, and goals that influence this process. The data for this study were collected through in-depth interviews with 14 parent carers from 12 families. Each of these families had a young child with a long-term physical or cognitive developmental disability and was implementing early intervention and/or home program recommendations. Data analysis was guided by the research aims and informed by an ecocultural framework. The findings from this analysis include the common themes drawn from the raw data and the common narrative themes from across all the family stories. These are presented in Chapter 4. Chapter 3 is a compilation of the extended narratives and vignettes that I wrote for each family in my study. These are presented to give the reader an understanding of who each family is and an idea of what they juggle in their respective family routines.

CHAPTER 3

Narrative findings

3.0 Overview

The results of the narrative analysis are presented in this chapter in the form of nine brief vignettes, three extended narratives, and the common narrative thread s from across all the family stories. The vignettes and narratives that were created from the stories narrated by each of the families that took part in this study are presented in sections 3.1 and 3.2 respectively. Each vignette contains an introduction of the family, an overall look at how they manage to juggle the various demands of their routine including early intervention and a brief look the meanings they attribute to life events and disability. The narratives were created to gain a richer, deeper, understanding into the values, beliefs, goals, resources, and constraints that help parents balance work, family and early intervention. Rich insights from families about the meanings of early intervention and disability, and the rewards they gain from having their children with disability are also presented. In section 3.3 the results of the narrative analysis are presented, that is, the common narrative threads that were drawn from the stories of each of the families that participated in this study.

3.1 Vignettes

3.1.1 Leigh

"Leigh" is an English name that means "Meadow". It also carries the meanings "calm" and "weary". Leigh is an intelligent woman with a sharp wit. I gave her the name "Leigh" however, because she exuded a quiet confidence and was generally soft spoken. She was also one of the parents in this study who explained, quite articulately, the fatigue and exhaustion she experienced from keeping up with the demands of caring for her child with disability.

Leigh's daughter Sierra was born in Calgary. When Sierra was diagnosed with Autism, Leigh, her husband Craig, son Aiden, 13, and Sierra, now 6, moved to Edmonton to be closer to services and family for support. When Sierra was four, she was hospitalized for a seizure that lasted three hours. As a result of the seizures she suffered delays over and above the challenges she already had due to autism.

Everything is therapy

Leigh takes Sierra to regular therapy consultations, attends in-service classes for autism management strategies and doctor's appointments. Sierra also started to receive specialized services on her entry to grade one at school. In addition to these services, an aide comes to work with Sierra after school for about two hours. Leigh and her family make great efforts to work with Sierra through therapy. According to Leigh, therapy for Sierra does not end with the aide's home visit. She explains, *"Yeah it happens and to be aware of the expectation from the service provider [names service provider] that this is not the only therapy that happens with Sierra. We are also living therapy. It is not a case of, 'We are going to sit with an hour for her and with her and work on speech'. . . . You are playing with this toy. You want 'more', you have to sign. If you know [you're] going up and down the stairs, we are doing it in a manner prescribed by OT. If it is: we are outside and playing, we are going to work on the two foot take-off and landing from PT. [It's] Just knowing that we are implementing therapy goals throughout the day (p.23, I1) Everything is therapy. Absolutely everything. . . . Even something as simple as eating: when she has noodles. . . . we make sure that they are longish so she is forced to manipulate them with her tongue, her lips. . . . So eating is therapy. . . . We are kind of geeky that way. Yeah we are. Nothing is basic in our world because we know that, you know, therapy has to happen with us all the time. So yeah that was us saying, 'Hey we are not just going to feed her. We have to make it therapy'." (p.24, I1)*

Of teamwork and teachable moments

Within their routine, Leigh takes up most of the household and child care responsibilities while Craig manages finances and home maintenance. When Craig has the time he assists Leigh with Sierra's self-care tasks. Aiden helps to watch Sierra while Leigh cooks dinner in the evenings and does some of the chores as well. She says. *"It is a team effort and when I say nothing happens in isolation. . . . If I want to do stuff in the garden on a weekend, I am in the garden, Craig is in here with Sierra. It's never a case of just going and doing something unannounced. You have to announce: 'I am going to the basement now, somebody watch Sierra' or 'I have to run up to the garage to get* *something. Somebody watch Sierra, [or] I am going to get the mail, somebody watch Sierra'. So nothing happens in isolation. Something always has to give." (p.19, I1)*

Leigh talks of using every day events, good or bad, as a "teachable moments" for her son and for herself as wel*l. "We are human, of course. It will happen. Absolutely, and you just ready yourself for the day and realize that, pardon my French, 's*** happens'. What are you going to do about it? I mean even little, minor catastrophes like Sierra got into a houseplant and pulled it down and there is pottery everywhere, broke, and there was dirt and I was just besides myself I was livid and I did not react very well. But it was teaching moment because Aiden was there to see me lose it and after I was done losing it and had my temper tantrum, I was able to sit down and tell him, 'Well I did not handle that very well, did I? What could I've done better?' Before, I did not used to have a lot of patience. I still do not have as much patience as I should, but when I do lose my patience, I turn it into a teachable moment for my son. Yeah. Loosen it up and realize that balls will be dropped, there will be blood. You clean it up and you move on." (p.29, I1)*

Aiden

Because so much revolves around Sierra, Leigh and Craig have made sure to encourage Aiden in his love for ice hockey. *"We knew that we were going to be spending a lot of time with Sierra, medical appointments, therapy. It is about Sierra, Sierra, Sierra. So we wanted something that is his. Hockey is it. . . . We do our damnedest to make sure we all are at games, Craig, me, Sierra, and Aiden. We will all go to games. . . . It is definitely a social event." (p.16, 17, I1)*

What I've learned from Sierra

Leigh talks about the positives Sierra has brought to the family. *"Well we definitely learn to have more patience, more forgiveness. When you go out into a public place and some child is screaming, you do not automatically think, 'Man that kid is a brat.' You think maybe he is special needs and the parents are doing the best they can because that is what I hope other people are saying to us if Sierra has a tantrum out in public of course- grabbing everything on the store shelf-they are not saying 'crappy parents'. They are saying, 'Oh tough day.' I hope.... We do not take anything for granted. We sure don't." (p.25, I1)*

3.1.2 Asha

"Asha" is an Indian name that means "Hope". Asha is a woman who was sweet natured and very matter-of-fact. Though she spent much time talking about the difficulties she had with her son and the restraints of her culture, she also talked about the positive aspects of her culture and community. She draws her hope and optimism from all lessons she has learnt from her son.

Asha, 37 immigrated to Canada from India with her husband in the late 90's. Both her children, Mahima, 12 and Anil, 7 are Canadian born. In 2003, her son, Anil, was diagnosed with autism. Asha had a hard time accepting the diagnosis. "*For a year I[couldn't accept that he had Autism], then slowly, slowly, I accepted that yeah, he has a problem." (p.9, I1)*

Early Intervention and the routine

Anil was referred for early intervention. This involved an aide, allotted by the service provider, who worked with Anil, at their home, three times a week using methods like, Picture Exchange Communication (PECS) and ABC (Antecendents, Behaviors and Costs) behavioural methods. After the first three years of intervention. Asha and her husband felt discouraged because they could not see improvements in Anil. However she still felt like it was important carry on with whatever therapy that was available to them. *"Still we cannot stop. That's the problem. Because we'll think, 'My god! My son should get whatever help he can'. We will accept it. The rest is up to us. We cannot blame them. Like whatever they can do they are doing." (p.27, I1)* Recently, Anil was assigned a new aide. Asha found her to be very supportive and since has been able to see more improvements in Anil's behaviour and skills.

Asha takes on the responsibility of child care and managing the home. They have a very traditional Indian household. She laughs and says, "*My husband. Same Indian style! No helping in cooking! Sometimes if he has the mood, then he will cook. Otherwise, I do it all!"* (pg.7, I1) However, Asha does appreciate her husband's support for Anil. "*His father-He's very close to him. He does that way. He is very supportive about Anil. He's very patient person." (p.29, I1)*

People don't understand

Asha misses her native India, but has to face the stigma that her community places on Anil's special needs every time she goes back to visit.

"I don't want to go back to India. . . . you cannot freely sit with somebody and talk. You have to keep some things inside. Even with your parents it's tough. People ask 'Why is he so hyper?', 'Why can't he sit still', 'Why can't you stop that?' I said, 'You cannot do anything about that. Some things you have to let be, because that's the way he is. You cannot control his running around, his laughing. That brain you cannot control." (p.33, I1)

Asha appreciates the independence and relative freedom from stigma that she experiences in Canada but still feels out of place sometimes. *"Even if you are a citizen, you won't feel that you are Canadian. Yeah, you are always outside person. . . . You can't get friends. It's very difficult to get friends here, no? Luckily I have some Punjabi friends here." (p.21, I1)*

There is an old lady here, she's very nice. I like her. She says to me 'Somebody in your generation did something and you are suffering for it'. I got a shock when she said that. I said 'It's not that!' See, people don't understand. That's the problem. . . . They'll not understand. That's the thing." (p.23, I1)

Worries about my children

Asha worries about how Anil's special needs affect her children now and how it will impact their futures.

"For her [Mahima] it's a big challenge. She'll say 'I'm the only one mummy. Nobody else's brother is like this. He doesn't speak.' She misses that talking. She is a very talkative girl. She misses that aspect of brother-sister right? Talking- he doesn't talk right?" (p.19, I1)

"Him, also I get so scared. My god, how will he live? Where can he live? We have to find out something, where somebody can take care of people like him. That's the scariest part I feel. My god! If you are big, you are independent, like Mahima, you don't have to worry, right? They get smart. They will live a life, a good life. Study something, get married, I don't know. God! I don't know. Those things we cannot think now too much (p.35, I1). We have to find resources. At least in this country there is help. . . . In

old age you get some money and we have to see for him too. He gets money too." (p.35, I1)

Things I've learnt from Anil

"It's so challenging for him. For us also it's a trouble but, we have to see his things too. He cannot tell anybody that he's hurt. At least my daughter-if she's hurt, or if somebody didn't play with her- she can tell us like 'Yeah, I'm hurt today, or she didn't play.' Like if he's hurt, or if he's not feeling good, he cannot tell us. We should appreciate what we have. That's what I feel I learnt from him. (p.24, I1) Some people are still crying. If they have everything, they still cry! Like I, I keep my positive attitude. Like whatever I do, I don't just sit and cry 'My son is like this'. Sometimes there's a point, like you get so frustrated, no? But I keep my positive attitude." (p.29, I1)

3.1.3 Eva

"Eva" is Hebrew for "life". Eva was expecting her fourth child and experiencing many struggles with the lack of community and support with child care. I named her Eva because she was pregnant and waiting to bring "new life" into the world. Eva was also striving for a better life for her disabled child and her other children as well.

Too much to manage

Eva, 25 is dealing with a lot. She is a stay-at-home mom of three: 6 year old Haley, 4 year old Aura, and 2 year old Nicholas. She is now pregnant with her fourth child and has been exceptionally fatigued in the last few weeks. In addition to this, Eva has been finding it increasingly hard to manage challenging behaviour from Aura who was recently diagnosed with autism. Just a few weeks before, Aura jumped over the fence when Eva wasn't looking and ran away. Eva had to call the police to help find her. *"The reason why we're cooped up is because she runs out and runs away and it's a safety hazard. . . . It's not good for a person to be cooped up so much." (p.11, I1)*

A few months before, Eva had been separated from her husband and had been staying at a shelter. Now they were back together and trying to manage responsibilities at home. Her husband is the only wage earner in the family. He helps out some of the time at home but childcare and housework always falls back on her. She is finding it hard to keep up, especially with the fatigue from her pregnancy. Eva just does not have the energy. "*My* *life is just like, is basically, I can do whatever I can do as long as I have child care, and that's not often." (p.7, I1)* Eva moved to the present house a few months before. She doesn't have a lot of family or friends nearby to help. Much of the time she depends on Haley to help out. "*She's independent. She takes care of herself. . . . I kind of get her to help out more then I should. She's only a baby herself right? So I try not to put so much on her. It's just- sometimes, it's just hard." (p.10, I1)*

The diagnosis–A relief

Eva does feel the weight of the challenges with Aura's behaviours. However, she is quite relieved to have a diagnosis in place. *"Just knowing- because before I felt kind of ashamed, like 'What kind of parent am I? Why is she this way?'- kind of thing and now that I know that it has nothing to do with what I did wrong, or anything like that. Some parents even have kids like even though they have completely healthy pregnancies and stuff and it's not anything they did wrong, it's just something that happens. So now that I know that I can , when people look at her and look strange at me I can just tell them, 'Yeah she was diagnosed with autism disorder, so that's why she does inappropriate things' and that's basically all I have to say and they understand, cause they would assume things. She looks completely fine right? She looks normal, but her actions say otherwise. They would look at me like 'Why are you-what kind of parent are you to have your kid in a harness?' or they'd look at me like 'What kind of parent are you to keep your kid in that?' 'And when she does things that are inappropriate, they would look at me like, 'What kind of parent are you?' basically. (p.20, I1). . . . So now I know why it was so stressful. I just thought maybe she just has a lot of energy. Maybe she's a different kid. It's different now, now that we know. It's better in a sense." (p.20, I1)*

The wait for early intervention

With diagnosis in hand, Eva is currently waiting for specialised services to be made available for Aura. *". . . I think in time that will happen too. It takes time to get everything rolling right? It takes time for her to get specialized services. (p.21, I1) When that happens, I think the people come here and work with her for three or four hours a day I think and try and figure out little things. . . . and make things safer and work on like making life easier for her I guess, for her and for the parents. (p.5, I1) It would take a few months, but that would be really beneficial. At this point like right now, we don't have any professionals involved, like we don't have any interventions right now, but when she* *starts going to school, there will be occupational therapists, speech therapists. There'll be music therapy and all kinds of things you know? (p.21, I1)* Eva had been advised earlier by the OT and SLP about using PECS (Picture Exchange Communication system) for communication and various ideas for sensory strategies for Aura. Eva has a lot interest to pursue these strategies but she has neither the necessary materials to implement them nor does she have the energy or time.

Finding help is hard

Despite the hardship Eva longs for and tries to find one-on-one time to interact with each of her children. When she does get free time in between she tries to do a little research on what's available in terms of resources and services for Aura. She also wants to join a parent group but time, energy and, most of all, support are hard to find. With these in place, Eva believes Aura can come a long way. *"I can see potential but she needs love, she needs her parents. So it's a lot of self sacrifice and a lot of things that make life really, really, difficult and if I had more help it would be different but I don't have that right now so, in time , when I start to get to know more people and get into more programs maybe I can get more help but at this time it's not like that." (p.20, I1)*

3.1.4 Luana

Luana is Hawaiian for "enjoyment" but as an English name it could mean "gracious light". I thought it was perfect for this mom because not only is she bubbly and merry, and full of light, but she accepts every situation with grace and optimism.

Luana, 37 is a bubbly, cheerful woman who lives with her husband Kevin and their daughters Anya, 7 and Autumn, 5. Anya has been diagnosed with Prader-Willi Syndrome which is characterised by emotional lability, food seeking, and some features of the autistic spectrum disorders.

The household

Luana describes their household as pretty stereotypical. "It's *funny how it's evolved. . . . when we talked about having kids. . . . we really were undecided about who was going to stay home with the kids. I mean it could have very well have been Kevin." (p.17, I1)* However, when it came down to deciding between their job situations and care for Anya, Luana and Kevin jointly decided that Luana would stay at home. *"As the years have gone* *by I would say we've become a very traditional, sort of stereotypical household where, you know, I do the vast majority of the cooking and the cleaning and homemaking....He's[Kevin's] the one that's fixing the toilet and mowing the lawn and scooping the poop and you know"(p.18, I1)*

Early Intervention – a "Catch-22"

Over the past year Anya has had therapy at school including speech, occupational, and physical therapy services, plus an aide that comes home to work with her three times a week. Luana and her husband have also signed Anya up for private speech therapy sessions once a week. Luana drives Anya across the city to a school that offers services that are not available closer to her residence. In addition to this she has regular meetings with Anya's multidisciplinary team, appointments with the doctor (for which the family drives up to Edmonton from Calgary), and she coordinates and transfers information between services to keep each of them updated on Anya's progress.

Luana finds that participating in therapy services for Anya can be a conundrum, "*Definitely having all those appointments and having somebody come in and you know, it's a Catch 22, cause' you know there'd be a week where the aide would be sick or whatever. And I'd be like it was nice to just have nobody coming . . . and it's nothing to do with her, I mean she's wonderful and flexible, but it's just another person to do something for . . . . But on the other hand, you know I feel so lucky to have these services, because then I don't have to schedule an hour or twice a week or everyday or whatever to do these therapies with Anya. I can just be 'Mom' and I don't need to worry about whether we've practiced her pencil grip. I don't even have to worry about it. Somebody else is looking after it. Woohoo! So it's a bit of a 'Catch 22', because I feel like when we don't have that, and I don't do it, I feel so guilty and I feel like we should've worked on that, didn't get to it and then you have that 'Mommy guilt'." (p.18, I2)*

Just let her be!

Luana talks about how trying to incorporate therapy for Anya is so much a part of her. ". . . . *sometimes I'll catch myself and be like 'Back off already! Just let her run around!' You know what I mean? Instead of making her run to a target! Like I do find that I sometimes need to step off, you know? Because it is so engrained to just 'Work on it, work on it! You can do it!' You know? And sometimes I just think, 'Oh shut up Luana!' You know?*

[laughs] 'Just let her be a kid for ten minutes' . . . . So at this point it's coming pretty naturally. Maybe too naturally!"(p.28, I2), she laughs and says.*"You know your life and things become so integrated that it's hard to discuss it from a higher perspective or like to back out of it, you know in real life even, sometimes." (p.33, I1)*

3.1.5 Lydia

Lydia was the name of an enterprising business woman in the Bible. She was a God fearing woman. She was generous and opened her home and her arms to those in need. I named this mother "Lydia" because she is, like her namesake, a woman who is enterprising, uses time and opportunities to her best advantage as well as to help others around her. She also attributes her strength and hope in life to her belief in God.

A much needed change in pace

Things had changed a little bit over the last year for Lydia, 43, her husband Matthew and their sons Shawn,7 and Evan, 5. The year before, they had so much going on. They had gone to China to explore treatment options for Evan's Spina bifida. They were looking into spinal cord regenerative techniques. They were also running a support group for parents of children with disabilities.

Lydia had decided a change of pace was needed for their family.*"I think we've slowed down a bit of outside stuff and done more as a family because I think we were trying to do too much (p.3, I2) . . . . So, we don't, like we don't have as many people over, we don't go out as much. We've kind of slowed down the pace of our life a little bit more than that we'd before. . . " (p.3, I2)*

Lydia and her husband Matthew and the boys love spending time together biking, camping or even staying at home and watering the garden. Lydia has a systematic routine going in order to manage the household and childcare. She works four days a week from home and finds "blocks of time" in the day to implement Evan's therapies while multitasking. She made the decision to take on fewer hours of work in order to spend time with Evan and work on his therapy instead of having what she calls, "a revolving door" of different people coming for inconsistent periods of time to work with him through EI.

Teaming up with the early interventionists

Working with the interventionists is a team effort for Lydia and she considers herself an important member of the team. *"I tend to be a very involved person and so I want to know what's happening. I sit in on the majority of the meetings where the consultants come out. I want to know what they're hearing and what they think the issues are and what we should be working on next so that we can incorporate that into what we're doing. I also have the most knowledge of him and what he can do and so there is often times, where spending an hour with him, you don't get a full picture of, you know, what's important for him to be able to do. And so there's a lot of input that I have and then feedback that I get from them because I don't have a background in OT, PT, speech-language, all of that education. . . . So we bounce ideas back and forth then we come up with programs." (p.5, I1)*

Our priorities vs. their priorities

Lydia and her husband implement therapies for Evan outside of and in addition to what the consultants have recommended "*. . . . we have the best interest in him or we have the best reasons to be able to help him. And so sometimes there's things that are missed or things that are not necessarily a priority for other people that are priority for us to-well actually in, in the reverse, there's priorities for them. . . . You know, it's[therapist's priorities] not a huge priority for us right now. . . . It's more important for us right now just for him to strengthen his legs and build muscles and things . . . . We have an exercise machine that we bought two years ago and he does that an hour a day and that's not really a priority in their mind but it is in our mind because he's, he is developing so much better by using that exercise machine, both physically and cognitively. So yeah that's something that we do outside of the programming because we believe that it's important for him."(p.5, I1)*

Looking at the positive

Other families of special needs children had advised Lydia to give the appearance of struggling when the case worker would come to their home in order to assess their need for funding. *"So, unfortunately that is what the system supports. The more need that you can show the more funds that you get. . . . I'm not going to come down, my hair in curlers and you know what? I am not going to sit here and tell you "Woe is us" for what we have to go through."* Instead Lydia chooses to focus on the positive. "*I am going to tell you the celebrations of things that we've achieved and accomplished. And that's what I am* *going to focus on. He [Evan] does not need to hear what he cannot do. He needs to hear what he's done and that's what we need to work on and grow on. We are not going to grow if we keep talking about what we are not and we can't do. The only way we can grow is if we were saying, "Look at what we've changed and let's look at what we can move towards" and so, yeah, when I sit and talk with the social worker, I am not going to sit here and tell you "Woe is us". Like that's not in me and I don't want to be like that and if that means that I lose some funding, then I guess I lose some funding." (p.30, I2)*

3.1.6 Ruth and Jason

Ruth is a Hebrew name that means "friend" or "companion". Jason, also of Hebrew and Greek origin, was the name of a man in the Bible who was known to be hospitable and a good friend. I chose these names for the parents in this vignette because two of the important narrative threads that ran through their story were "teamwork" and "friendship". Jason wanted to be interviewed along with Ruth, and together they provided some valuable insights.

Ruth, 41, her husband Jason and their three boys were born and raised in Canada. Ian was born to them about 18 years after their first two boys, Dan, 24, and Nathan, 20. *"I think it helped. Yeah. It made things-the experiences with two normal kids basically made a transition to him or special needs easier." (p.20, I1),* says Jason. Ian, 7 has a condition that results from a chromosomal deletion. He has significant physical, cognitive and speech challenges as well as a number of medical issues.

Ruth and Jason work full time. Ruth is an accountant and Jason manages a cemetery. Ruth says that she is fortunate to have an understanding workplace where they let her work from home or take time off for the numerous medical appointments Ian has.

Early intervention at school and home

Because of their busy work schedules, neither Ruth nor Jason have much time in the evenings to work with Ian on his therapy so they have opted to put Ian in a private school where they are sure that he will receive occupational, speech, and physiotherapy regularly. When Ian turned six they had to make the decision to either keep him at his current school or send him to a school where he would be integrated into regular classroom settings. They would have to pay 'out-of-pocket' for these services. They did not want to move him because they felt that he would not get the attention that he gets at his present school where his therapists and teachers who know him well. They also felt that they received support through parent training groups with the program that Ian was with currently. Jason and Ruth spent a lot of time negotiating and writing many letters to the concerned school board to try to reason with and convince them to sponsor Ian in order to keep him where he is. They were finally approved to continue with the same program.

At home Ruth and Jason try and integrate some aspects of intervention into the daily routine. For example, they encourage Ian to eat with his adapted spoon, drink with his adapted cup, or to try to walk with his walker. However, when the schedule gets busy, they feed Ian or carry him through the house to save on time. When he's not in the mood to walk after a long day, they let go of therapeutic goals and let him have some downtime. Recently the school has been using picture cards to teach Ian to communicate but Ruth says it's hard to do at home because they don't have the same resources at home as at school.

Home is a team effort

Ruth and Jason try and run the household through a team effor*t. "We have a good family support system."* Their sons and Ruth's sister Mia are integral in keeping a routine running smoothly. This includes household chores and care for Ian. Jason says "*I think it helps too that the boys are in themselves accommodating. They know the routine. They're very tolerant and they have changed dirty diapers. We try to spread around too."(p.21, I1)* Auntie Mia is at their home almost on a daily basis, helping out with meals and child care. Ruth and Jason speak of adjusting their routine to Ian, and Ian adjusting to their routine. Jason says, *"It wasn't like we sat there and we have a routine or something you know all of sudden here is our special need kid and now we're going to have to make an adjustment to this kid. Things happened."* Ruth adds, *"And we try and bring him into that."(p.13, I1)* They consider themselves a hockey family. Jason coaches a little league hockey team and Ruth and the boys support him at practices and games. *"We were busy with hockey before we had Ian, but Ian just comes to games. It might mean that I have to leave a little earlier, but so be it. Ian still has to come out to the games. . ." (p.13, I1)*

Humour in the everyday

Ruth and Jason are laid back personalities who find humour in the everyday. When bombarded by questions from strangers about Ian, Ruth talks about how Jason deals with the situation in a humorous manner. *"Jason says- he goes, he just- when they want to know and you don't want to be bothered answering a whole bunch of questions you just say 'He (Ian) has got 22 Q 13.3 deletion' and then Jason just waits and then says 'It's contagious!' [Strangers say], 'Okay!' and they leave." (p.14, I1)*

Ian teaches us

Ruth believes that Ian has taught them to appreciate growth milestones much more than they did with the other two sons. *". . . the simple things when he first sat up it was so exciting-two years old, he is finally sitting and a bigger celebration where, Dan-yeah it was a big deal because he was our first child. Nathan was 'Oh good you sat up! Yay!' For Ian [it was] 'Oh finally!' So it was very-because of the difference in the boys- it was more exciting when Ian did something." (p.29, I1)*

Ruth says Ian has helped her other sons become more aware of the unique needs of others such as himself. *"I think Ian's helped the other two. They're very tolerant with a lot of stuff too now. . . .The boys are quite tolerant with other people. When they see someone else who's different, they're like 'Oh, okay'." (p.21, I1)*

Jason thinks having Ian has taught the family, as a whole, some lessons. *"I think in a way it helps with responsibility I guess. . . . you know people taking care of each other. . . . Like there is always somebody. . . . I think it's also easier, getting the boys to do stuff in some way, kind of thing, maybe when they are older they'll [be] in a say, volunteer kind of thing. They will kind of step forward to do stuff. . . ."(p.29, I1)* Ruth adds, "*It's brought everybody closer. We are all working together cause' everything revolves around Ian." (p.29, I1)*

3.1.7 Maleah

"Maleah" is a name of Hawaiian origin. One of the meanings of "Maleah" is, "unique little girl" or "beautiful young woman". Maleah, like the meaning of her name, is a beautiful and unique woman. She is unique mainly for three reasons: she was the only single parent in this study, she came from a large family that spans five generations, and because she was also the youngest participant in this study yet she seemed wise beyond her years.

Maleah had Jonathan when she was 20. She muses over how Jonathan's paediatrician was her paediatrician just five years before. "*I've known him since I was born!"* she says and laughs. *"I stopped going to him when I was 15 and then I bring Jonathan to him when I'm 20. So I only didn't see him for only five years of my life which is pretty crazy right?! It doesn't happen to most people!" (p.11, I1)* 2 year old Jonathan has profound developmental delays in motor, cognitive, and speech areas. Maleah is often quite busy trying to keep up with the various challenges of dealing with his disability, "*I kind of stopped being young. I'm a 22 year old who's actually 40, I just went straight into the mom role and I take care of him all the time."(p.14)* Maleah is part of a five generation family; her great-grandparents being part of the oldest and her son, the youngest. Family gatherings are big and there is a lot of support for her especially from her mother and her grandparents*. "My grandparents have always been big in my life. Like my mom was a single mom, growing up too. So my grandparents were big in my life. They're like my second set of parents." (p.13, I1)*

Appointments and Appearances

Maleah has made certain decisions in order to manage life and the challenges of Jonathan's disability. She works, for a friend of the family, just one day a week in order to qualify for subsidized housing and welfare, as well as, to be able to manage all of Jonathan's appointments and therapy. *"We don't have a lot of order",* she says*, "We kinda do what has to be done. . . .We don't have any sort of routine." (p.1, I1) "My phone has all our appointments in it all the time. I'd say, in certain ways I'm organized and that kind of way I'm really organized cause' I have to be right? With his appointments, I miss them and they [the services] get mad and then I have to book another appointment and most of the things that Jonathan goes for are booked three months in advance." (p.21, I1)*

Maleah makes sure to keep herself healthy and appear well put together. She says *"Not having enough sleep, not having enough time for myself. . . . I don't like looking like I'm struggling, which I mean I am [struggling] some of the time, but that doesn't mean everybody has to know about it, so my mom thinks I put too much towards that. I mean that's also how I get respect from people at the hospital right? If I look like I'm put together then they'll listen to me right? Like so, it's just, if you look like you're dishevelled and things are going crazy then people won't believe that you know what's best right?"(p.18, I1)*

Early Intervention

In terms of EI, practitioners have recommended that Maleah do various exercises and activities with Jonathan. Range of motion exercises and manipulation of cheek musculature to facilitate independent feeding are suggestions from the OT and tone stretches from the PT. Maleah implements recommendations when she finds it convenient to do so. *"When he [Jonathan] was going to school, his physical therapist wanted me to do them five times a day. And it was like "You're crazy, it's not happenin!" So I mean at that point, I was working more; I was working three days a week. So three days a week he was actually getting it three times, because they would do it in the morning, then he would come here to my grandparents house and my grandmother would do it and then I would do it in the evening. . . .but it still wasn't more than three times and she wasn't very happy with it, and I was like "Sorry! But it's not happening. I don't know what to tell ya!"(p.5, I1)*

Making Choices

Maleah's been trying to get Jonathan into a preschool where he'll have services everyday compared to having therapy a few times a month like he is receiving currently. She is willing to give up her dream of pursing a degree in fashion designing and merchandising in another city if Jonathan gets accepted at this preschool. *"I'd say working- being able to make a career for myself-I kinda forget about it. I try not to think about it. . . . I mean I'm big on 'everything happens for a reason' right? So I don't think about what I don't have, it's just, 'I don't have it' right?" (p17, I1) "Nothing is certain in my life." (p.8, I1) "Everything depends on Jonathan. Jonathan's my life so Jonathan comes first" (p.9, I1) "He's so sweet. He loves me more than anybody else which is like lovely. . . . He's my reward. He's just awesome. I love him." (p.17, I1)*

3.1.8 Etana

The meaning of the name "Etana" in Hebrew is "dedication" or "strength". Etana is a mother who has been a strong advocate and a driving force for obtaining services for her son Tomas.

Fostering independence

Etana talked about a photo on her wall. *"Tomas' [hair] is very short and like the military cut and Jacob's is long and shaggy and oh yeah! They're very different individuals,* *which is good. You want them to be that." (p.30, I2)* The twin boys are six years old. Tomas has attention deficit disorder and speech delays. *". . . we don't treat him any differently. I don't make him exempt from anything than if he didn't have a speech challenge or ADHD and stuff like that." (p.28, I2)* From the time they finished kindergarten, Etana has tried to make sure that the boys are not always together for every activity. *". . . even the camp that they're at this week they're not together at all. So I'm really trying to foster Tomas' independence and increase that as much as I can. . . . he's a lot shier than when Jacob's not around but like he'll do well." (p.6, 7, I2)*

Family life

Etana and her husband Chris share the responsibilities of raising Tomas and Jacob, but Etana says that about 90% falls to her most of the time because Chris gets home very late in the evening. *". . . he's usually always home to at least read to one of them and stuff like that. . . . he does the morning routine with them, so getting breakfast ready for them. But I usually have all the lunches ready the night before except Chris' [lunch]. I told him 'You know I have to make three lunches. You can make your own! So I can't do it all!' I tell him!" (p.18, I2)" I do make the boys help me. I ask them if they can come and help me take stuff out of the fridge and set the table properly and stuff. When we go grocery shopping, I make them help me carry the grocery bags or help me get things off the shelf so they feel like they are participating and they have to realize that it's not just the woman's job to do things." (p.17, I2)*

As a family they are very, as Etana describes, "outdoorsy". "*All summer we camp, and do different things like that. We go to the park together and we hang out there. We travel a lot. In winter we always try and go on a 'hot' vacation as everybody calls it. So we do a lot of travelling whether it's within Alberta or on an aeroplane type thing. We'll do stuff outside on the trampoline. We do try and do a lot of family things as we can. We play games. . . . in the evenings sometimes depending on if it's rainy outside, we'll play Wii or do something like that. We'll play board games on the weekends as well". (p.27, I2)*

Early Intervention

Etana has been proactive about accessing services for Tomas ever since he was diagnosed. *"Like I really pushed and I was very proactive when they were little. I did a* *lot of research online. I went to the health unit. I was very, very vocal. And I think that, that's what some of these parents need to do. . . . if they've gotta advocate for their children then they've just gotta speak up. Whether it's your doctor, or teacher, or anything, you've just gotta be so proactive for your kids. . . and depending on whatever kind of disabilities or problems that maybe occurred. So it's hard." (p.21, I2)* Etana had been struggling with the school board to get an aide who would work year long with Tomas. Because of the politics within the school board Tomas ended up having four different aides in the same year. Etana felt this created an unstable experience for Tomas. Etana and Chris finally decided to change school programs to suit Tomas' needs. "*We don't have to do anything. We could just let him suffer. I guess that would be it but no, we want him to be understood. We want him to remain calm and do well in school and with others and stuff like that. (p.19, I2). . . . my biggest thing right now, is him getting the services that have been promised and that he needs. But once he gets there and he gets going with the help he needs in the school system, he'll do very well. He's actually, he's a very smart child and he just needs that push to show his smarts off. . . (p.26, I2)*

Life lessons

Etana finds opportunities to teach the boys life lessons on fairness and their individuality at every opportunity *". . . they have started forming their own friendships and last year they each went to birthday parties individually, so that was a huge thing, because the other one would say, 'Well why can't I go?', and I'd say, 'You're not invited!'. So a couple of times a parent would say, 'Oh no, he can stay' I said, 'Oh no! No, that's not fair.' He wasn't invited to that party so I'd say, 'You're not going to stay'. So the parents were quite shocked that I would say that. But I thought, 'No'. That's how they're going to learn. They're individual people and I'm not going to treat them as one."(p.8, 9, I2)*

Being together as a family is what helps Etana keep perspective. *". . . we're a family and everybody has challenges in life. . . .We've just gotta accept everybody for who they are and that's how we live our lives. [Just] because Jacob gets frustrated because Tomas is littler than him and not the big brother [the older twin] and Tomas can't say the word 'fish' properly we just go on with life. It's not going to make or break us. As long as we're together I guess is the big thing. As long as we're family and we work on it together and everybody strives to do their best." (p.29, I2)*

3.1.9 Carissa

"Carissa" is a Greek name which has the meanings "love", "grace", or "kind". "Carissa" is also closely related to the name "Charity". Carissa is a woman who believes in serving and giving back to the community. She is involved in numerous charities and she volunteers at community events.

Carissa, her husband Brian, and their two sons Gavin, 6 and Liam, 4 were all born and raised in Canada. When Gavin was about three years old, he accidently fell back in his high chair at the dining table and suffered a head injury. As a result he has associated problems such as a lack of peripheral vision and decreased proprioception.

Early Intervention

Gavin gets occupational therapy and physiotherapy four times a week at his school, and once at home. "*They come and they spend 2-3 hours with us, they show me what they do and then I just work it in [into the routine]." (p.22, I1)* Carissa tries to follow, as closely as possible, the recommendations from her son's therapists. "*I just go with whatever they say, and then I keep-I have a binder with all the things that they do with him because they send us notes home every week [about] what they're going to do for the week and then I just integrate it in."(p.23, I1)*

Carissa has been told by Gavin's therapists that he needs to practice whatever they do at school exactly the same way at home. She has also tried to recreate the school environment at home. *"Yeah, I get hand outs. . . . I sign to him like they sign. . . . We have words that they use at school and we cannot have different words. My words have to be the same as them so I have to meet with them lots to see what they're saying to him. . . . My bathroom looks like their bathroom. . . . You cannot have a school and a home for Gavin; it has to be the same. So our bathroom has the same toilet seat, the same words on the wall, everything is the same."(p.20, 21, I1)*

Carissa appreciates the recommendations that Gavin's therapists give, but finds some suggestions hard or sometimes even a bit childish. *"Sometimes I get frustrated sometimes I think it's silly. Like they had this purple blanket and they wanted Gavin to go in it. They wanted us to bounce him. Well personally I couldn't do that by myself. I need Brian here. Gavin didn't like it so he fought me on it. So that [recommendation] I didn't like. But* *they're pretty good at helping me to change it around like and telling me how to deal with things. Or if I'm being too easy on him, they tell me to toughen it up."(p.22, I1)*

Family life and routine

Carissa and her husband are high school sweethearts. Their close relationship helps them work together to keep their family and routine going. *"Brian and I are very team oriented. We're very, very close. We're- we've been together forever like 20 years. So everything is together. We're like-we have friends but we're, we're the best friends. . . . and with what we've gone through, we have just always have done it together. . . . So [we're] even closer than what we were before. So, we do everything together." (p.9, I1)*

Carissa is a stay-at-home mom who gave up work after Gavin's accident. Brian is an engineer who works full time but is able to work from home on occasion. This flexibility is helpful when Gavin has appointments with doctors or therapists. Carissa is in charge of all of Gavin's therapy related responsibilities and the major portion of the domestic workload. After dinner, Brian helps out with the dishes. When Carissa has had an especially hard day with the children and needs to leave the house for some time, Brian takes over with the boys

Carissa has created a strict routine that revolves around Gavin's needs. She is careful to keep the routine as rigid as possible for him because he tends to get upset in new situations and may be at risk for a seizure. For example, due to his very short attention span Gavin cannot tolerate waiting for more than a few minutes. So Carissa times Gavin's arrival at school so that he can go to his class without waiting "*We leave here at 8:30 and we do that deliberately because Gavin can't wait. He has no attention span to wait, so we're deliberately late for school so he doesn't have to wait for the teacher to come get him. So when I get to school I unload Liam, and put him in the stroller and we park in the same spot, same area, same spot every day. And then we-I'll take him in to the school. We have to wait a couple of seconds or minutes for the teacher to come and get him and then he goes into school and that's very structured.* Gavin also has difficulties sleeping through the night and tends to wake up 4-6 times every night. This also interrupts Carissa's sleep on a daily basis.

Carissa and Brian are both very involved with charities and community events because they are strong believers in giving back to the community. As a result Carissa is busy with Gavin's strict routine, her domestic workload as well as her charity work. However, she sees it as an opportunity to serve the community and to socialize with other adults. *"So we have our responsibility to the community too that we do but I want to do that because that keeps me sane. That keeps me level headed with the kids, right? To see adults. We've always done charity work all our lives even before the boys were here. . . . That's very important." (p.14, I1)*

Liam

Carissa feels that Liam sometimes gets left out amid all the attention given to his big brother. *"I always feel bad for Liam and I always say this that Liam got the used dresser, Gavin got the new dresser. Gavin gets to go swimming, Gavin gets to go to gymboree, but Liam....I always feel like 'Oh he's missing out.' Gavin gets to go out. Like Brian will shop and take him for a car ride to go fill the cars up with gas but Liam stays here with me. Like I always worry that we'll forget him." (p.26, I1)*

The future

Carissa has worries about how Gavin will be treated because of his disability. Like every parent she too has hopes and dreams for her sons. "*That [there] will be a lot of struggles and labelling that Gavin will have to get through. [For]Liam, I don't see those [obstacles]. I'm worried. I hope that Liam will be the leader and not a follower. I worry Gavin will be the follower. . . . I really worry about that you know that they make their own decisions and the right decisions and they follow our path with charity and helping other people."(p.26, I1)*

Not taking anything for granted

Carissa feels fortunate for the life that her son has been given. She also feels strongly about not taking anything for granted, whether it is family, developmental milestones, or life itself.

"We could have buried him. . . . they told us he was going to [die], so I'll take whatever I can get with Gavin. . . . We are very grateful, the little things we don't take for granted, the new words, the taking the steps, unscrewing a pop bottle. We make big deals over the little things. The little things are very important to us where people think we're nuts."(p.17, I1)

For Carissa and her family, almost having lost Gavin caused them to change their priorities. The challenges are many but so are the rewards. *"Like for us, it's very-we're very grateful, very grateful for Gavin so we're more than willing to change ourselves for having him here. . . . Gavin is very important to us like Gavin and Liam are very like, I'd give everything up; well I did and it was very hard on me like I have very hard days where it's not easy. . . . but you know it's worth it. In the end, it will all be well worth it." (p.37, 38, I1)*

3.2 Narratives

3.2.1 Gareth

"Gareth" is a Welsh name that means "gentle". Gareth is a man that exudes quiet strength and a gentle spirit. "Vivian" comes from Latin origins and means "full of life". Vivian is a vivacious woman who is very active in the community. She is very social and is enthusiastic about people and new cultures. She is also very proactive with regard to her daughter, Avigail's intervention. Avigail is a Hebrew name that means "a father's delight."

I am...

My name is Gareth. I am from Canada. I am a husband and a father. We are a family of four; my wife Vivian, my two daughters Ariella and Avigail, and me.

You could call me a pretty laid back kind of guy. I'm more of an introvert. I like my own space and my own time to do things.

My girls

"They're a group of ambitious people! All three are very social and love to meet people." (p.9, I1)

Vivian

My wife is a very active and social person. She likes spending time with other people. She has a large network of friends on Facebook and she always wants to connect. She's always very busy and likes to host and have people over at our house. She's involved in a lot of church activities and goes on mission trips and stuff. She loves to travel; a passion that I share with her. She likes ethnic foods and loves to cook so she tries out different foods very often.

Ariella

Ariella, my five year old; *“. . . she’s a party girl!”(p.33, I1)* Just like her mother, she loves to meet people, enjoys it when there are friends over, likes to go out and eat, loves to travel, and experience new things and stuff like that. She loves books as well.

“It’s funny [how] my wife and my five year old are so similar, which keeps my life pretty busy.” (p.9, I1)

Avigail

Our second daughter Avigail is 2 years old. She’s a very happy baby and she’s very cuddly. Like her mom and big sister, she also likes to be around people, but she’s a little more sensitive to groups. She gets upset if groups get real loud, but she’s very content being around people talking. She’s just a cute baby.

“. . . all three girls are kind of the same. I can see the teenage years being very stressful!” (p.9, I1)

The past year....

“. . . this past year, it was kind of a unique situation for us . . .” (p.6, I1)

Avigail

Avigail has Down syndrome. The past year, her first year, was challenging. She was in the hospital several times. She had an open heart surgery. She also had pneumonia. She was hospitalized when she was only six weeks old, for about two weeks. They found out that when she was drinking it was actually going into her lungs. They then put her on a feeding tube. This was two months after her heart surgery. Avigail is, even for a child with Down syndrome, physically delayed. She’s just turned two and I think most Down syndrome children walk by three. Avigail at two isn’t even crawling yet.

She’s had a rough last year. We all have.

Moving in with Mom-in-law

My father-in-law passed away in March. My mother-in-law is used to having someone around her all the time and was taking loneliness a bit hard. We thought that moving in with her would solve two problems: since we live outside the busing district and Vivian doesn't drive, it would be easier for Ariella to get to school and also we'd be with Vivian's mom during the transition.

There are pros and cons to having a different person live with the family.

Having her around was quite nice. She would have breakfast ready every morning and take care of Ariella as she'd get ready for school. We'd just have to drag ourselves out of bed and off I'd go to work. My wife would then just have to take Avigail to the Candora society. I'd come home and she'd have supper ready, so we'd eat at five and then take Ariella to T-ball or dance. Ariella would be in bed at 8:00 always. We had bit more of a routine. My mother-in-law likes to cook and clean and stuff like that. So it took the domestic role off my wife and she could spend more time with Avigail. On the downside though, there was a constant expectation about cleaning up after ourselves and things like that. It created stress because everything had to be clean. With us, we don't always have to pick up after ourselves and don't mind if our daughters make a bit of a mess. They can leave it there for the night. That's no big deal. Our kids sleep their own schedule whereas my mother-in-law would go to bed at 10:00 and then the TV would have to go down, but our kids sleep through TV at our house. Her cooking is good, but since she can't stand other foods, it's always the same, you know, pork chops, chicken and potatoes and we like diversity in our food. My wife likes to make meals which we couldn't do with my mother- in-law because she was in control of the kitchen. So things like that were sometimes difficult.

We would go home to our town house on the weekend and we would enjoy those weekends away. It's just nice to be in your own space and our own schedule and our time. We're back at our place for a couple of months for the summer, but when school starts up again, we may probably move back in. Personally, I would like to sell our townhouse, buy a new house, and move close to our mother- in-law but not with her.

Arielle's struggles

During all of Avigail's hospitalization, that year, things were especially tough for Ariella. She was so used to spending her days with Vivian, going to different groups and doing things together. And now here we were in the neonatal paediatric ward and all it was-was a little room and there wasn't really much space for a three year old to be in there 12 hours a day. She got sick of it and wanted out. Vivian's parents took her for a couple of hours a day, but all she wanted was to be with Mom and Dad. Mom and Dad had always been there and suddenly they weren't. During those times she was miserable and her attitude stunk, and she didn't want it. But Ariella is flexible and she adapts well. She quickly got over it and I don't think she ever held resentment.

Vivian

Vivian's had to deal with a bunch of stuff too. During Avigail's hospitalization she was torn because felt obligated to spend time with both Avigail and Ariella but both kids couldn't always be together. It was difficult during those moments. Then, her dad passed away, which was tough. She also had some issues with her mom that she was dealing with during that time.

Me

With the recession, I got tanked from my job in landscaping. I was able to find another job in a construction company. In some ways, this has worked out to be better. Of course the money isn't as good, but I know that I can always be home at 5:00 and I have Saturdays off. So I'm able to spend a lot more time with the family. Before, when I came home late, or could not be home at an expected time, Vivian would be upset because by 4 o'clock, she would have had it with looking after the girls by herself all day. But more than that was the expectation that I should spend time with my family. I would come home from work already tired and then she'd say "Well why aren't you doing stuff? Why aren't you planning dates?" She would try to encourage me to do stuff and I'd say "I don't really feel like doing anything."

Now...

Vivian at home

Before our children were born, Vivian worked as a childhood educator. She's worked in all sorts of childcare centers and social services. *"She chose to stay at home and that was our choice even before we had kids that she was going to stay at home with the children and that's been great." (p.3, I1)* She felt that it would be hard to spend all day looking after other people's kids and then coming home to her own. We often talk about her getting a job at Starbucks or something just so that she can get away from the house a few hours a week. But she actually likes to be at home because the little bit of time that she is at home and not at groups, she's very busy doing things with the kids. She loves to spend time with the children. She's always taking them to one group or the other, five days a week! Music groups, play groups, playschool. We figured that things would change a bit with the arrival of our second kid, but because Avigail needed more attention, it worked out great that way. She has the flexibility in her schedule to accommodate Avigail's needs. So, she really doesn't miss work.

Our routine is no routine at all

"*We're not meticulous people. We're not routine rigid people" (p 39, I1). . . . "As a family we don't really have routines. . . . It feels like chaos all the time. . . . there's something to do every day, or somewhere to go. I think my wife and my 5-year old thrive on chaos! Always not knowing what's going to happen. They get frustrated by it, like, my wife will say, 'Oh we never know what we're going to do. We can't seem to book something solid.' [And I say], 'Well that's the way you make it, if you changed it then you probably wouldn't be happy!'" ((p.40, I1)*

Typically, I get up first, I get Ariella to wake first, get Avigail out of the crib, bring them down stairs, give my Five-year old breakfast and change the Two year old's diapers. I leave for work, and then about 20 minutes or half an hour after that, Vivian wakes up. Ariella occupies herself by reading books or something. Avigail doesn't move around a whole lot .So she doesn't look for trouble or anything. Ariella's pretty responsible so we know that nothing bad is going to happen in those 20 minutes. After that if it's a school day, my wife takes Ariella to the bus, and then she takes Avigail to the Candora society or some group so long as the weather is good. They either take the bus or walk.

I'm at work all day. I come home about 5:00. Since Vivian and Ariella have a very busy social life, we're always running off somewhere whether it's T-ball or birthday parties, church events, errands, grocery shopping, or needing to pick up something. We then come home and have supper. Supper usually happens between 5 and 8 depending on what we're doing that evening. Ariella's in bed about 8-8:30. Then we're usually cleaning or doing chores or whatever stuff around the house until about 9:30. So it's after that my wife and I have a little kick back time to relax, go online or watch some TV. Sometimes we just play or do a few exercises with Avigail if we remember. We then put Avigail to bed around 10:30. She likes to be held to fall asleep. Then about 11:00, we go to bed.

Thursdays are a little different because that's the day Vivian goes out with friends for coffee. If she wants to be with friends for coffee, I drive her. I'll take the time. I have to make sure to help her to get that time away, like she needs time away sometimes and I'm fine with taking the kids for an evening and stuff like that. That's not a big deal. "I've been pretty active with the kids all along (p.5, I1)." I take over with the girls and we play, watch TV or do something together.

We love to do things together as a family, but Vivian and I try and spend as much time as we can together too. We try and have at least a once a month, a weekend like a Friday or Saturday night, just the two of us. My mom likes to babysit so she'll take the kids for the weekend.

Who does what

"My wife and I. . . . we support each other quite a bit." (p.29, I1)

I would say that the bulk of the work is with my wife because she takes care of Avigail when I'm at work all day. When I come home from work, I'm often taking care of the kids, and playing with them and keeping them entertained. I take them off her hands for a while so that she can prepare supper. We're always together at supper time. Avigail's in her high chair and we give her some mashed potatoes or something that she can handle. TV's off and we eat together.

My wife is in charge of the kitchen. When she cooks, I help her with cutting up the vegetables and doing the dishes. I usually handle breakfasts, because it's simple things like cereal, but my wife packs lunch the night before. Vivian multitasks. She'll do six things at a time! She's got the laundry going while she's making supper, and in the middle she'll look at face book for ten minutes. She runs around a lot! After Ariella goes to bed, and I'm around to look after Avigail if at all Avigail needs any looking after and Vivian's able to finish off all the chores and stuff.

I take care of things like the finances, vehicles, and household repairs, paying the bills and stuff. We divide up things like cleaning. She tells me what needs to be done; like mopping the floors and I help out.

Bath time is just before bedtime. I usually handle bath times because it's in the evenings. They really enjoy bath times. I have a little blow up tub that fits half the big bathroom tub. So I fill it up and Avigail's in the inflatable tub and Ariella is in the other half of the big tub. They play in there for about 45 minutes. We wash their hair and then take them out one by one. We have fun together, they really have a blast!

At bed time we get together on our bed and have story time and prayer time. It's something I initiated long ago. All three girls will hide beneath the covers and then we have prayer time. For Ariella it's more of a play time though!

My 5 year old's responsibilities aren't huge I guess. She's just not supposed to make a mess and has to clean up her mess after she makes it because usually it's just toys or books. She's responsible to keep them in their proper place.

Ariella's a great big sister and watches Avigail a little bit, but we want to always be aware that we don't want to put everything on her and have her watch out for Avigail all the time. We don't want her to take that role.

Groups, groups and more groups

"I don't know how many groups my wife is involved with and I hear about them but the number of them I don't know!" (p.10, I1)

Vivian does play groups, cooking classes, book reading. She also does voluntary work at the library. She used to do some music groups like Sing song and Learning time or something like that.

There's the Candora Society and a lot of inner city programs which involve parents and kids. My wife takes both the girls. She used to take Ariella to a dozen different groups over the first three years of her life. She and Ariella did a lot as Ariella was growing up and now it's the same with Avigail. Now that Ariella's in full day kindergarten, Vivian has Avigail all day and so they're doing all these different groups, pretty much all day. They'll do one in the morning and a different one in the afternoon, almost every day of the week. They go swimming and to the zoo and do a lot of different activities and field trips. Vivian tries to include Ariella in the summer time or when Ariella has a day where she's not at school, the three of them will go out and do activities. *"Vivian always has one kid doing something." (p.11, I1)*

As for me, my buddy and I, we do a dad's group once a month, I take Ariella and Avigail. It's like a play group.

Early Interventionists

"Vivian really appreciates them coming to our house and observing Avigail. . . . and them giving recommendations (p.13, I1). . . . "Ah yes there are always recommendations!"(p.16, I1)"The challenges are more just all the doctor's appointments or PT, like you've always got to keep your schedule somewhat open for appointments." (p.18, I1)

The people from early intervention used to come once a month or once every two weeks but it's kind of phasing out now. Vivian's very involved with the Candora society, which was referred to us by early intervention. The occupational and physical therapists come about once a month and they've recommended physical development things, and things for eating because Avigail has eating issues. They're the ones who promoted Candora Society to Vivian.

The workers that we've met are very pleasant people. I don't interact with them as much as Vivian and it's been positive for Avigail. Vivian's never said anything negative about them. We've really appreciated the advice they've given. In fact, because they came and observed Avigail and spent some time, the speech therapist noticed that she had a pretty serious feeding issue. When Avigail would be drinking her milk she would choke on it or it was actually going to her lungs. The minute we found out, we were able to take her to the Glenrose and have a feeding study done because Avigail already had a file there. We were concerned, but our physician didn't seem to be. It's tough to get to the physician's for everything. They don't have the time to observe. He doesn't watch Avigail drink or eat or anything so it was positive to have these people observe her for some time and make recommendations. We've changed some of her feeding habits since. We now get her to sit up while having the bottle, not let her fall asleep with the bottle. We've also thickened the liquids up a bit so that they don't go slopping into her lungs. That's been the biggest change of all the recommendations that we've taken.

They bring her a lot of toys to get her to push buttons and keep her interactive and motivated. They have different chairs for her to sit in. There used to be a bubble chair that would help her develop her back muscles so that she would be able to sit and now she's sitting. Now they have taken the sitting stuff away and are trying to do stuff that will get her to move. Right now they're trying to get her to sit up from a lying down position. They taught us different rotations that we have to simulate. Like when we pick her up we have to simulate the movements of a person getting up from a lying position. Another thing we are doing at home is brace her knees against a chair when she's standing. We use a tea towel to support her waist around the chair.

Avigail doesn't speak, but she was making babbling sounds so the speech therapist told us this and got her a hearing test and figured that she isn't hearing very well. So now she has two hearing aids. Hopefully that will improve her hearing. Now she's learning baby sign language. She's got a few words down. It's slow but she's getting there. That's what we hope for, that she's always progressing and that she's always learning.

Avigail's two now and you can get PUF funding and get involved with other programs but Vivian's just waiting until Avigail gets closer to school age. Vivian knows the system because she worked in it a little bit and she says "Well I'd rather that Avigail had a worker when she's in kindergarten or grade 1". Vivian has the foresight to know that if we take the funding right away then when Avigail hits school, there won't be any funding for the programs left. We're waiting so that the case worker will be available when she really needs it.

What we do with early intervention

". . . if we force any of our girls to do anything, we feel that they would probably reject the intent of what we're doing anyways." (p.39, I1). . . . So then they'll associate learning with force and they don't want to learn anymore because they're feeling the pressure to have to accomplish something. . . " (p.39, I1)

Sometimes Avigail doesn't mind standing, but some days she just doesn't want to, and just like any kid, you don't want to force learning anything. If we try to force her to stand, she might just not want to stand at all then. There's other physical development stuff, but we don't force her too much because she may learn to hate it.

We're supposed to do these things every day but some days when we're going somewhere, we can't. Sometimes we remember at 9:30 at night and we get her a chair to practice. *"It's kind of whatever we remember like usually at 9:30 night and we're sitting. Oh yeah we're supposed to be doing something right? And so then, 'Oh yes okay, well* *let's get a chair. Let's get her to practice.'"(p.15, I1)* Or like on a Saturday or Sunday evening because that's usually our downtime, when after our Five year old goes to bed. That's usually our time to kind of relax a little bit. We use that time to play with Avigail. We'll roll the ball to her and she'll roll it back and then sometimes I think "Oh we should try different things, enough of the rotations". Sometimes it's just kind of our quiet time and play time. We were always busy with Avigail with all the recommendations for keeping her sitting up and keeping her occupied. One day she just sat up without support and didn't even know it. It was just part of her play time. So we use playtime the most to do these things.

My wife has said that she feels like it's up to her to catch up or make it better in some way. She feels that pressure as a mom. Some days she's like "Avigail should be progressing faster." And then other days she'll say "Avigail is who Avigail is, and she is going to develop the way she develops." So some days she feels that way and some days not.

Trade-offs

If there is something I wish we could be more involved with, it would be at church activities. But, I don't know if we've ever really felt like we've made trade-offs. My wife and I tried to develop a family life even before our first was born. So when she came into our lives not a lot changed. We still went over to friends, we still went camping, and we did a lot of travelling. When Avigail came along, she was a lot weaker. We haven't gone camping since because we don't have the facilities, but we still got away. Three months after she had a heart surgery we went to Cuba with her. "So we never really felt like we should be trading anything, no differently than any other family with two kids (p.32, I1)." We're able to cart Avigail along. She doesn't protest. She doesn't have her own will in that sense. She just comes along. We do what we do and she's there.

Vivian was a restaurant reviewer for a while, where she did make a little money on the side, but after Avigail was born, that was one thing that did end because there was so much head space involved with our daughter that she just couldn't find the time to write reviews. That is something that she does miss.

A father's delight

"My girls, all three of them, love the new experiences." (p.37, I1)

We enjoy Avigail very much. Just having our two girls, we really enjoy taking them out on day trips. We've also taken them to Mexico and Cuba. In fact we went to Cuba just three months after Avigail's surgery, but Mexico was especially fun because she was able to respond a bit. She would just sit in the sand and put a handful in her face! She ate sand! She liked it! We'd say "Stop it!" But you know, these are new experiences and we really enjoy those experiences. Always doing something new. It's fun watching and it's fun just being with the family and going through new struggles and triumphs together, the new experiences and enjoying them. Those are the rewards.

Challenges

Like for any kid, you hope for the best. We hope for our five year old, as she gains more independence that she won't misuse it or do anything that's damaging to her, and that she makes good decisions with that independence. Avigail on the other hand will never be fully independent and we are aware of that. We're trying to figure out how to raise her so she'll have as much independence as she can.

She will probably be teased and she will probably struggle with her peer group. Her peer group will definitely be different. Ariella always had peer groups right from when she was born. Avigail doesn't have a peer group even now. Her peer group, if any, is babies. She's two years old, she has 6 to 8 month olds in her peer group, and they'll pass her in a few months. In a few months, they'll be walking and running around and Avigail will still be on the floor. So her peer group will always be changing. She'll be able to play with other kids with Down syndrome or who are handicapped, but right now we're not involved and we don't have anybody. Since my wife doesn't drive, she's not able to go to a Down syndrome group, because they're spread all over Edmonton and St Albert's. There's no one living close. So there really isn't a peer group, so we'll see.

What's Avigail and what's Down's syndrome

I think that my family is never going to be rigid and do things that way. I think we've seen in a Down syndrome society, parents become very rigid with their first child. They become very routine with their kid and maybe that's why they are a little more developed, I don't know. There's a lot of time that the parents spend doing this or doing that. We haven't done nowhere near what other parents have done. Ariella being our first kid and between her's and Vivian's busy social networks, we probably haven't done what we should have done with Avigail, but Avigail is part of our family and that's kind of the way our family is. *"She's got to go with the flow of the family." (p.41, I1)*

"Where most people follow or have changed the flow to suit the child, here the child has to change to suit the flow and that's how it was when we had Ariella. That was kind of the way it was even when she started. So like there's a flow and that's how she's going to have to adjust to us and that's probably why they're so close to being the same because Ariella has changed to be like mom." (p.41, I1)

They say that if you set Down's syndrome kids to a routine they stick with it for life. It's tough for them to deviate. So we've never had a routine and so Avigail has shown that she's somewhat flexible and adapts to situations .But we'll see what happens over the next few years.

"We'll see what's Avigail and what's Down syndrome. There's always trying to perceive what's Avigail and what's Down syndrome. . . . Because Down syndrome kids have a tendency to be this or that like when they get stuck in a routine they don't change as much. . . . we'll see what's Avigail. If she is flexible, if she is not, if she is adaptable. We'll see what's Avigail and what's Down syndrome." (p.41, I1)

3.2.2 Alessa

"Alessa" comes from "Alexandra" which is Greek for "Defender of men/protector". Alessa has been the backbone of her family and household through her son's diagnosis and her husband's anxiety issues. She "fights" for services for her son. She also vehemently protected and guarded the time and space that her husband needed to recuperate from his nervous breakdown

I am Alessa. I am a mother, a wife, a teacher, a day home provider. My husband Mark and I have two boys, Zeph and Alan. Mark and I were born and raised here in Canada.

Alessa

"I'm not science minded. My brain just doesn't work that way. Anecdotally.... I love anecdotal stories." (p.3, I2)

Before Zeph was born I used to teach high school. I taught English for six years. I really loved what I taught but I didn't really love teaching as such. You know teenagers can be a pain in the butt and the paper work and everything. But I loved that I could teach English. I've been almost seven years at home now and that's a long time.

I enjoy yoga. I do it twice a week. It's my time for myself and away from everybody else and everything else.

Zeph and Alan

Zeph is the older of my two boys. He's seven now. He's an independent little guy. He loves to be on his own, doing his own thing. He will just vanish. He likes that. He likes to be invisible. As an infant he was crazy hard. He cried all the time and he would cling to us. But as he's gotten older it's gotten better. As a toddler in preschool he was pretty ok. He's in grade one now. He loves to ride the bus to school. It's the highlight of his every day!

Alan is my little guy. He's three. He's just begun preschool. Up until last year he was at home with me.

I sort of miss my boys during the day now that they're both in school!

Mark

My husband Mark is a software engineer. He's very Science oriented and technical. You could say that math is his thing! He loves hockey too. Zeph is very much like Mark.

The Long road to Diagnosis

We always knew that something was up with Zeph from the time he was born. He was very, very terrified of strangers and he hated new places. He would just tuck into your body and burrow himself into you.

In hind sight I think the paediatrician we were seeing suspected that he was Autistic but she never said anything to us. She just suggested that we take him to the Glenrose. I said to myself, "Why would we do that? He's already so anxious, why would we take him to a place where everyone is going to poke and prod him?" She never said to us what the issue was. I think I would have preferred her to say "Well we're querying Autism" because at the time we weren't going to put him through that for no reason. I could have saved myself the anxiety from self-diagnosing my son.

That is the classic thing with special needs. Nobody ever wants to break the news or say things plainly.

We elected not to go to the Glenrose until he was a little older. Once he was about three, we went to another paediatrician. He did a bunch of tests to rule out what could be causing Zeph's odd behaviours. He didn't want to do a referral to the Glenrose without the results coming back, so nothing happened for the next year.

At three and a half Zeph could tell you if he wanted some food or milk but not much more than that. So I went to see an SLP and she said "Wow! This kid needs to be in the PUF program." So he got that funding strictly based on his severe speech delay. One year down the line, we got into the Glenrose after being on the wait list. Though he scored above the cut off of the autism tool, the diagnosis was still unclear because they felt that he had a severe cognitive delay, speech delay and severe anxiety. So they held off for another year. His speech started to get better and with PUF he was doing much better. This was when he was turning five. His language and his anxiety improved but his autism did not, so they sent him back to the Glenrose and they assessed him again. This time he was diagnosed with OCD, anxiety and autism. We then finally started looking at specialised services for him.

Mark's hard time

About two and a half years ago, my husband had a nervous breakdown. Mark has struggled with anxiety all his life. It's a family inherited thing and Zeph has that too. I had always known that it was there and he's always known that it was there but it was never to the point that it interfered with life or how he functioned at work. We were actually in the middle of a home purchase and ended up having to pull out. I think that was the straw that broke that camel's back. It was really hard for a year and he was on medication.

It was a little difficult because all this started happening with my husband around the same time when all of Zeph's stuff started happening. I didn't want to let him deal with more than he could handle. He couldn't really take on a lot more of the responsibilities because he was trying to make himself well so that he could be part of the family and productive at work. But the consequence of that was that I didn't have a lot of freedom because he was anxious about being home alone with the kids whether they were in bed or not and things like that. So a lot of stuff started falling on me. I was doing 90% of the work.

He's been getting better over the last year and a half. We got some counselling recently and talked things out. I found that I was really protective. I wouldn't tell him when I needed help around the house for the fear of putting pressure in him. He's been getting better at that though. I think I still tend to do more than I maybe did before but I'm also finding that the stronger he gets the more confident I am in him and the more willing I am to lose my temper or get frustrated about things. Before I'd keep quiet and just deal with it and that could lead to more resentment in some form. Things are definitely way better than before.

Our "Everyday"

I get up at 6:30 every day and soon as possible after that, I wake up Zeph and Alan. I turn on their lights, open up their windows. They slowly wake up, while I get breakfast ready. So they wake up between 6:30-6:45. I start encouraging them out of bed and they usually come straight to the table. So while Zeph's eating at the table, Alan and I will do cuddles on the couch first. Then Alan chooses what cereal he'd like to have. While they eat breakfast, I get the finishing parts of Zeph's lunch ready which I would have started the night before, and put it in his backpack. I show him his schedule which is just pictures on a strip of what his day is going to look like from now until after school. So they're usually done breakfast, or close to being done, go to the bathroom, do the dressing, brushing teeth, washing all that sort of thing. After that they usually have anywhere between five minutes and a half hour to play depending on how long breakfast took them. Then at about 8 o clock, Zeph's bus shows up and he's off to school.

After Zeph's out the door, Alan and I have about ten minutes and he just goes back to playing or whatever and I do some last minute stuff for me to get ready to go out into public! At about 8:15 we head out. School starts for Alan at 8:30. By the time I get home from dropping him off, it's usually quarter to nine. At that point if I have grocery shopping, errands, anything like that, I'll usually do that then. Sometimes I have something else to do for the morning in that time. I may have an appointment with the program coordinator, so I drive out to the city for that. In such cases, I do all my errands after nine in the night when the kids are in bed. A lot of the time, the free time I have between 9 and 11:15 really ends up that I'm doing some kind of thing for Zeph. Whether it's emails or phone calls or things like that, just to get that out of the way when I have quiet.

At 11:15, I go get Alan from school. If I have day home that day, I also pick up my day home child, Savannah at that time. Usually we go to Tim Horton's or the Dollar Store because Alan gets a treat for letting me go at school. I have to bribe him! We come home after that at about 12-12:30, and the kids play, I make lunch. They eat and at about 1:30, Alan's going down for a nap. I rock him to sleep and my day home girl has some quiet time. I have about an hour window there to cook, clean, do laundry and whatever else. If I didn't get a chance earlier, I get to the phone calls or emails for Zeph's stuff. Usually I eat lunch then too because I don't always eat lunch with the kids depending on how easy it is to make lunch. You get up and down a lot with the kids. So you really don't get to sit and eat your lunch very thoroughly! It's just motherhood I think.

Around 2:30, I start waking them up. Zeph gets home about 3:00 and all the kids have their snack together. If it's a day when Zeph's aide comes, it'll be at about 4:00. During that time, I prep supper and try to keep Alan and Savannah away from distracting Zeph. The aide leaves at about 5:30. Mark comes home around that time too and Savannah's dad comes to pick her up around that time. After that, we all have supper together. Recently, we've started to go to the park after supper's done. The boys are really into riding their bikes to the park. Sometimes, if I'm not caught up with work, and dishes, and things, I may not go. I'll stay behind do dishes, clean up after supper and get the rooms set up for bedtime. They usually get back from the park around 7:15. About 7:30 we do tubby. They may have a small snack before, and then they jump into the tub, jump out, pajamas, brush teeth and they're ready for bed. We each take one child, read stories, do cuddles and say "Good night". After that, I'm cleaning out Zeph's back pack and getting his lunch ready for the next day.

If there's laundry that needs folding, Mark helps and we do that together. We do a lot of reading so if there's time, we do that. Or I'll just go watch some TV for a bit and he works on the computer. We don't really spend much time together as we used to in the evenings. It's kind of hard to connect because by the time the kids go to bed, that's sort of when you finally get a moment just to breathe and kind of do nothing for a few minutes! Mark goes to bed around 9 or 10 and I get to bed more like 10 or 11. Yeah and then the next day, it starts all over again!

Dividing responsibilities

“. . . we’ve always been good about [dividing responsibilities] before he had his hard time and about-we pretty much did everything together even when we had just one child. We would always do it together.” (p.8, I2)

Before Mark had his anxiety issues, we were very much 50/50 in our house and family work. He used to do laundry, dishes, vacuuming, mowing the lawn, and other things. It wasn’t really “Mom’s in there doing that and Dad’s over here watching TV” or something. He’s always been good about that. When he had his hard time; that was the first time in our “parenting careers” that he had not been part of it.

We still do some things together. When it’s bath time, we’re both in the bathroom together with the kids. Or if not one of us will sit in the bathroom while the other gets the rooms ready for bedtime. We split bedtime where we each take one of the kids and read stories to them. He does the occasional vacuuming, and takes out the garbage and the recycling. Pretty much everything else is still me. Especially Zeph’s stuff. That’s completely and utterly me.

I would say that I expect a lot less of Mark now than I did before. It’s probably protective.

Zeph’s world

“Because of his anxiety he really likes routine. . . . He is looking for the thing that is regular.” (p.3, I1)

I really plan ahead every morning to give Zeph time to do his thing. If you tack on one extra thing all of a sudden it gets crazy. He doesn’t do well with a rushed crazy atmosphere. He needs to be steady and relaxed. I think that’s typical of all kids. He loves taking the bus! And the bus driver loves him too! To Zeph she’s just a rock star! He wants to be a bus driver when he grows up. He keeps asking “Why don’t we have a bus?” It’s good that he loves it because last year he was having a hard time separating from me at school. I would have to sort of pull him out of the van.

Zeph’s social skills are improving but school is still a challenge. It’s hard work for him because he’s behind his peers. He’s mainstreamed in a regular class because they’re trying to make it inclusive education. That’s how it is with special ed. these days. But I can see that he gets frustrated with the work. A typical class is distracting for him. Typical kids love their surroundings to be very colourful and busy. For Zeph that's hard. If you go to his room, you'd see that he has no pictures, no books. We had pictures up in his room, but he took them down. So we've just let them stay down. He's hypersensitive to all that; colours, light, sounds, sniffles, coughs.

Zeph is very "black and white". For him "school is school" and "home is home". You don't do school work or "table jobs" at home. That's why he's so resistant to any sit-down work and has such a hard time with his aide coming home. He just thinks it's the funniest thing in the world when he sees a teacher outside of school like at the store or something. *"He's thinking 'What the heck are you doing here? This is not where you exist. You live at school! This is the wrong environment for you!'" (p.15, I2)*

Before he used to have a hard time with strangers but now, as his social skills have been improving, he's gone to the other extreme. He will go up to anybody and say "Hello my name is Zeph. How are you?" And he'll follow them around. But he wouldn't know whom to befriend and whom to avoid. So he's gone from one end right to the other.

Intervention

"I think sometimes I put a lot of pressure on myself that we have to do these things while we can because early intervention is key.. . . . we can't miss the time. It's more that 'just'. It's not 'just' playschool and it's not 'just' summer camp and it's not 'just', you know? It is important because it is hopefully getting him somewhere so I think that's maybe more taxing. . . ." (p.15, I1)

Zeph's aide comes here on Mondays and Thursdays for an hour and a half. So about half an hour of that is sort of work, which is usually like games and linguistics like speech language pathology stuff. There's a program planned for him that she's trying to achieve. The last half of it she brings games and toys and things that he can play. It's teaching him turn-taking and choices and things that he really has a hard time with.

Saturdays is speech group for him from about 10 to 11:30 in the mornings. It's an actual group that works on speech goals with other peers with ASD. On Wednesday's he has his anxiety group, "Cool Cats". In between I meet with the SLP, the OT, and the program coordinator. I drive to the city for that. Most times, I'll go to them because if they come to me, we're charged for their travel time. It comes out of Zeph's pot of money. So I prefer to go to them because that means that Zeph will have an extra hour with the professional.

Almost every day of the week there's something big or small. It could be an appointment with one of the professionals, the FSCD worker or the team. It could be Zeph's therapies or it could be phone calls and emails that have to be addressed. And that's not even school!! I don't know how a full time working parent could do it! I just don't know. The professionals are usually pretty flexible and you can meet them in the evenings if that's your only time. But that's also your time with your children.

Intervention and us

"Yes the strategy that I'm using is my own. So it's like I'm fulfilling it but he doesn't know it! [Laughs](p.21, I2)). . . . we're just doing it in the act of living!" (p.23, I1)

"I think we incorporate a lot of stuff and we don't even think about it. . . . It's not odd or different to us. It's just how we've always done things. I think even before you know you have a child with special needs you just start tailoring life to make it easier. So if he doesn't like it you avoid it and you do this. . . . I'm sure normal families do that too." (p.19, I1).

There are some things Zeph just won't do. He won't sit down and work on something at home. Home is his safe place, his place for downtime. He just won't cooperate. But there are some things that we work on in our day. One of those things is community safety. Learning how to be aware of the road, of cars and crossing the street safely. So for instance, if we're going to the park in the evening, we'll practice that as we're going. If we're crossing the road I'll say, "Zeph, we're at a road, what do we do first?" He'll say, "We need to look" and so he'll look and then I'll say "What do we need to do next?" and he'll answer accordingly. Or we'll say, "Well why are you wearing a helmet today?" and "What's that good for?" *"You know practice safety stuff in like a 'teachable moment' is what I call it. . . . Rather than sitting down with work per se." (p.21, I2).* It's just part of his day and his schedule.

The other thing that I'm trying to help him with is his independence when he's getting dressed. A typical seven year old can get themselves dressed but he has a hard time with the motor planning that it takes to put clothes on. He's also highly distractible. Getting him dressed is not going to take five minutes. It's going to take 15 [minutes] or more if I want him to put on his own jacket, his own shoes, brush his teeth, comb his hair and do self-care in the way a typical 7 year old would. So I need to wake him up at 6:30 even though his bus doesn't come till 8:00. He doesn't have to put on his own clothes. I could do it for him in three minutes, but then he's not practicing or learning or fulfilling his goal.

A lot of his program plan happens in the morning. *"He's most receptive. It's the natural place for them to happen in the morning." (p.28, I2)* and that's the only opportunity he has to get dressed. So if I don't plan ahead for him in the morning, then that part of the program will not happen. *"So I think it's a (sic) constant and to a certain extent as a mother you're always doing that [planning ahead]. But I think it's more because there's actually something on paper that says this needs to happen as opposed to something you'd like to happen that's just in your own head." (p.28, I2)*

We have things that are part of his program that we should follow through at home but that we probably don't enough. His aide at school has told me that he needs to work on his alphabet but he already has so much going on! His social-emotional [skills] is more important to us than "Can he write his ABC's?" We want him to feel good. That's first. And we want him to be able to socialize with kids. That's a higher priority to us than academics.

Struggles with the system

"*. . . . and you've got the services then usually too. So I don't know how you do it. I don't know how you'd take advantage. Like maybe you just don't. Because it is your choice. You don't have to have services. Nobody is forcing you to do it. But you need to pursue it (p.16, I2).*"

In the in-between time, sometimes during the day, is when I am doing a lot of the phoning if I need to call FSCD or the autism follow-up clinic. When Zeph was in the process for getting his approval for specialised services I had to keep phoning the FSCD social worker that handles our case because she needed to make addendums to our agreement whenever we wanted to pursue any specialised services. So I would call our service provider and set it up first, then I would call our worker to get approval and then go back to the service provider and say I have approval and then they call my worker and then my worker calls me and says "It's all good". There was a lot of phoning back and forth, between the three parties.

I think the most taxing thing is the appointments and the phoning. "*If you want your child to have the things that they are entitled to, then you have got to go and get them for them. You have to make it happen as a parent. They are not going to just show up at your door and say, 'Here's the SLP and here's the OT and here is the psychologist and here's the behaviourists and . . .' You have to go and say 'I want this' and they say 'Absolutely. Fill out this form and have this interview and do this intake. . . '" (p.4, I1)*

Another thing is that a lot of the time the FSCD workers think that specialised services introduce more breaks for parents whereas it's really the opposite. You have more e-mails; you have more phone calls and more meetings. Technically a parent is supposed to be around when the aide works with their child. We're supposed to learn how to implement the program plan so we'll pull from the system only for three years and not for eight years. Well the FSCD worker from that same system told me, "Well you've three hours of respite *and* you have an aide that comes in twice a week." The time that the aide comes to work with Zeph is not a break. *"Really the FSCD workers should experience a day in the life or a week in the life because it's busier and more stressful. It's not a break." (p.23, I2)*

I'm an expert too

"There is a team of people there saying 'Well we can have this person. We can do that thing. We can do this thing'. It is more the experts looking at him and deciding that this is the best stuff for him, rather than me. I mean I am an expert on him too but it's easier and they are probably more-they have more insight than I do because that is their training." (p.10, I1)

There's a lot of running around to get the worker to listen and to get a service provider and to pursue specialised services. There is a team that is prescribing what he should be doing, what he needs to improve rather than me saying, "Well this sounds good and that sounds good". Or me looking at the list of things and saying "Well can I get into this? Can I get into that?"

"I took two courses-I was interested in the SLP program" (p.2, I2). And I think the temptation to be a professional like an SLP, like, she's 'it'. Like she's the top of the chain

of command so to speak. Like she garners a lot of respect and you know I liked the idea of having that kind of, not power necessarily. . . ." (p.26, I2)

You don't get much respect as a parent and you get even less as a stay-at-home parent. Right now, when I go to school as a parent, or to FSCD, when I talk to people at the centre the attitude is "Yes that's fine, thank you very much" and not "OK!" because I'm not a professional and I haven't got the credentials. Whereas if an SLP came in and said the same thing it would be entirely different. I would love to have that respect. I don't get that as a day home provider and I didn't as a teacher. *"I would have enough letters after my name that you would have to listen to me, instead of having to be bitchy, to make school listen or to make FSCD listen." (p.26, I2)*

Trade-offs

"I think there has been lots of sacrifices and lots of hardships you know and emotional mostly." (p.34, I1)

Much of the downtime that I do have is spent on phone calls and on e-mails regarding Zeph's stuff so there's not much time for me or my husband.

The other thing is on a personal level and a financial level, I've given up a career that I enjoyed and brought us another income. My husband doesn't make enough for me to stay home and not do anything which is why I have my day home. We live in a small house and drive old cars, and we don't go on fancy vacations. But on the other hand, I stay home so that Zeph can access services. I don't think he could have done that if we were both working full time. It would be very, very hard.

For a while in between, last year I took a couple of courses as prerequisites for the SLP program at the university. It was good to get back into school because it gave me intellectual purpose. It was pretty intense. I had classes two nights a week for three hours each. To be gone that long was too much for the family. Zeph's behaviour started to go downhill. I think a lot of factors contributed to that but my going back to school was part of it. I thought then that this was too ambitious at this point. So for now I've put it on the back burner. I hope to revisit the possibility again in the future.

With having services for Zeph, it's just busy and it's hard to have strangers in your house. We're not used to being so busy. With Mark's hard time "busy" is not conducive. It increases stress. You have to be OK with letting people coming to your house. Not as family or anything but coming to work with your child, in every room of your house. And sometimes it's not necessarily fun stuff like taekwondo or gymnastics or hockey.

The rewards.... I don't see too many

"I know this sounds really pessimistic . . . I don't see a lot of benefits that it really has had for the family or our life so much." (p.34, I1)

When I think of Zeph's future, I think that people will treat him differently. He doesn't look different. So because he doesn't look different sometimes people don't always accept the oddness-even other children. Whether it is adults or kids, they just think he is weird or he is rude or he's misbehaving or something like that. It's just normal behaviour for him. It is just autistic behaviour. You can help things be more socially acceptable but you are never going to eradicate it completely I mean for him. And for me, of course I want a normal little boy so I think in that sense I don't see that many positives. You know maybe I will have a different perspective later but that is where I am with it right now.

And for Alan he doesn't have a normal sibling relationship. He will probably be more sensitive to special needs and empathetic to special needs and stuff like that. My husband and I are really concerned and interested about how things are going to happen because Alan and Zeph are kind of on par right now. Alan can do a lot of things that Zeph can't right now. As Alan starts to get older and realizes that I wonder if he's going to be ashamed. He is not going to have a sibling relationship like you and I have with our brothers and sisters. How is he going to react to that? Is he going to be resentful of it? If Alan goes to the same school as Zeph, is that going to be a stigma for him? Is he going to feel that he has the weird brother or is it going to be okay? Is it going to be? I think about that a lot. I don't know how many benefits I see for him.

Letting go of dreams

"*To let go of the room looking a certain way or what your child should like to do or you know. . . . I think I'm better at that now than I used to be a few years ago." (p.14, I2)*

It still makes me a little bit sad. We went to the bank and we stopped Zeph's Registered Education Savings plan; basically his savings for university. Well he's never going to university. And so we had to kind of say “Goodbye” to that, which was really hard. *“I think that’s one of the hardest things with a special needs child-like if they’re not born with Down syndrome or born with a cognitive delay that you know about right from day one. Because for 2½ or 3½ years, you have dreams for your child.” (p.13, I2*) You expect him to one day go to school, make friends and go for swimming lessons. It is hard to accept that your child is not going to have the future you dreamed for him when he was born and when he’s little. He may probably never have a girlfriend, or graduate from high school and university, or get married and have kids. *“Pretty much all of those things you have to let go of, or we had to let go of.” (p.13, I2)*

Of course you never know what the future is going to hold and you can always be positive and things like that. But at grade one, he’s significantly behind his peers. So it’s good to be hopeful but I think for me, I’d almost prefer to be realistic and prepare myself for the very real possibility that this child will be with me for the rest of my natural life and probably Alan’s too. If that gets overshot, beautiful! But if it doesn’t then it won’t be like I had dreams that did not get fulfilled. Not every child fulfills those dreams. Not even a typical child sometimes. *“You know I’m not saying that these things have to be achieved in order for me to feel or for that child to feel successful in life . . . . but you do have dreams and the hopes that you know these are the things that, you know, the good things that you want your child to have. So that’s kind of hard to let go of those things.” (p.14, I2)*

The conquest of the bouncy house

“There were lots of things I think he would have really loved that he just couldn’t do . . . for him he sees something he really wants to do and he can’t and that’s sort of I think his toddlerhood in a nutshell.” (p.12, I2) So you know sometimes it’s hard to accept cause’ you have an image in your mind of what a child should be like.”(p.12, I2)

You know the bouncy houses that kids have at farmers market and birthday parties and things like that? Well I can remember when Zeph was about three or four years old, he wanted so badly to go into one every time he saw one. But when he would get his head into the little entrance, he’d come out and be “I can’t do it”, and he’d cry and scream cause he wanted to go in but couldn’t. He would yell and scream and people around me would wonder what’s happening. *“And in the end, I would be hugely upset and I’d be like ‘Well why am I so upset? Who cares if he goes in a bouncy house or not?’ Cause really,* *is that the measure of my mothering skills?-whether he will go in a bouncy house and have fun?" (p.12, I2)* Still it is upsetting because it is something you feel a child should be able to do and that they should be able to enjoy and he couldn't. I used to find it really upsetting.

This year however we went to an autism walk and he was able to go in a bouncy house and bounce! And he had a fabulous time! It meant so much to me. *"I don't think somebody else can really get it because they'd be like "Big deal, who cares? It's just a bouncy house", but it takes on a larger meaning for him and me." (p.12, I2)*

It's the same thing with birthdays. For years and years until he was six he didn't want any birthday parties and until last year he never opened presents. He couldn't stand the pressure of people watching. So for his birthday parties we just wrote "no presents please" which is so opposite of what little kids do. Until recently he didn't get the point of the whole celebration. Now he does and he loves birthday presents. *"So that's huge for me. And before I found it-it was really, really sad for me, you know?"(p.3, I2)*

So when Zeph does well in something, like at summer camp for example, it's more than, "Wow you had a good day at camp. Right on". It's "By Golly! You did this!" It's a way bigger deal. So your ups are a little bit higher and your lows are a little bit lower when things don't work out.

No regrets

I've let go of some dreams for Zeph and I've made some choices for our family. But I don't think that those are not worthy choices. *"Like I think if I'm 80 and look back, I think I would regret it more if I hadn't taken on this role. I don't think I'm going to look back and regret it. I think, while I may regret a missed opportunity, I won't regret the action it took. . ." (p.27, I2)* and what's come out of it.

3.2.3 Sabah

"Sabah" is an Arabic word that means "dawn", "light", "morning" or "promise". Sabah is a bubbly woman who brightens up a room when she enters. She exudes joy and is optimistic about the future. I named her Sabah because not only was she full of light but her home was also well lit and decorated with bright colours.

It was a Saturday afternoon. I came to a row house. On the front lawn was a tricycle and a couple of toys. Sabah's welcome was very warm and friendly. As I walked in, she introduced me to her little ones and her cousin Shaina. They were in the front room watching the "Backyardigans". She invited me to their kitchen which was bright and full of light. We sat at the dining table and proceeded to talk. Here is her story.

My name is Sabah. I am from Zimbabwe. In 2007 my husband and I moved to Canada from Zimbabwe, with our boys, Andrew and Caleb. Cara, my youngest, was born here. We're both charted accountants. *"...most of the people that came from our country, the ones that I know are also chartered accountants because that's how they got to leave the country." (p.12, I1)*

Meet the family

We're six people in our home; me, my husband, my cousin Shaina, who has come to Canada as the children's nanny, and my three kids. Andrew is 5, Caleb is 3 and Cara is 1, going on 2.

Settling in

The first year and a half here, we had a crazy routine! We were both working and my husband also was busy studying to convert his CA. Every day it was; wake up, wash the kids in the morning, feed them, pack their food, get ready for work and take their car seats to the car. We took turns bathing and feeding them. When one of us bathed one, the other one fed the other! Then it was dropping them off at the day care. My husband dropped me off at work before he got to work. Again in the evening, it was picking us all up, cleaning and cooking and by the time we were done, we were "just all out" and the next day, the same crazy routine. It was so hectic because we had to work around our work.

Even on the weekends it was somewhat the same. One of us would clean while the other cooked. *". . . my husband is not a fun cooker!' (p.17, I1)* But when worst comes to the worst, there's no other way! It was really crazy and hectic!

Being in a different country

Sabah's hospitality and cheer were evident throughout our conversation. I especially remember how she offered thrice to drive me back to my home after our interview. She *thought that it was too far and the wait for a bus on a Saturday was too much. I took the bus, of course, but the fact that she did not think that it was out of the way for her to do such a thing for someone she had met for the first time was somewhat unusual to me. To her it seemed only normal.*

Canada is very different from my home country. People here keep to themselves. I don't know why. Maybe it's the long winters. Maybe people don't want others involved in their lives. It's very, very tough to make friends here. To this day I can go to work and there's no person of whom I can say, "Oh this is my friend". I don't know how others manage but it's been so hectic for me that I stopped trying.

I do have one or two neighbours to whom I say "hi", but people just mind their own lives and don't get involved. Sometimes I wonder-if my child was to run out into the street and a car was coming to hit him-if my neighbour would run and catch him. I don't know, just because of the way things are. People here are polite but I don't think they want to be too friendly because they don't want other people to be involved in their lives.

Back home, as much as people are nosey sometimes, and they want to know other people's business, I think "*it's a good thing because you get I mean to know each other and [for] everyone in the community, everyone is a family." (p.11, I1)* When we were at home, we would never worry about the babies. We have lots of aunties and cousins who'd take care of them. So babies are not a stress when you're at home.

I know a couple of people here who're also from Zimbabwe. I remember in the earlier days when I was on mat. leave; they'd leave their babies with me sometimes when they had an urgent outing. I know they'd do the same for me if I needed that help. But we don't live close to each other and they're all working just like me. There are no 'stay-at-home' moms amongst ourselves. For that reason, and also if Shaina was not here, in an emergency, I would be forced to call a day home, pray that they're ok and leave the kids there. I'd be leaving my children with complete strangers and that's the truth. But you have no choice in such a situation. It's really tough in this place that way. *"Seriously, if I were to move out of this place-there's no one I'd miss." (p.11, I1)*

Andrew

Andrew incurred a brain injury when he was around two and a half years of age. He wasn't born with a disability. *"He was a normal sweet little baby running around,* *already talking and everything." (p.37, I1)* It happened when we were back in Zimbabwe. He got very sick one day and we took him to the hospital. There was a time when the oxygen didn't reach his brain. He was never the same after that.

Finding a place for Andrew

Because of our extremely hectic routine at the beginning, nothing really happened for Andrew, in the first 6 or 7 months. We were still trying to place him somewhere and get him signed up for programs, trying to get hold of a social worker, trying to find funding for any intervention program. He wasn't yet signed up for school. So we started by putting him in daycare, but obviously the complaints there were, "He needs more attention than the other kids". The lady there was really sweet around him, but she thought he needed to be a year behind, and we tried to negotiate with that because we thought, with him being so young and trying to find a place in the world like all other three year olds, all he needed was a little more attention. So it wasn't so bad at first. As he started getting older and moving on, we put him in another daycare and I remember he was chased out after one week. They said that he was a rather high risk person. I remember they went out one summer day and the next thing you know, he had a big bump on his head and we had to take him to the hospital. In the end he had a tough time at that day care, because when he's in an environment where people are not happy and are busy screaming at him, he gets stressed and frustrated and then starts peeing on himself. So we had to draw him out of there. It was hard to find supports at the time after that. So I extended my leave till Shaina came because it was too stressful for him and we didn't want him to be in a place where he wasn't wanted.

We finally found a place for him at Scott Robertson. Up until the end of last term he went there and was with an early intervention program called "Kids North". Once or twice a month, they send in therapists to look at him and whenever he needs more support, they bring in somebody to help. So programs were available everyday where they would be working with him on his speech and his gross motor skills. But now things are going to have to change because he will be going to kindergarten. So we're looking at a kindergarten program for kids that aren't too extreme because Andrew is at the mid way point. He's not too far behind, but he can't be put in a normal class. He's in between and there aren't too many programs that are for "in-between" kids, so he's left floating around in the middle of all this. So now we're on waiting lists at the Brain Injury Society. They have a kindergarten program that is for children like Andrew but we're waiting for them to call us to assess Andrew.

That's the problem with things. There's always a waiting list; for intervention programs, for camps, for daycares, for everything. You just have to keep trying things out. I just feel that there isn't enough information out there and it's difficult to find resources. I found the Paraolympic Sports Society swimming classes for kids his age, by accident. If you don't search for, or bump into things by accident, there's no way anyone will tell you, and though the social workers try I don't think they have enough information to spread around. There're very limited resources. I know because I tried to phone the hotline for disabled kids. Even for a daycare that takes special needs kids they have a waiting list and they tell you that they'll call you when his turn comes. Imagine, to this day he's still on that waiting list. And this is a year later. So yeah, there are just too few resources.

Shaina's arrival

"[*If Shaina wasn't here], I think by now you would have found out that I would not have done this interview because we trying to catch up with so many, many, many things. But Shaina makes a big, big, big difference." (p.31, I1)*

Before we left Zimbabwe, we knew we would need an extra hand to help. With the types of jobs we have, when you're on audit anything can happen, and sometimes you can end up working until midnight! So we applied and filled up forms to bring Shaina here through the nanny program. But because of the nanny regulations, she could not come until a year and half later. Shaina's my cousin. She's here as our nanny, but the fact that she's family makes a big difference. I think it would be different if I had just a regular nanny.

It was so crazy before Shaina came! I thought that I would have a nervous breakdown! My husband was studying, constantly with his books and I was on mat. leave for Cara that whole year. So I was the one doing everything by myself. Getting the kids ready, feeding them. I even did the programs on my own! By the time I was done getting the kids ready I'd be so tired. I would try and lay down once in a while, but, yeah, it was so bad! After she came the new routine started up and things began to fall a bit more into place.

Now it’s Shaina who cooks and is with the babies during the day. She’s the one who does breakfast and the bath during the weekdays. In the evening she gets their snack going , and when we come back in the evening one of us will cook, depending on who’s available, because sometimes I come back late. She’s worked very hard to get them all to sit at the table and eat. She also helps Andrew with his writing a lot. Shaina’s made a big, big difference.

Our routine now

Usually my husband and I head out for work at around eight in the morning. The boys are signed up for school. Shaina gets them ready, and sees them off at about eleven. She’s here with Cara the whole day and after the boys come home at about four she takes over with them too. They spend the rest of the day playing. Andrew has music lessons and therapy on Monday and writing lessons on Thursdays so I drive him to those after I come home from work, on those days.

Apart for work, our studies, and the kids, the other things that we have to do are doctors and dental appointments for Andrew because he has a lot of dental problems too. Then there’s all the testing for the Brain Injury Society assessments, the other babies’ appointments when they get ill, and when they need their shots and things. So it’s either me or my husband taking us because Shaina doesn’t drive. Most of the time it tends to be me because my husband needs to work on his MBA assignments.

On the weekends I take over from Shaina so that she doesn’t get too stressed. That’s also my time with the babies. I take them to swimming lessons on Saturdays because they need to start getting active in sports. We spend a lot of time playing over the weekend.

How we get things done in this house

Sabah showed me around the house; the bedrooms, the bath, and the basement. She tried to walk me through their day-to-day happenings.

To get things done in this house we manage time because in the end it’s all about time. If we wake up early the house will be in order. There is no such thing as “sleeping in” in this house!

In the mornings, when we bathe the babies, we now make sure to have them in the tub all at the same time. I put in the bubble bath. They love it and it’s so much more fun, it’s faster, and it’s more efficient. It would take forever if I were to bathe them one after the other. After they’re out, I wipe them down and dress them right there. The good thing is Caleb is beginning to dress himself so we encourage him to help Andrew as well. I tell Caleb to help Andrew with his shoes. So now he knows that when mummy and aunty are not there, Caleb will help him. There are times when it’s going to be just the two of them and as long as he knows that Caleb is there he’s going to be fine.

When Andrew was at school, they stopped helping him because they wanted him to start doing it on his own. But he used to get frustrated and sad because he found it so tough. The other children were all dressed up and he would still be struggling. But he has to learn. So we buy him T-shirts that are easy to wear and put elastic in his trousers, so that when he has to go to the bathroom he can go quickly because he just moved out of diapers. We‘ve also got him shoes that are easy to slip on. Whatever we buy for him, we make sure it’s something that’s easy for him to use. We usually let him try before we go in and help.

Of course it would be much easier to just help him but we want Andrew to try doing things on his own. Otherwise when he goes to kindergarten it’ll all be just killing him because it’s going to be so much more tough. But the thing is it’s difficult when we want to go somewhere because you don’t want to waste time. If he’s going to do it himself it’s going to take forever. So we try and make sure that we plan things so that it gives him time to do it himself. Like if we’re going out, we start getting ready at least two hours early, because once things are rushed in this household everything will just go crazy. So it’s all about managing time. We try and set things up much before time so that one can do things at their own pace.

With things like cooking and cleaning what we do is we get them to go and play in the basement. We call it “Andrew’s office”! We’ve set it up for them so that it’s warm and comfortable with all their toys and cars. It’s safe and we can hear what’s going on all time. So that’s how we get them out of the way to put the house together!

“A meal time is crazy in this house!” (p.20, I1) Caleb and Cara think they’re babies and Andy sometimes pretends that his hands don’t work. Half the time they want to be fed. But the good thing is Andrew has now begun to eat on his own and he uses his spoon very well and he’s beginning to eat with his fork. When Andrew starts eating, everyone starts behaving. Usually Cara sits in the high chair. But when the worst comes to worst, if

one of them is being naughty they get to sit in the high chair! So whoever doesn't want to get stuck in the high chair has to eat! As a result, it's not so crazy!

We use a non skid mat to help Andrew eat. It's one of the helpful suggestions they gave us at the school sessions. We know his plate is not going anywhere, so he has no choice but to eat! He takes time, and tends not to concentrate on eating so they gave us a timer to help him understand how much time he has to finish his food. We just have to watch out that he doesn't choke so I have him sit either next to me or Shaina.

Most of Andrew's activities for his gross and fine motor skills are all done at therapy. In the house, we get him to do stuff like throw and catch and hitting the ball. All the things he couldn't do before, he's doing now. He is beginning to initiate play. So we play throw and catch in this house on a daily basis. It's not normal and it's not something I used to entertain; but because it's a learning process for him we do it. We play as much as possible on the weekends**.** Sometimes we get him to ride the adapted bike we got for him because he needs to improve his strength. It's so stressful for him that sometimes I feel like I'm punishing him. So that's a big challenge for him.

So we've taken the suggestion from the therapists and try and do it at home. As crazy as some of them sound they work!

My sweet little babies

"Look at that situation there!" she said to me, and pointed in the direction of the little ones. Caleb and Andrew were fighting over a toy. "He [Andrew] won't fight with him normally. When the worst comes to the worst he ends up giving it to Caleb" "He's not one person to start noise. . ." (p.14, I1)

"I have the sweetest little babies." (p.13, I1)

Andrew is such a hard worker and I think that's why he's managed to come this far in his life. He's so determined and so motivated and that's the best thing about him. Kids like him can become angry and frustrated with life. But I know he's got a nice heart. *"He's just such a happy soul!" (p.15, I1)*

Caleb and Cara have had a big influence on Andrew. He realizes that the smaller babies need care as much as he does. He's the more patient one, the calmer one. He recognizes that he's the big brother and *". . . he takes his place as the elder one. He wants still to get* *that respect. He wants you not to treat him like a baby because he also believes he's a big boy . . . he's supposed to show the other babies what's supposed to be done." (p.14, I1)*

Caleb and Cara are very much like each other. Just the way they sit and the way they eat, and the temper tantrums! *"Ah! Caleb and Cara are stuck together more than Andrew. Andrew can stay on his own and doesn't bother anyone. But they're all so sweet together." (p.14, I1)* They take note of Andrew and play with him as much as possible. Once in a while they fight and so on. They know that they have each other and that's what keeps them going.

My husband

"My husband has got a crazy enough life on his own!" (p.16, I1) He's really busy with his studies. And since Shaina's here to help us, we don't demand too much of his time because he has to study so much. But whenever he gets time he plays with the boys. He tries to make his presence felt because they obviously adore him. He's their father after all the manly figure in the house. He especially loves to talk to Andrew, because he knows he [Andrew] wants to talk a lot. So my husband tries to make time whenever he's available.

Trade-offs

There are things that you have to give up sometimes or sacrifice. Family time is one. *"There's no family time . . ." (p.30, I1),* because I normally drive Andrew to all his programs and things. It's just the two of us that go because it just makes things easier. Everyone else stays at home. That's the time we all could have spent, together at home, catching up with your day. By the time we get back from that activity, everyone is so exhausted, they just want to sleep.

And obviously the relationship is a big thing. *"You do worry about those things because you do need time to be a woman and a man, you know, without having to worry about other things and unfortunately there's always something to worry about . . ." (p.34, I1)* Sometimes people are not happy with the way things are going, you know, it's just things that come and go. You just do your best to keep things moving and pray that things work out, to keep our family together, because we need each other. Here in the middle of nowhere, where there is no one else, you need to stick by each other and if the bond breaks then everything changes.

Another big thing is that you limit the time you've got to play with and get to know the other babies. I think the biggest sacrifice I've had to make is Caleb. *"It's so tough to sign Caleb up for lessons on his own without having to consider what is going to happen to Andrew." (p.29, I1)* You can't do that because then Andrew gets frustrated and disappointed. So in the end, it is actually Caleb that is most disappointed. So by all means possible, we try and sign Andrew for an activity to which Caleb can also go. But a lot of the times, these programs concentrate on physiotherapy, gross motor skills, fine motor skills, and you're thinking, "Why would I sign Caleb up for that?" So in the end Andrew ends up going to those by himself. Caleb should have been signed up somewhere for soccer, and beginning to play soccer, but we always end up thinking "When are we going to do that? How will that work?", because Andrew is still too weak to be playing soccer.

Even when I'm trying to focus attention on everybody, Caleb will always be the last on the line. At the dining table Andrew or Cara will be the ones who sit next to me because they need help. It's definitely not going to Caleb, which is frustrating because I know he feels it. *". . . what makes it worse is that he's still a baby and needs the attention, but sometimes I feel [pauses] he just has to live with it." (p.26, I1)* As much as he won't say it, I do think he feels left out. It's just tough but it's the reality that Andrew will have the first hand at help or anything. It's either Andrew or Cara. Maybe things will change when Cara transitions. But it always has to be Andrew first. I think that's the biggest sacrifice we've had to make. Sometimes I fear that as the other kids get older they might end up drifting away because they don't always get the attention that Andrew gets. As a result you wonder "How will the other babies react? What are they going to do with their lives?"

There are smaller sacrifices too. Sometimes I just want to relax and do nothing! You do tend to lose out on sleep, because either we're studying, or working, or trying to catch up on pending household chores. We end up doing stuff late night. But because my husband and I are late night people we can finish all this work even at one or two in the morning. It's not normal, but what is abnormal has become normal in this house. But you know, besides missing out on family time, which I feel is important, I don't feel like it's a job that I'm doing-doing things for Andrew. I like doing it because I know that it's good for him. We don’t try and make it feel like we’re missing out on so much. We would rather not be doing anything else. We love doing it because we know it’s for him. We know that when Andrew is fine, everyone else is happy.

Our blessing

As a Christian, I see having a child with special needs in the family as a blessing, and to realize how important every child is and how different all the children are. Sometimes it’s a burden and it takes a toll on you but you have to be so optimistic about your children.

Andrew has changed so much. He’s doing so much we thought he would never be able to do. He’s beginning to talk. He’s singing. He’s so musical! That’s why we like the “Backyardigans” so much! He’s beginning to play with the other kids because he thinks like he’s one of them. He’s a bit more confident. I think that’s a really big thing.

I think that seeing all this everybody is a bit more happy, because that’s what it creates for you, it creates a bond. To know that, as much as we’ve gone through all these trials, we’ve done it together. It makes you feel more respectful toward the person that is around you, because we’re going through these challenges together and that we haven’t died; it means that we are good and we can still do it together and keep on working on it.

What keeps us optimistic

When Andrew was sick at the beginning, he was unable to do anything. Two weeks after we had been in the hospital, the doctor told us that he did not expect that Andrew would ever do anything. He wasn’t talking. They told us that he’d be a cabbage forever. They said “Ah you can consider therapy; it may work, it may never work”. So we took him to physiotherapy and in 9 months, he was walking. Occupational therapy was a bit more challenging because of the fine movements. But to think that he’s eating on his own now! For him to be where he is now is a big, big, blessing. So much has happened over a short period of time. That’s what keeps us optimistic. So for us we know that it’s just a matter of time. We know that there are wonderful things in store for us and in store for him. We just keep working towards him getting better and doing as much as we can do. *“He doesn’t have to be perfect because he is perfect the way he is now for us anyway. We could never have asked for more. . . He was never supposed to be anything. We had already accepted that and moved on with that, but he has come back.” (p.38, I1)*

3.3 Narrative Analysis

A narrative approach was used to understand how parents experienced the various facets of EI in their routine and how they attempted to balance the responsibilities of that routine. While thematic analysis aided in finding a number of themes and patterns that were specifically related to accommodations, values, goals, resources, and constraints, a narrative analysis was helpful in understanding the meanings that parents attached to the experience of EI in their daily routine and how values, goals, resources and meanings were related to each other.

The stories that families told showed that balancing demands and constructing a routine that included EI involved more than adapting routine tasks. The main narrative threads or themes that are presented below are derived from a combination of the organizing plots, the temporal nature of family stories, and the meanings attached to those stories. The common organizing themes (*plot*) from across family stories were that of struggle and of triumph. Parents made sense of their present experience of EI and disability through telling stories from their past and expressing hopes for the future (*meaning making* and *temporality*). For example, while telling their stories, parents seemed to have epiphanies about what success meant to them.

The main four narrative threads that emerged from analysis were:

3.3.1 The meaning of success

Parents pondered the meanings of success. The meanings ascribed to success were different for each participant. Meanings differed depending on what point parents were at in their lives or at what point they were within the narration of their story. Sometimes the meanings of success were derived from the norms dictated by society and culture. For example, to some parents, success was defined more by the achievement of good character than by the attainment of developmental milestones or skills. Some parents asked themselves if their success as a parent was necessarily determined by whether their child achieved “normal” skills. For other parents success was being an “ideal” parent in their own eyes and by society’s standards.

3.3.2 Who is my child?

Parents told stories so that I, the interviewer, could understand their child’s character. For some parents, telling personal stories seemed to help them better understand their children. Some parents saw their child’s disability as being separate from their child’s identity. For example, Gareth was still in the process of trying to understand who his daughter was as a person and which of her characteristics was a result of Down syndrome. Other parents saw their child’s disability as a personal characteristic and felt it was what made their child who they were. For example, one parent described her child as being “perfect just the way he is” (Sabah, p.38, I1).

3.3.3 Never still

Whether their narratives were of triumph or struggle, parents were never passive. Parents were constantly in the state of “doing”; they were “fighting for,” “seeking,” “finding a place,” “finding friends,” and “looking for child care,” as a few examples. Whatever decisions they made, whether “fighting” to get services, or slowing the pace of their lives, parents were proactive. They were constantly negotiating their values, goals, meanings, culture, community, and the past, present, and future when constructing their routines or making decisions to implement EI. Even in making trade-offs; in “letting go” of certain responsibilities, dreams or hopes, parents seemed to be proactive.

3.3.4 The source of motivation

Through their narratives, parents revealed the source of motivation for their decisions and actions, whether personal or EI-related. Some decisions and actions seemed to be the result of intrinsic motivation. For example, parents would decide to go against the advice of the school or health care system because of the lessons they had learnt from their own experiences in the past. Another example of that kind of motivation is when parents made decisions that may have seemed uncommon or unusual in their communities, but which they intuitively felt were right for themselves or their families. Other decisions or actions seemed to be derived from extrinsic motivation. For example, some parents talked about the need for therapy being “engrained” into their minds. Another mother talked about the need to train herself to implement therapy because she felt that it was what she was supposed to do. One mother talked wanting to pursue studies in a rehabilitation field because she felt that rehabilitation professionals garnered more respect and a sort of power that a stay-at-home parent did not have. In this mother’s case, the source of motivation was her desire to gain respect from others, including her child’s health care team.

CHAPTER 4

Thematic findings

4.0 Overview

In this chapter, the findings from the thematic analysis are presented, including the various demands that these parents have to manage on a day-to-day basis, the accommodations that families make in order to create and sustain a routine that is meaningful to them, and the factors (including parental beliefs, values and goals, and material and social resources and constraints) that influence the decisions families make regarding whether and/or how they implement EI for their child.

Thematic analysis was underpinned and guided by the principles and tenets of ecocultural theory (e.g., accommodations, values, goals, resources, and constraints). Recurring patterns or themes that were related to these tenets were drawn from the data. To understand how parents were managing to balance the responsibilities of the daily routine, it was important to first know what they were dealing with on a day-to-day basis. The findings that address this aim are presented in the section that follows immediately. These findings are depicted briefly in Figure 1.

4.1 What are parents dealing with on a day-to-day basis?

The analysis of the data revealed that parents deal with and negotiate many different issues and responsibilities on a daily basis. These fall into either of two main categories: (a) juggling the practical demands of the daily routine, and (b) dealing with the constraints and demands of the social and cultural environment.

4.1.1 Juggling the demands of the daily routine

The analysis revealed that families juggled the practical demands that were related mainly to their personal needs, the needs of family members, and the mundane tasks of the everyday routine.

"Myself, family, and the everyday stuff." Parents tried to keep up with various aspects of their personal well being. Catching up on sleep, regular doctors' appointments, eating well, exercise, career, and personal goals were all aspects that parents recognized as important and necessary for the wellbeing of their family and for sustaining a routine. However, when they perceived their child's therapy or health were at risk of being "dropped," they were more likely to let go of aspects of their own personal well being.

Parents also seemed to juggle their anxieties and fears about the futures of their special needs child and their other children. They were often not able to give what they felt was ideal attention to their typically developing children, and often worried how this would impact those children's futures. For example, Sabah described her fears about her children drifting away or rebelling later on in life:

> *We always fear that the other kids might end up drifting away because of attention things because they're obviously, once they grow, and they become a bit more independent- Andrew will always be-as much as he might change and he might become independent he is always going to be different from them. As a result you always have to fear what's going to happen to the other babies. How are they going to react? What are they going to do with their lives? (Sabah, p.35, I1)*

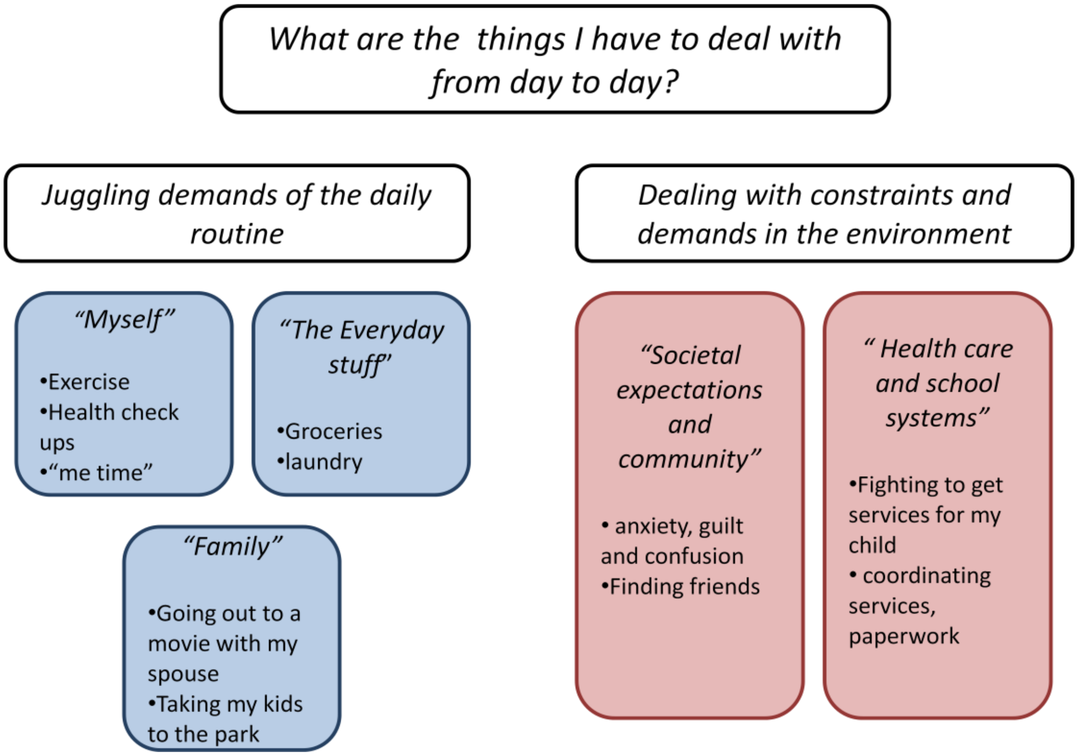
Worries about keeping the marital relationship healthy were part of the parents' juggling act. They recognized that the busyness of everyday took a toll on their marriages. They talked about struggling to find time to spend with their spouses.

> *You do worry about those things because you do need the time to be a woman and a man, you know, without having to worry about other things, and unfortunately there is always something to worry about, yeah. So, oh well! Take each day as it comes and hopefully everything works out? (Sabah, p.34, I1)*

The most obvious responsibilities that families mentioned that they had to fulfill to keep a routine going were the usual daily chores or errands, such as cooking, grocery shopping, laundry and house cleaning. Other responsibilities that families spoke of were careers; child care; transporting their children back and forth from school and extracurricular activities such as soccer practice, swimming or music lessons, and day-care or day home; supervising homework; their children's health and spouse's health, including doctor's appointments and medication; and occasional elder care.

The routine everyday tasks seemed to be the juggling balls that were usually constantly up in the air. From their descriptions of what it takes to keep their routine going, every parent seemed to associate the mundane tasks as being inherent to a successful routine. Even though parents constantly emphasized that time and attention for their spouses, children, and themselves were more important than mundane tasks, it seemed that spending quality time with the family was one of the harder aspects of the routine to keep up in the air.

Figure 1. What are parents dealing with on a daily basis?



4.1.2 Dealing with the constraints and demands of the social and cultural environment

Families also seemed to be dealing with demands and constraints that came from the society and community and were specifically related to their child's disability.

Societal norms and expectations, and the community. Every family and individual is surrounded by expectations and norms of the culture and society within which they live. However, the families in this study expressed that they faced stigma and attitudes from the society in general, which were largely related to their child's disability.

a) Feelings of anxiety, guilt, and confusion. Not knowing from the beginning that their child had a disability brought some parents feelings of anxiety, confusion, guilt and shame. Parents themselves felt unable to understand their child's "peculiar" behaviours or actions. These feelings were aggravated when they were questioned by people in the community about why their child behaved in ways that were outside societal norms. For example, Eva described feeling guilty for her daughter's odd behaviour and she could not understand or make sense of this behaviour. She also felt the need to explain it to people when she received stares from them in public. Once she had a diagnosis in hand she felt a sense of relief.

> *But now that I know, now that she's had her diagnosis . . . it's better in a sense. . . .before I felt kind of ashamed. Like, "What kind of parent am I? Why is she this way?" kind of thing, and now that I know that it has nothing to do with what I did wrong, or anything like that. . . . So now that I know that I can, when people look at her and look strange at me, I can just tell them, "Yeah she was diagnosed with autism disorder, so that's why she does inappropriate things". And that's basically all I have to say and they understand, 'cause they would assume things. She looks completely fine right? She looks normal, but her actions say otherwise. (Eva, p.3, I1)*

Some parents felt that health care professionals deliberately kept their suspicions of a diagnosis from the parent. They said that this increased their worries and anxieties about not knowing "what was wrong" with their child. They felt that if medical professionals had been more straightforward about the diagnosis, it would have saved them a lot of stress in their lives and would have given them more reason to comply with numerous appointments and diagnostic tests for their child. Alessa explained that she felt a lot of anxiety until the time she was told that her son had a diagnosis of autism.

> *When he was 18 months, the doctor-the pediatrician that we were going to-did want him to go though the Glenrose and I do think in hindsight she probably suspected he was autistic but she never said anything to us. . . . that is the classic thing with special needs; nobody ever wants to break the news or say things plainly. . . . we started to think "Well what is the issue? What is the problem?". . . . So then it makes more anxiety rather than less for the parent. You know it is just better to say, "Well you know I am wondering if there might be"-you know-"we're querying autism here, doesn't mean that there is but let's go and rule it out" and you know, I think then we would have been well-that's different . . .(Alessa, p.4,5, I1)*

b) Dealing with stares from strangers. Parents often encountered stares and questions from people when they took their child to a public area or event. Especially in cases where their child did not have a visible appearance of disability, parents felt that they or their child were judged either because of the child's behaviours or because of an adaptation that parents chose to use. For example, Eva felt judged for using a harness on her daughter, Aura, who had autism and tended to run away frequently. She also described receiving stares for Aura's strange behaviours. Ruth and Jason received stares and questions regularly for using a stroller instead of a wheelchair for their six-year-old son. The babysitter whom they employed reported that she often faced a lot of criticism from people in public for taking him in a stroller when they went out for walks during the day.

> *. . . the wheelchair is the cue where her stroller is just-they're looking and it's funny cause people, they want to know but they don't want to go out and usually it's the rude ones that ask her and give her heck like "Why are you doing this?"(Ruth and Jason, p.14, I1)*

Parents felt that the society was a little more understanding of their child if there was a visual cue of disability, like a wheel chair. Parents did not always choose to have this visual cue. This was for the sake of convenience or to avoid their child being categorized or labelled as disabled. Either way, parents seemed to encounter and deal with society's judgments on a day-to-day basis. Maleah worried about what the future would bring as she was already facing questions from the community about her two-year-old son who had special needs.

> *Wheelchairs too. I hate wheelchairs! A lot of people stare at us, not because he's special needs. Most of the time you can't tell. Well he's pretty big and he doesn't move lots but a lot of the time, it's like-you [interviewer] even thought he was sleeping right?....So I can't imagine when he's in a wheel chair, how many people are going to stop and ask me.... I already get stopped. I can't imagine when he's [older]-when people actually realize there's something wrong with him right? So I don't know. I guess we'll see. (Maleah, p.17, 18, I1)*

c) Finding friends in a foreign land. Families in this study who had recently moved to a new town or city or who were new immigrants found it challenging to locate supportive community. Some parents explained that a lack of community led to loneliness and furthermore they felt that there was no one to turn to in the event of need or an emergency. Some immigrant families still felt like they were strangers in a foreign land even after having lived in Canada for an extended period of time. Asha was one such mother who felt like an outsider, although she had lived in Canada for more than 10 years. Moreover, there were times, she said, when felt as though she had to fight for services, partly due to her ethnicity.

> *It's a lot of discrimination. Even if you are a citizen, you won't feel that you are Canadian. . . . Yeah, you are always [an] outside person. You will never be considered- but some [people] are good. Some are not that open too. You can't get friends. It's very difficult to get friends here no? Luckily I have some Punjabi friends . . . (Asha, p.21, I1) But you need somebody also. You cannot just isolate yourself. (Asha, p.31, I1)*

Finding friends or a supportive community was important to these parents for the purposes of support with child care and having people around them to whom they could relate. However, they were often unsuccessful at finding this support even when making concerted efforts. Like Asha, Sabah found it hard to make friends. Sabah had moved to the Canada from her native Zimbabwe just two years before and found that a sense of community was lacking.

> *People here keep to themselves. I don't know. Maybe just because the winters are so long, it's very difficult to make friends, because I know. Even from work to this day there's no person that I can go to work and say "Oh, this is my friend." People are busy with their lives. It's very, very tough to make friends. . . . Back home . . . as much as people are nosey and they want to know other people's business it's a good thing because you get, I mean you get to know each other and everyone in the community, everyone is a family. Here, it's so tough. It's just so tough.* (*Sabah, p11, I1)*

Health care, school systems and society in general. Engaging in the health care and school systems on behalf of their children posed an added responsibility for parents in this study. Some of the issues they had to deal with regularly were tackling negative attitudes, extraordinary amounts of administrative paper work, and constantly fighting for adequate and appropriate services for their child.

a) Tackling attitudes at school and within the health care system. Some parents talked about dealing, on a nearly-daily basis, with challenging attitudes from the staff at their children's schools and from service providers. Especially at schools that promoted inclusion, parents felt that part of the negative attitude came from the fact that the staff was not necessarily trained to manage special needs. Other parents felt that their opinions about their children were not always respected and that the professionals who worked with their children were considered more of the decision makers and the “experts.” Some parents felt that some of the service providers and professionals that worked with their children, dealt with them (the parent) in a condescending manner. Alessa felt that the opinions of working parents, especially those in the medical field or who held a professional degree, were more valued than those of a stay-at-home parent. This was part of Alessa’s motivation to pursue a career as a speech-language pathologist.

b) Administrative paper work, finding and fighting for services. Parents revealed that they spent substantial amounts of time on a regular basis looking for services, coordinating services, and passing on information between case workers and therapists, or fighting for services for their child. This process was time consuming and frustrating for parents, but essential in order to access the services to which their child was entitled. Parents expressed that the substantial amounts of time they used to coordinate services for their child could be put to better use in their daily routines. Some parents voiced that it was not their job to coordinate services but that it was the responsibility of the service providers.

> *A lot of my time is spent on the phone and filling out stuff. Numerous documents that I find are useless. . . . Like there’s no point finding, like if the parent feels like it’s a mountain to access it. Like I have enough on my plate than to make all these things I need to do. (Vivian, p.29, I2) I’d say I spend a good two or three hours a week, either tracking Avigail or looking up policies on line to see if Avigail qualifies for something because somebody told me that she might, you know what I’m saying? So it would be so nice if I had somebody to say, “Avigail is at this stage or this age you know she can apply for this, this and this, here are the forms. There you do this.” That would be so much easier than [what] I get. (Vivian, p.31, I2)*

In addition, families were required to meet often with their child’s multidisciplinary team and discuss their child’s needs for specialized services. One parent described this process as “justifying” their child’s need for services, and feeling like the parent was put “on trial” in front of the panel of experts (Alessa p.19, I2). Parents felt that the glitches they faced in the system had more to do with school or hospital politics than the nature of the intervention per se. For example, Etana described how the school changed her son’s educational assistant four times throughout the year, which consequently created instability for him and did not help in his academic progress. Etana had to constantly take up the matter with the school and emphasize the need for consistency for her son. Many of the parents in this study, including Etana, described this process as “fighting for services.” Another issue that families had to deal with on a regular basis was finding a program that corresponded with their child’s level of learning and development. Parents found that the services available to them were either too advanced or too basic for their child’s learning level. To parents, this was more than finding a place for academic advancement for their child, but finding a place or a “world” in which their child could find his niche. Sabah described how her son Andrew was left “floating around” in a system that seemed to have no place for him. She was constantly searching for the right kind of services and environments where he could grow and develop.

> *Like it’s either in the extreme, extreme case so then we take him to a more extreme program where they are taught to do things at a much slower pace or he goes into it like kindergarten and gets the support or in just regular kindergarten so there’s no midway point and unfortunately that’s where he is. He’s midway point not extremely there but he’s not extremely behind to so he is just floating around in the middle of this. (Sabah p.7, I1)*

c) Finding childcare and support. Another responsibility that parents had to juggle was child care. Parents reported that child care for a special needs child was hard to find. Daycares were generally not equipped for their child’s needs, and if they did find an appropriate centre, they often faced long waiting lists. When they had no other choice, parents did opt for a regular day care but often found that it was not a conducive atmosphere for their child with special needs. Sabah related an incident at her son’s daycare where she felt that neglect by the day care staff caused him to have an injury. She felt that her son was not wanted at the day care because he was an “at-risk person” and that he was not being treated well there. She ultimately withdrew from that day care. Eva found it hard to access child care as few centres were willing to take in her special needs daughter. The search for affordable child care and support was a constant task for the families in this study.

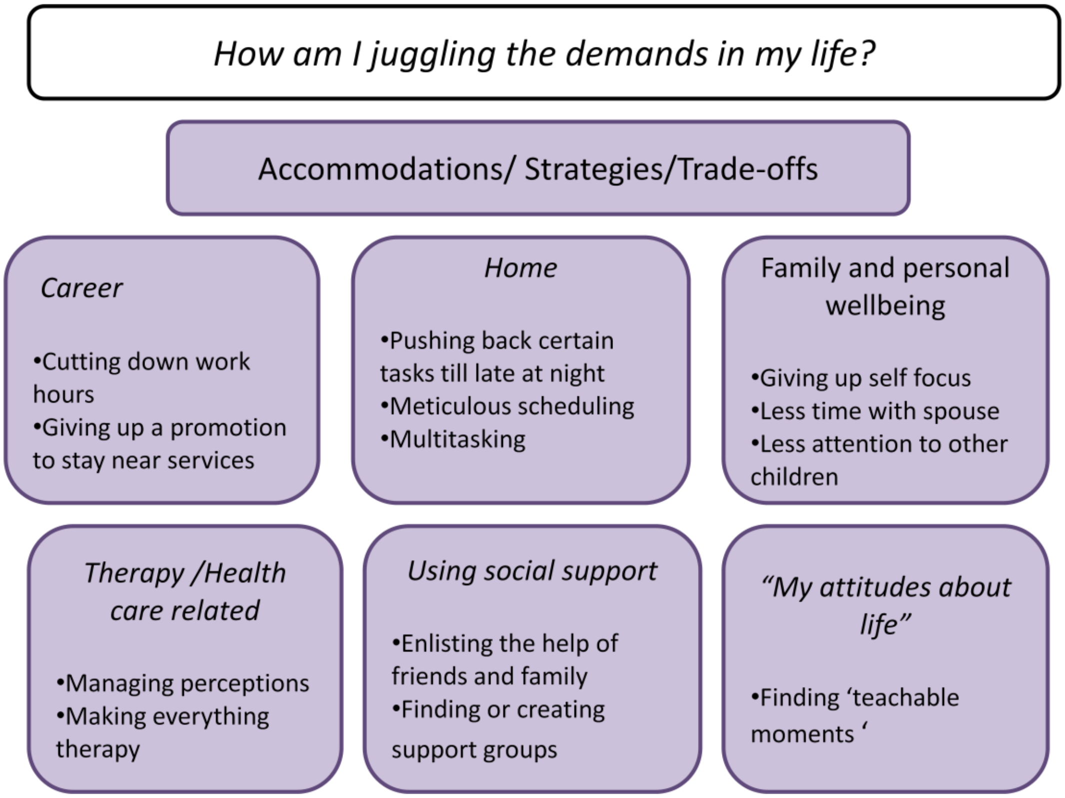
> *When I was in that other place, my old address, there was a childcare they provided there, but I couldn’t keep her there because she was-she needed one-on-one and they didn’t have enough staff there for that and it was just too much and so I had to find a different day care for her, and the day care that I tried to put her in, I couldn’t keep her there either. They said they couldn’t handle her and it was too much and that there’s*

> *actually a better program suited for her and their program didn't meet her needs and so I had to take her out of there. So that was discouraging. (Eva, p.15, I1)*

4.2 How are families juggling the demands of work, family, and EI?

In order to juggle the various demands that were discussed in the previous section, parents made various adjustments/adaptations, and trade-offs. They used common sense strategies and innovative ideas in their efforts to balance work, family, and the demands of EI, to create routines that suited their needs and lifestyle.

Figure 2. How are parents juggling all the demands in daily life?



4.2.1 Accommodations /Strategies

According to Bernheimer and Weisner (2007):

> Accommodations are usually adaptations to everyday routines, not responses to stress; are responsive to how children impact parents' daily routine, not to children's test scores; are related to parents' differing goals and values; do not fit a single script or model for what is good or bad parenting; and predict family

> sustainability of daily routines, rather than child outcomes. Accommodations can and do change—so interventions can indeed find their places. (p.1)

The accommodations and strategies that families used to balance the demands of their daily routine and those of EI are presented in the following section.

4.2.2 Career

Parents described making changes in some aspect of their careers or jobs in order to make time for other things in their lives that they saw as priorities; including, fitting in the demands of early intervention. Mothers, in particular, made these adjustments or trade-offs. Many parents decided to give up work and furthering their education because it was hard for them to balance family life, appointments, and therapy along with a career. Struggling to maintain this balance took a toll on other areas of their lives such as health. For example, Asha left a night job because she was unable to handle balancing her domestic responsibilities and therapy for her son Anil. She ended up sleeping only four or five hours every night and it started to affect her health. Her husband persuaded her to leave the job finally. She hopes that she can pursue work when her son is older and more independent, but fears it may be too late for her by then.

> *Whatever I can do I do. But I don't know the working part-I get so tired, no? I cannot balance. I realize that working and doing this at home, is so much [more] stressful. You have to choose one. Yeah, but as you get older you don't get jobs.* (Asha, p.34, I1)

Parents described cutting down on hours of work to stay at home and work on therapy with their children or cutting down on vacation time to transport their children to therapy programs. For example, Etana would often give up vacation hours to drive her son to appointments in the city, which was a distance from their home. Other parents adjusted work hours or worked part time or from home to supervise their child's therapies. Lydia scheduled her work around her son's appointments and the family's needs. She chose to adjust to the therapists' schedules, sacrificing her own convenience to make sure that the same therapists worked consistently with her son rather than changing therapists constantly at every session.

> *. . . sometimes I've had to shift my hours that way or if we have other appointments and other commitments during the day and I'm not able to work in the afternoons then I have to shift my hours to evenings or sometimes I have to shift it to weekends. . . . So we've had*

> *to do some shifting there but like I said I just don't want anybody coming and looking after the kids and the people that come, I want to make sure that they are right for the children and they're right to look after them and they're going to be a part of our lives, not just somebody that shows up for a shift, right? So that's been pretty important to us. . . . So that, again there's trade-off, right? There are compromises. If I had just anybody here, then I could probably work more, I could probably do more but that's not my priority so I you know, I tend to, well try to put their needs first and then everything else fits around. (Lydia, p.9, I1)*

Some parents explained that they gave up work or did not pursue a career because they felt that there were not many career options that were flexible enough to accommodate their child's numerous medical and therapy appointments as well as unpredictable health care needs. Other parents stayed home because suitable childcare was expensive and hard to find. It seemed more economical to stay home and look after their children rather than spend their wages on childcare. Some families decided to forgo promotions or furthering their education because either involved moving to other regions. Parents felt apprehensive about moving and taking the risk of having their child lose therapy services. Another parent decided against taking up a promotion in a different city because he felt that the process of setting up services for his son in a new place would be too onerous or his son and the family as a whole. For example, Maleah was waiting to see whether the therapy at her son's present school was beneficial. If so, she decided that she would forgo moving to another city to pursue her education.

> *Work! That's one of the biggest reasons that I don't work. I mean even if I could find a day care to take him full time I would still need to be able to take off all the time. I mean the last month I've had three appointments per week. How on earth can you explain that to a job? There's no way! . . . So, I mean, that's where it's kinda hard. I mean, what's the likelihood of me finding a job that's going to let me off one day a week so that I can take my son to the hospital right? (Maleah, p.20, I1)*

4.2.3 Home

Parents made time and space for therapists or aides to work with their children at home. For some parents, this meant pushing aside certain household tasks or hours of work. For others, it was about having someone other than family or friends in their house, and for others it was feeling the obligation of preparing the house for the arrival of the aide or therapist or planning the daily routine around their child's home therapy session.

Luana described it as a "Catch-22," because as much as she appreciated the therapists coming to help her daughter, she felt that it meant preparing time and space for the session. The alternative was also undesirable; if she was not willing to have the therapists come to her home, her daughter would miss out on therapy. Asha explained that it was sometimes stressful to have to have someone in the house because she would have to structure the family routine according to the aide or therapist's schedule. Others, like Alessa, explained that to have therapy conducted at home, one had to be comfortable with having an outsider in the house.

> *It's just busy and it's hard to have strangers in your house. You know, we're not used to being so busy. Definitely with Mark's hard time, "busy" is not conducive to lowering stress. It increases stress. So I think the challenge is, you should be OK with strangers- not strangers cause' you get to know them and they get to be friends. But you have to be OK with people coming in your house, you know, not as family or anything, but coming to work with your child you know, in every room of your house and that kind of thing. It's just busy. And sometimes it's hard cause' it's not really necessarily fun stuff. It's not like you're taking your child to gymnastics and Tae Kwan Do and hockey or something like that. (Alessa, p.23, I2)*

Parents seemed to associate building a routine mostly with everyday household tasks such as laundry, cooking, and cleaning. Many parents expressed that they felt frustrated when they were not able to keep up with these routine tasks. Moreover, much of their routine was determined by the needs of their child with special needs, which led to often unpredictable and unstable routines for families, which ultimately left parents feeling fatigued and stressed. That said, many parents described strategies that they used to keep the household routine going and to save on time. To accommodate EI and other day-to-day demands, many parents let go of household chores to save on time or fulfill priorities. EI-related responsibilities were one such priority. Sometimes parents let certain household chores, like cleaning or house maintenance, become lower priorities on their list of routine chores so that they could find time for other routine tasks. Some parents left laundry, house cleaning, and sometimes even cooking to the late hours of the night. This change also affected their sleep patterns. Many parents also felt unable to maintain a fixed schedule that was convenient for them. Instead, they found themselves building a routine around medical and therapy appointments for their child.

> *We're more tired probably than a typical parent, I would say. And I leave all my like, laundry, till 10:30 or "Oh, I forgot to chop vegetables but my worker is coming tomorrow morning, so it's 9:30, better get the board out." So those sorts of things I push, like the mundane tasks, off till the kids go to bed because either I'm busy with Avigail or I'm gone to an appointment with Avigail or I feel bad because Ariella hasn't had any attention. So yeah, I'd rather play with Ariella than chop vegetables. You know what I mean? So there just doesn't seem to be enough hours to do everything or I'm scrubbing toilets at midnight, you know, that sort of thing. Maybe midnight's pushing it, but 10 o clock.(Vivian, p.15, I2).*

> *Like I said: the cleaning. I just didn't add that to the list because usually it's always pushed off to the side. That ball is just never up in the air! So I mean, that's kind of the thing that I purposely push off to the side, so that I don't have to worry about dropping other things. But a lot of the times, out of the hospital and work, I get dropped right? So if I can't fit in anything else, I'm the person that gets dropped. That's why I push cleaning, cause' if cleaning moves in there too, I'll get dropped a lot more (Maleah, p.18, I1).*

Some of the common-sense time-saving strategies that parents described included completing household chores and errands when the children were sleeping, meticulous scheduling, packing lunches the night before, internet shopping, scheduling appointments close together in the same area, bathing young children together to save time, saying "no" to more than they could handle, and calling a friend or family member for support or help when things got out of hand. Another important aspect that families described, to keep a routine going, was teamwork between family members. Many parents described splitting chores between themselves or getting their children involved in household tasks that the children were able to handle. Some parents also described using these situations as opportunities to foster a sense of responsibility in their children. In most families, however, it was the mother who took on the larger portion of the domestic workload.

> *So the first thing I do is obviously the bath. So I normally bathe the babies at the same time. So the three babies bathe and then I bathe then we come down for breakfast. (Sabah, p.3, I1)*

> *. . . I usually have all the lunches ready the night before. . . (Etana, p.18, I2)*

Parents talked about prioritizing what was important and then finding time to fulfill those priorities. Alessa described how she tried to find "windows" of time during her day, while running her day home, to make and return phone calls, transport her children to and from school, prepare meals, and do laundry. Likewise, Lydia organized her day with to-do lists and multitasking.

> *. . . being organized is definitely something you need to do, right?. . . keeping sort of a "to do" list of things, when you run out of something that you need, throwing on a grocery list and having it there and so, you know, being organized and being prepared for things . . . . planning the day out and trying to see what, figure out what you're going to do and looking for opportunities to multi-task like lots of multi-tasking that I do. . . . So there are things like that. There is well, and things like laundry, right? You do it you know, sit and watch it, you do other things . . . . I tend to group things that have to be done in similar areas and figure out how to do that and so you know if I'm going to three different stores, if they're all in the same area, try to do that all at the once, that kind of stuff. (Lydia, p.12, I1)*

Almost all the parent carers who participated in this study described spending substantial amounts of time researching information for services and advocating for their children. Parents talked about actively researching information on line, in the newspaper, or asking their child's pediatrician or parents of other special needs children. Some parents talked about making time late in the night to do this research. Others made time in between routine household tasks and still others talked about using any "down time" or free time they had for themselves in a day for these tasks. Many times they found information by word of mouth or, as one parent described, "By accident," because services were not advertised well enough or information was not made available by their service providers.

> *Like I really pushed and I was very proactive, when they [her sons] were little. And my mom was talking to me about her co-worker who was having problems with her twins. And I said, "Well, have you tried this, this, this, or this?" She said "Well, what is it?" She didn't know anything about any of these services. And I had found them, not necessarily because I'm a nurse, but I did a lot of research online. I went to the health unit. I was very, very vocal. And I think that, that's what some of these parents need to do, is if they've gotta advocate for their children, then they've just gotta speak up. Whether it's your doctor, or teacher, or anything, you've just gotta be so proactive for your kids. And depending on whatever kind of disabilities or problems that maybe occurred. So it's hard. (Etana, p.21, I2)*

4.2.4 Family and personal wellbeing

Though parents considered their family life and personal wellbeing to be of great importance, they made many adjustments and compromises in these areas of their lives. Parents made their health and wellbeing one of their lowest priorities so that they could manage to balance their daily responsibilities. Leigh described this as giving up "self focus." Mothers especially felt that they had made themselves the lower priority. Alessa, for example, explained, "Anything personal, anything for me would probably, you know-[it] already takes a back seat anyways" (p.22, I1). Parents often put off exercise, doctor's appointments, or routine health check-ups. Almost all the parents described constantly being sleep-deprived, or their sleep being interrupted. Parents recognized this trade-off or adjustment as creating a vicious cycle, wherein compromising on health and sound sleep took a toll on their general wellbeing. This made it hard for them to keep up a routine that they felt was stable or productive. Leigh, for example, felt like she and her husband were "chronically sleep deprived" and operating in "survival mode." As a result they often felt as though they did not have the time or energy to fulfill other routine tasks.

> *For each of us, well, I know that we have each given up self-focus. For example, I have not seen a doctor in a year and a half. It just has not been a priority. I know I should but we sure do not do this self-care that we, that we all know that we should. It is easy to put off a doctor's appointment and our routine physical because, god! Finding the time or finding somebody to watch Sierra while I go to a doctor or finding a doctor. Everything has to shuffle and you could just go for routine physical-forget it. It is too hard. So we have definitely given up self-care. We have given up a hell of a lot of sleep. (Leigh, p.20, I 1)*

Family relationships were a priority area for parents, but often the time spent with a spouse or their other children was contingent on the time and energy that they had in a day. A few couples whose children were all very young described using bath time or meal time to regroup as a family. Most families, however, found that what many parents referred to as "family time" in the evenings was taken up by a home visit from the aide or an appointment or special class for their special needs child. By the time the day was over, the members of the family would be too tired to spend any quality time with each other.

> *Oh family is-there's no family time because normally I drive Andrew on his own because it makes life easier but that means everyone else stays at home. That's the time we could've spent with everybody at home. You know, trying to catch up with your day. By*

> *the time we get home from that activity everyone is exhausted and no one wants to do anything. People are just going to sleep. (Sabah, p.30, I1)*

> *Like they're [the therapists or aides] usually pretty flexible and you can meet them in evenings and stuff like that if that's your only time. But that's also your time with your children. (Alessa, p.16, I2)*

The struggle to find quality time seemed especially true in terms of the marriage relationships of the participants. The "busyness" of everyday took a toll on the marriage. Partners found themselves either too tired or drained of energy to spend quality time with each other at the end of the day and often found it easier to spend some quiet time alone. Even when couples found time to take a break together it was hard to find suitable childcare for their child with disability during the time they planned to be away. A few parents mentioned that they were attending marriage counselling services or considering it.

> *Well, like I was saying, just compromising our own relationship a lot of times, you know. And I think that can be a really challenging one cause' I think most spouse[s]- a lot of spouses-that have especially young kids tend to fall into that. You know, that's why there are all the marriage therapists say have a date night-a regular date night-right? And how many couples actually do that . . . . but yeah, I think that's one area where we'[r]e kind of starting to realize that we need to not compromise so much, you know. But that's a biggie". . . (Luana, p.22, I1)*

> *I can think of lots of-like personally there is not as much time for me or my husband, not as much down time. Like the down time I do have is spent for this type of thing or making phone calls regarding something like this regarding Zeph's stuff. (Alessa, p.22, I1)*

Many parents felt that their time with their other children was sometimes compromised because of the many responsibilities they had in a day. Parents also felt that they placed more responsibilities than were ideal on the siblings of their special needs child, but this was also a way in which they could manage their routine. Another concern for many parents was that the opportunities that were presented to their other children were often contingent on the opportunities that were available to their special needs child, that is, their other children's opportunities depended on the amount of time and money available after using resources for the special needs child. Some parents signed up their special needs and typically developing children for activities that the children could participate in together. However, if such activities were not available, their typically developing child would usually miss the opportunity. For example, Sabah felt that her middle child, Caleb, was sometimes "traded off."

> *Oh, there are a lot of things I have to trade off. You know, you have to make so many sacrifices. Like you limit the time that you've got to actually be using to even play and get to know the other babies; you know, it's different because most of the time when you're here instead of focusing your attention on everyone. . . just like I was telling you, like Caleb will be the last person that's on the line. . . . I think the biggest sacrifice has been Caleb because you know, we really cannot do much with him without having to consider Andrew. So, we try, by all means possible, that whenever we try and sign Andrew up for an activity where Caleb can go in, we try and get him in there. (Sabah, p.29, I1)*

4.2.5 Health care system and therapy-related

Navigating the heath care and school systems was a complex task that was part of the daily routine for all the parents in this study. To access the appropriate services and funding for their children, parents had to go through substantial amounts of administrative paper work, do background research on the steps they would have to take, coordinate services and often fight to have their voices heard. Parents described strategies that they used to make the best of this complex system. For example, to save on funding money, Alessa made the effort to transport her son Zeph one hour into the city for therapy sessions rather than have the therapists come to her house. If she chose home sessions, the service providers would charge her from the funds allotted to Zeph for services and as a result, leave fewer hours for Zeph's therapy.

> *In between, I meet with the SLP, the OT and the program coordinator. So yesterday was the meeting with the program coordinator in the morning. And I went to the city for that. Most times I'll go to them because if they come to me, we're charged. Not personally, but from his, from his pot of money, if they charge for travel time. So if I go to them that means more time for Zeph. If they come to me, less time for Zeph. So I prefer to go into them cause' then that means that's an extra hour for him to have with that professional. (Alessa, p.16, I2)*

Parents also described the strategies they used to manage their service providers' perceptions to get respect, funding and services for their child. The data analysis revealed that keeping up a certain appearance within the health care and school systems was more likely to work to the parents' advantage. Some parents, like Maleah, felt that there was a need to look healthy and "well put together" to be respected and heard.

> *Not having enough sleep, not having enough time for myself. . . . I don't like looking like I'm struggling, which I mean I am some of the time, but that doesn't mean everybody has to know about it, so my mom thinks I put too much towards that. I mean that's also how I get respect from people at the hospital, right? If I look like I'm put together then they'll listen to me, right? Like so, it's just, if you look like you're dishevelled and things are going crazy then people won't believe that you know what's best, right?(Maleah, p.18,I1)*

Contrary to Maleah's experience, Lydia had been told that, to access more funds for her son, she would have to make sure to look "needy," this meant keeping a shabby house and looking worn out when the social worker came to assess their needs. She vehemently disagreed with this strategy, as she felt she was entitled to funding without having to "prove" her child's eligibility in this manner. Another mother talked about having to "prove" that her daughter was eligible for much-needed diaper funding. To do this she would have to record the weight of her daughter's diapers daily. In order to fulfill the weight criteria, she fed her daughter more liquids than usual. Parents felt that some of these strategies were the only way to overcome the obstacles in the system and access the funds that they felt their children needed and for which they were eligible.

> *So like, if it's and [you know] and there are families that are under more severe situation[s], I can absolutely appreciate that but when you are told by other families "When our social workers come over, don't clean your house, don't get out of your pyjamas, don't wear make-up". . . . unfortunately, that is what the system supports; the more need that you can show, the more funds that you get. . . . I am not going to sit here and tell what you "Woe is us," for what we have to go through. I am going to tell you the celebrations of things that we've achieved and accomplished. . . . Like that's not in me and I don't want to be like that-and if that means that I lose some funding, then I guess I lose some funding. . . (Lydia, p.29, I2)*

Another strategy that parents made to fit therapy into the daily routine was to adopt the mindset that "everything is therapy." Parents also used expressions like: "It's engrained into the mind," "We have to make it therapy," or "It's not 'just' regular summer camp." Most parents made the deliberate effort to incorporate goals into their routines and to remind themselves of their child's therapy goals till the goals became a natural part of their every day. For example, Luana made "X's" with masking tape on the stairs in her house to encourage her daughter Anya to alternate her feet while she climbed them. Likewise, Leigh explained that she received, from the service provider, the awareness that therapy did not stop with a session but that the family was "living therapy." To this end Leigh used, as much as she could, every part of their day to encourage her daughter to achieve therapy goals. For example she would use meal time to work on Sierra's oromotor strength and hand-eye coordination. Alessa was another mother who found that though the mindset was engrained into her thinking it took a deliberate conscious effort for her to incorporate therapy into the routine for Zeph. She found this process fatiguing.

> *Just knowing that we are implementing therapy goals throughout the day. . . . Everything is therapy. Absolutely everything . . . . We are kind of geeky that way. Yeah we are. Nothing is basic in our world because we know that you know therapy has to happen with us all the time. So yeah that was us saying, "Hey we are not just going to feed her. We have to make it therapy." Playing outside, you know, there is (sic) a lot of challenges for her outside. There is a place whenever we go anywhere it is not just like, for example, walking across the parking lot, it is not just "walk on concrete." It is "walk on parking barriers so it is like a balance beam and take your time" and Sierra has to go along the balance beam and go back again, why not, and do it again. . . . I mean there are times when we absolutely have to get stuff done and I am sorry there is going to be no therapy going on. (Leigh, p.23, 24, I1)*

Many parents, though therapy had become part of their lives, seemed to come to a realization that having this mindset that "everything is therapy" meant sometimes forgoing their role as just "mom" to become their child's "therapist." From their stories, parents conveyed the value they placed on being a parent. However, they seemed to deliberately take up a therapist role to fulfill their child's therapy goals.

> *Sometimes I'll catch myself and be like "Back off already! Just let her run around!" You know what I mean? Instead of making her run to a target! Like I do find that I sometimes need to step off, you know? Because it is so engrained to just "Work on it, work on it! You can do it!" You know? And sometimes I just think, "Oh shut up Luana!" You know? Just let her be a kid for ten minutes, you know? So at this point it's coming pretty naturally. Maybe too naturally! (Luana, p.28, I2)*

> *You know, your life and things become so integrated that it's hard to discuss it from a higher perspective or like to back out of it, you know, in real life even, sometimes. (Luana, p.33, I1)*

Some parents said that they even went out of their way to find private therapy that they paid for "out-of-pocket" in addition to what was being offered for their children.

This seemed to stem from the feeling that the services that their child was already receiving weren't enough and that he or she needed more therapy.

4.2.6 Using Social Support

Families often used the assistance of their friends, families, and support groups to help juggle the multiple demands of life and the routine. Some parents talked about the help they received with child care from friends and family in the community. Parents enlisted the help of aunts, uncles, and grandparents, in an emergency, or when they needed help to babysit or to transport their children. Aside from practical help, parents seemed to draw much strength from the encouragement and moral support that they received from their own ethnic community or support groups. Parents talked about meeting up with other parents of children with special needs and gaining insight and support from them. Sometimes parents themselves took the initiative to form support groups with other parents who were in similar situations with a special needs child. Many parents expressed that they looked for avenues to socialize and spend time with other adults. They wanted to be around people who could be their friends and not necessarily talk about special needs. For example, Vivian went out of her way to look for a support group for mothers from different cultures so that she could make new friends, learn about new cultures, and engage in conversation that did not always focus on special needs.

> *Yeah, I think I found it by myself. I was at the mall and they had an advertisement and I went to check it out and it suited my needs, like the moms are all really laid back and like easy going and lots of different cultural diversity and I really like that. Our potlucks are awesome! (Vivian, p.20, I2)*

Though it took some time for Sabah to find friends from her ethnic community, they have become a form of support for her family. The parents in the community make time to bring their families together and hold events. The parents in this study also talked about using opportunities in the community, whether it was social gatherings with their own communities, or city programs, to foster skills in their child. These events were more economical for families and provided a comfortable environment for them with other members of their own communities. Asha took her son Anil to as many programs as she could in her locality, to encourage Anil's socialization with other children and to improve his attention span while doing activities. She took him to park outings and to the local pool as well.

4.2.7 My attitudes about life

Families did not limit themselves to describing strategies that dealt with accomplishing tasks in their routine. They also talked about adopting positive attitudes toward life and their child. For example, parents explained that they tried to find humour, amusement, and pleasure in the small and big events in their lives and used these instances as "teachable moments." Also, their spiritual beliefs or life philosophies, their beliefs about their child, and their views about raising their children in the world helped to shape their routine.

a) Teachable moments. Parents used pleasant and unpleasant situations as opportunities to teach life lessons themselves and their children. Parents called these situations "teachable moments". Leigh explained how she turned a situation, where she lost her temper, into a "teachable moment" for her son.

> *We are human, of course. It will happen. . . . What are you going to do about it? I mean you can reel about and I mean, even on days when, I mean even little, minor catastrophes like Sierra got into a houseplant and pulled it down and there is pottery everywhere, broke, and there was dirt and I was just besides (sic) myself. I was livid and I did not react very well. But it was teaching moment because Aiden was, so Aiden was there to see me lose it and after I was done losing it and had my temper tantrum, I was able to sit down and tell him, "Well, I did not handle that very well, did I? What could I have done better?" Teachable moment, absolutely. . . . So I have turned everything as much as I can into a teachable moment. Before, I did not used to have a lot of patience. I still do not have as much patience as I should, but when I do lose my patience, I turn it into a teachable moment for my son. (Leigh, p.29, I1)*

Parents also explained that they did not necessarily stick to a therapy program exactly as prescribed by their therapist; instead they chose to teach their child skills through real-life scenarios that presented themselves in the daily routine. For example, Alessa described how she preferred to use everyday activities like crossing the road or going to the park as teachable moments for Zeph rather than sitting and doing a table top activity.

> *So for instance, if we're going to the park in the evening, we'll practice that as we're going. Or we'll say "Well, why are you wearing a helmet today? And you know, "What is that good for?" You know, practice safety stuff in like a "teachable moment" is what I call it (Alessa, p.21, I2).*

b) My beliefs. Some families had strong religious or spiritual convictions that they felt helped them go through life. They believed that things “worked out” because of prayer and divine intervention. For example, Lydia believed that her schedule worked out to be convenient for her because of prayer. Maleah lived according to the philosophy, “Everything happens for a reason.” Sabah explained that she lived by the phrase “Take each day as it comes.” Sabah was able to be optimistic and hopeful about the future because she viewed her life situation and her child through the lens of her faith.

> *You know, but yeah, besides that I think it’s just one of the-it’s a blessing and as a Christian, a child with special needs in the family because it’s a blessing and that should begin to realize how important every child is and how different all the children are and sometimes it takes so much of a burden and a toll on you. But, the good thing is [tech gap] you have to be so optimistic about your children, you know, and we are so optimistic about Andrew. We know wonderful things are in store for us and in store for him and, as result, I think that [is] what keeps us going. (Sabah, p.37, I1)*

c) The rewards of having my child. Regardless of religious conviction, all the families spoke of how much they valued their child with special needs and found motivation and hope from watching their children grow up. They talked about the rewards of having their child with special needs and how their life experience was all the richer because of this. Parents were able to appreciate life and milestones more because of their children. Some parents expressed that their child had given them a different perspective on the meaning of success. Many parents felt that having their child opened doors to valuable opportunities that they might not have previously pursued. Families were also able to meet new people and make new friends. These opportunities also seemed to help parents view their lives, no matter how hectic, as rewarding. Parents also talked about loving their children just as they were and believing in their immense potential.

> *I think I’m a better parent or I shouldn’t say that cause’ I’m maybe not! But a better parent like, like I think I have more broad goals for my kids and I’m not as narrow-minded of what success is. So for example with Ariella, “Oh we want her to go to university and we want her to this and this” and those aren’t bad things but I think with Avigail [child with special needs], it’s changed my perspective that we want our kids to be members of the community and be productive and whatever road that takes, that’s ok. So I would say that I’m a better-I’m a more appreciative parent and probably[a] more*

> *broad spectrum parent. Like "Okay, she's not walking and that's frustrating and maybe she'll never walk, but let's look at something she can do". (Vivian, p.24, I2)*

d) Bringing my child up in the "real world"/not treating my child differently from others. Families wanted their children to have real-world experiences and opportunities. Parents explained how they raised their child with special needs just as they did their other children. The same rules and discipline of their home applied to their special needs child as to the child's siblings. For example, Ruth talked about how she disciplined her son Ian, who had special needs, as she did his brothers when they were younger. Parents exposed their children to different experiences, as long as the experiences were safe. They did not always take over for their children in challenging situations. Parents wanted their children to understand that in the family's absence they would have to fend for themselves in difficult or challenging circumstances outside their home environments. For example, Lydia wanted to foster independence in her son. Lydia made sure to convey to the therapists working with her son that she did not want them to rush in and help him every time he found a task difficult or frustrating. Like Lydia, many parents believed that their children were capable of achieving goals in life. Parents felt that as with every typically developing child, their special needs child should be allowed to grapple with difficult situations, within reasonable limits, before achieving success.

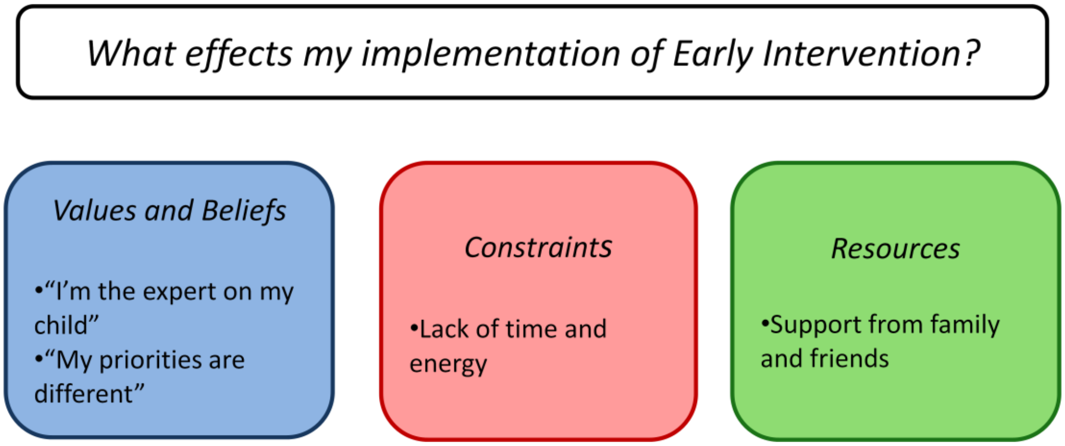
> *. . . I don't think things would be different cause' we try and not- we don't treat him any differently. I don't make him exempt from anything [because he has a] speech challenge or ADHD and stuff like that. (Etana, p.28, I2)*

> *Well, he's treated like the other boys. If he's going to throw a tantrum, he's going to have a time out in his room or he's going to be separated. We tell him it's not tolerated. He'll try and talk back to you now. He'll go "uh!" at you. It's like "don't talk back to me" and we'll send him to his room". (Ruth, p.28, I2)*

4.3 What affects how and to what extent families implement early intervention?

The section below presents the values, goals, resources, and constraints that influenced parents' implementation of EI. Some examples are presented in Figure 3.

Figure 3. What effects the implementation of EI by parents?



4.3.1 Values, goals and beliefs

As discussed in the previous section, families talked about the beliefs and life philosophies that motivated them and helped them to manage all their daily responsibilities and care for their families. Families used certain mottos or phrases in their stories that reflected their values and beliefs. Families also attributed meanings to various life events. These values, beliefs, and life philosophies played a part in how parents determined life goals and made decisions about their family, their child and, also, EI. For example, a family that believed success is measured by character and not developmental milestones did not necessarily value a therapy goal for achieving motor skills as much as they did the goal of being a productive member of society and a compassionate human being. Likewise, a parent who believed that "Everything happens for a reason," was able to accept changes and challenges in life more optimistically than, say, a parent who felt she was constantly "fighting" through every life situation. A philosophy, belief or meaning, whether negative or positive, seemed to help families make decisions in a way that suited their personalities and lifestyles. Families also directly voiced their thoughts on EI and how their beliefs and goals might affect their implementation of it. Presented below are the values, goals, and meanings that seemed to determine how or whether parents implemented EI in the daily routine.

4.3.1.1 "I am the expert on my child"

Parents strongly voiced that they were the persons who knew their children best and what was best for their children. When their opinions were respected and considered, parents felt more inclined to participate in intervention for their child. Also, parents' beliefs that they were the experts on their children determined what aspects of the prescribed intervention they would incorporate. For example, Lydia is a parent who sees herself as the expert on her child and views herself as a team member on her child's team of developmental specialists. The respect that she received motivated her to be involved actively in her son Evan's therapy. She described incorporating the therapy that she felt was useful based on her knowledge of her son.

> *I also have the most knowledge of him [Evan] and what he can do and so there [are], often times where spending an hour with him, you don't get a full picture of, you know, what's important for him to be able to do, that kind of stuff . . . . So there's a lot of input that I have and then feedback that I get from them because I don't have a background in OT [occupational therapist], PT [physiotherapist], speech language, all of that education, that kind of stuff, right? So we bounce ideas back and forth. Then we come up with programs and so yes, I'm involved with that. (Lydia, p.5, I1)*

Maleah made it clear to her son's practitioners that she was the expert on her child and demanded the respect that she deserved. When she felt that a health practitioner did not respect her opinions or her knowledge, she said that she would "talk back." The respect that she received seemed to play a role in her motivation to pursue services, either medical or rehabilitative, for her child. Some parents felt that though they were the experts on their child, it was, more often, the professional's expertise that determined the goals for their child in EI. As much as they felt their knowledge as a parent was important, they felt that perhaps the therapist or practitioner was "right" because of their professional training. Alessa wanted her opinions and her feedback to be heard and discussed alongside the professional opinion because she felt that this would make her son's therapy more useful for him as well as the family at large. However, she sometimes felt that her opinion was not respected.

> *There is a team of people there saying "Well we can have this person, we can do that thing, we can do this thing." It is more the experts looking at him and deciding that this is the best stuff for him, rather than me. I mean, I am an expert on him too, but it's easier and they are probably more, they have more insight then I do because that is their training. (Alessa, p.10, I1)*

As experts on their child, parents often made decisions that went against the opinion of the professional. These decisions were not only based on their knowledge of their child, but also on some of their own experiences. For example, Etana and her husband decided not to advance their son into a higher grade at school despite the opinions of his teachers and aides at school because they felt that he was not ready to face the challenges of a higher grade. Similarly Carissa wanted her son to stay back a year for the same reasons. Though she was entitled to make the decision, she talked about having to “fight” it out with the school authorities.

> *I had to really fight for him stay in [pre]kindergarten because they really wanted him in kindergarten. I had to fight to keep him at Elmwood but it’s the parent’s choice and I’m the one that knows him the best. (Carissa, p.2, I2)*

It seemed as though families were willing to find a balance between their own expertise and that of the professionals. However, they seemed more motivated to pursue intervention when their opinions were valued.

4.3.1.2 “Is this beneficial?”

A family’s adherence to a therapy or home program seemed to be largely dependent on how beneficial parents perceived these programs to be. Asha was an example of a parent who felt that the therapy that was suggested for her child was not benefitting him at all. She still continued with the program because she was afraid that if she voiced her opinion she would risk losing even the services that she was getting at the time. On the other hand, Etana valued the speech services that her son was receiving as part of a study. These services were located in the city, about an hours’ drive from their home. Etana used her vacation hours frequently to drive her son, Tomas, to appointments. They would return early from vacations just to make sure that he didn’t miss any. Etana and her husband greatly valued their family vacations. However, she was ready to compromise for the sake of therapy she perceived as beneficial for her son.

> *When we were doing Corbett clinic that would be six hours a week I was giving up of vacation time. Yeah, so that was a lot of vacation time I had to give up. And then usually when we go for an appointment almost probably once a month. . . . So that’s usually depending on the time of the appointment, it’s a full day that is done. So usually . . . I tell work, “It’s for my son.” Like my family comes first. My job is my job but my family’s more important than this job-type thing. (Etana pg, 22, I2)*

4.3.1.3 “My priorities are different”

Some parents felt that their goals and priorities in life were not necessarily what the professional or even the society saw as important or necessary. Parents talked about how their priorities influenced the extent to which they followed the prescribed therapies or what aspect of the therapy program they decided to implement in their routine. For some parents, like Lydia, strengthening her son's lower limb motor skills was a priority. She felt that this was not necessarily as important a goal in the minds of the professionals.

> *And so sometimes there's things that are missed or things that are not necessarily a priority for other people that are priority for us and so it's important for us to....Well actually in, in the reverse, there's priorities for them or things like that consultant stuff like that. You know it's not a huge priority for us right now. He's doing lots of that but it's not something that we're focusing our time on. [It] is more important for us right now just for him to strengthen his legs and build muscles and things. Like we have an exercise machine that we bought, we bought two years ago and he does that an hour a day and that's not really a priority in their mind but it is in our mind because he's, he is developing so much better by using that exercise machine, both physically and cognitively. So yeah that's something that we do outside of the programming because we believe that it's important for him. (Lydia, p.5, I1)*

Vivian and Gareth explained that their goals for daughter Avigail were not necessarily only to achieve success with developmental milestones. Rather, their goals were part of the bigger picture, which was for their daughter to become a productive member of and contribute to the greater good of society.

> *Well I think generally our goals like, the goals that the therapists help us with are very different from the goals we have from Avigail as a person. So I would say that Gareth and I have thought about who we want her to be personality-wise and a person productive in society rather than, well, can she walk or not? To me that's irregardless. If Avigail never walked, we'd figure out what to do with her in a wheelchair. Like you know what I'm saying. So I think our biggest, like, what we do is we expose Avigail to a lot of different environments. . . . We're not sure now what her capabilities will be, but we'd like her to have [a] feeling like she's productive in society. (Vivian, p.21, I2)*

Parents often put off fulfilling a therapy goal to allow the child to just spend time with the family or have some down time. Vivian gave an example of this when she talked about allowing her daughters to play and spend time together during bath time where usually she would use that time to fulfill a therapy goal for Avigail.

> *Oh well, for bath time I suppose, like right now we give Ariella and Avigail a bath together, so they just play together, I don't really interfere with their bath time, but if Avigail was bathing alone that would be a time to bring out bubbles and make an "O" and blow and see if she would mimic it. Or maybe you'd do more messy play there because it's with textures she might be uncomfortable with because it's in a tub. Those sorts of things, but I personally haven't done that yet because that's Ariella's and Avigail's play time, and they play quite well together in the bath. So I just kind of left it. (Vivian, p.10, I2)*

4.3.1.4 Societal perceptions

Part of what motivated parents to implement EI had much to do with what was discussed earlier in this chapter, that is, the mindset that "Everything must be therapy." Parents seemed to be convinced that making therapy a priority was the best for their child. This mindset seemed to motivate them toward fulfilling therapy goals for their child. Many parents viewed therapy as "the right thing to do" or, as one parent described it, "the key." It seemed that the health system and society at large had influenced parents to adopt this mindset. Though many parents found it hard, they put pressure on themselves to incorporate therapy. Their belief that "everything must be therapy" motivated them to find time and resources to do so.

> *I think sometimes I put a lot of pressure on myself that we have to do these things while we can because early intervention is "the key" and you know "blah, blah, blah" and stuff like that and we can't miss the time. It is more than "just," it is not "just" playschool, and it is not "just" summer camp and it is not "just," you know, it is important because it is hopefully getting him somewhere, so I think that's maybe more taxing because -- I think all families are crazy busy -- you know, you choose to be. (Alessa, p.10, I1)*

Intrinsic values, beliefs, and meanings attributed to life events seemed to greatly influence the goals that parents had in life and the decisions they made about their family and their implementation of EI. Also, parents seemed to try to find a balance between their intrinsic values and the expectations and norms held by society at large. Finding the balance that worked for each individual family determined, in part, how parents decided to implement EI in their routine.

4.3.2 Constraints and resources

Even when parents believed that therapy was a priority for their child with disability, the extent to which they could carry out EI was largely dependent on practical resources and constraints in their lives.

4.3.2.1 Constraint: Lack of time and energy

One of the main constraints that parents had was time. Many parents found that the frequency of a particular exercise regime was not practically possible in their busy routine that also involved family, household, and often career-related responsibilities. For example, Maleah, a single mother, was told to implement a physiotherapy exercise program about five times a day with her two-year-old son who had multiple disabilities. At the time, she had been working and found it impossible to match the prescribed frequency, even after enlisting help from family members.

> *When he was going to school, his physical therapist wanted me to do them five times a day. And it was like "You're crazy, it's not happenin'!" So I mean, at that point, I was working more. I was working three days a week. So three days a week he was actually getting it, three times, because they would do it in the morning, then he would come here to my grandparents' house and my grandmother would do it and then I would do it in the evening. So I mean it was pliable that, when three people are doing it, it's a little easier then, right? . . .Yeah, so, but it still wasn't more than three times and [the therapist] wasn't very happy with it, and I was like "Sorry! But it's not happening. I don't know what to tell ya! (Maleah, p.5, I1)*

Other parents talked about being too tired after their work day to pursue therapy with their children, even when they had some time in the evenings.

> *Sometimes. At least I do [therapy goals] sometimes, it's just like, by the time you finish coming home from work and you're dealing with supper or that. It's like "Arrrggh!! I'm tired." Or he doesn't want to. He's not in the mood. He just wants to play in his room or he wants to watch the TV or he wants to do something else. He won't even come to you to do anything. And you can usually tell. Like if he gets off the bus and he's sleeping, he probably had physio! [laughs] They made him work! (Ruth, p.15, I2)*

4.3.2.2 Constraint: Difficult programs and difficulties in adapting the program

Parents talked about finding certain therapy tasks more challenging than others. This seemed to affect their implementation of EI in their routine. Families were more inclined to implement a goal if it could easily be incorporated into a regular activity, for example at the park or in the bathtub. Sometimes families chose to adapt the goal as a whole or implement selected parts of the goal according to how it fit into their existing routine.

> *I don't know, but yeah, we just find it really hard to follow through. If it's paper work or table work we find it hard to follow through on that, but if it is more, you know "we'll try this in your play," or try "see if you can get him to roll down a hill when you are [at] the park" or-- like that kind of stuff isn't hard. (Alessa, p.13, I1)*

Some families found certain goals too difficult to slot into their routine or did not understand fully how to implement them and therefore would choose not to pursue that particular goal altogether. For example, Asha found some of the therapy goals difficult to carry out at home; she felt that they were not quite suited for her son and that they were too structured for her routine. Carissa found some of the therapy goals not only hard to implement but a little childish for her taste.

> *Sometimes I get frustrated. Sometimes I think it's silly. Like they had this purple blanket and they wanted Gavin to go in it, they wanted us to bounce him. Well, personally I couldn't do that by myself. I need Brian [husband] here. Gavin didn't like it so he fought me on it. So that [therapy goal], I didn't like. But they're pretty good at helping me to change it around like and telling me how to deal with things. Or if I'm being too easy on him, they tell me to toughen it up. (Carissa, p.22, I1)*

4.3.2.3 Constraint: Difficulties in accessing services

Another constraint that families found that influenced their implementation of EI was their ability to access desired services. For some families this meant difficulties in obtaining information about services or coordinating services. Parents described the challenge of accessing services to which they were entitled. They simply found it difficult to maneuver through the system because of the extensive paperwork and the numerous clauses in the policies that they had to look over before they could call the service providers and ask for services. Many of the mothers spent hours on the phone with service providers to get information and coordinate between the service providers and the therapists. Parents found it exhausting to do this and sometimes decided to wait for a while or not pursue the services altogether.

> *But I think for some things, like for funding as well as different types of therapies and stuff, it's just so hard being -- all these forms you've gotta fill out. There's so much you*

> *gotta do. And in some cases it's just like, "Why bother?" I can do it all at home if I get service for it once a month or whatever, so sometimes it's not even worth it. (Etana, p.21, I2)*

4.3.2.4 Resource: Family support and caring professionals

Among the resources that parents had mentioned, families talked about the support of family friends, and an understanding aide, interventionist or social worker. They felt that they had more time or opportunities to fulfill therapy goals for their child because of this support. Those families who had support from relatives were able to make time to implement interventions or just to relax when they needed to. Families also really valued the advice and expertise of interventionists and appreciated the genuine concern and respect they gave the families. Parents were appreciative when interventionists took the time to listen and incorporate family opinions and ideas into the therapy plan. When families perceived that interventionists genuinely cared for their child and the family, they seemed to feel more satisfied and content with the therapy process despite the challenges of fitting it into a busy routine.

> *To me, they're supporting us by giving us the information and the knowledge that we don't have and even working with him. So the time that I couldn't do one-on-one with him because of some of the other priorities in life, they're able to sit one-on-one and do coloring or do building or whatever kinds of things that are required (Lydia, p.6, I1).*

> *So for me I've sort of had someone there holding my hand and, not only holding my hand but kind of leading the way and they've helped me navigate the whole process as well of applying for specialised services and what the process is and you know, sometimes even more than my FSCD worker, you know? [Laughs](Luana, p.20, I2)*

4.3.2.5 Resource: Respite

Another resource that families greatly appreciated was respite funding. In fact most families felt that the more time they got for respite care, the better they were able to find time to manage other routine responsibilities. Furthermore, parents felt that respite funding gave them an opportunity to take a break and helped them recharge in order to come back to their routine a little more energized.

> *That has been really good. That has been a nice service to have because you certainly feel a lot more freedom to take more time for yourself. I think if you had to pay out of your own pocket I think you might think you were not necessarily worth it. But when the*

> *funding is there you can go, "I am worth it," because they are saying I [have] worth. They are saying you deserve to have this and you need it. So you get the funding so you use it. (Alessa, p.24, I1)*

4.3.2.6 Resource: Parent training, support groups

Parents also found parent training to be a helpful resource that went a long way in managing their child's therapy as well as their routine. Those families who didn't have access to training and resources felt that it would be helpful for them. For example, Ruth and Jason found the resources from their service provider to be helpful and relevant to their situation.

> *And the supports there, they even have -- Elves have regular -- like family courses on a Saturday where you can go learn about, just like we had one on communication devices. . . . They do try to do those type of things, twice or three times a month, whether it's on a weekend or that -- you can choose. You don't have to go. You can choose on (sic) which ones you want to go to, like they'll have some for children transitioning out of high school into adults and they help you out that way. (Ruth, p.10, I1)*

Eva wanted to be part of a group that helped parents of children with autism. Barring the obstacles -- lack of child care and transportation -- she felt that it would be a valuable resource and provide opportunities for her to meet with other parents and talk about challenges and strategies that she could implement for her daughter Aura, who had been diagnosed with autism.

> *I was going to try and get into the Autism Society one. I heard that that one was really good but then I would have difficulty getting there and getting childcare for the other kids. ....That looks like a really good support thing to get into, so then I can meet families with kids who have the same, with, you know, disability or whatever, and then we can get to know each other. And I can go visit them and their place will already be equipped for a child like her. (Eva, p.6, I1)*

4.4 Summary

In summary, the analysis of what parents dealt with on a daily basis and how they managed the responsibilities of the daily routine revealed that they used innovative strategies and accommodations but also had to make significant trade-offs. In terms of trade-offs, one of the major insights that emerged from the overall thematic analysis of data is that there seemed to be an order in which parents might let go of a responsibility or role; that is, an order in which a juggling ball was vulnerable to being dropped. The most vulnerable to being let go were the caregiver's personal time and interests. The second most likely "ball" to be dropped would be the family's interests as a whole and in particular the parents' marital relationship. The responsibility that seemed to have the highest priority in terms of being kept up in the air was the needs of the disabled child and, perhaps to a lesser extent, the needs of the siblings.

The analysis of the factors that influence whether and to what extent family members may implement EI led to the identification of a number of values, beliefs, goals, resources, and constraints. These factors influence parents' decisions regarding EI implementation.

CHAPTER 5

Discussion

This study sought to reveal an in-depth understanding of the experience of parents in accessing and implementing early intervention in the daily routine of family life. The parents who participated in this study addressed how they managed to balance the demands of their daily routines by describing the various adjustments and/or trade-offs they made, and the strategies they used to keep their routines going. Parents also described the resources, constraints, values, and goals that determined whether or how they implemented EI. Though parents appreciated the work of the therapists and services, there seemed to be significant costs associated with implementing EI. One major finding was that families have to deal with and negotiate their social and cultural environments when attempting to access or implement EI services.

5.1 Narrative threads

Narrative analysis brought out the main narrative themes or narrative threads that were common across all the family stories. These narrative threads represent parents' meanings and motives regarding accessing and implementing EI services as well as how these meanings and motives relate to the routine and the disabled child. Each narrative theme is discussed in relation to existing literature and research.

5.1.1 The meanings of success

Parents negotiated the meanings of success for themselves as well as for their children. These meanings of success underlay how they developed a routine, how they perceived their experiences with EI, and their motives in pursuing EI. Few studies have articulated whether or how parents of a child with disability negotiate the meanings of success. An example of research on parent perceptions of achieving success as parents is a qualitative study by Hinds et al. (2009). In this study, parents of children with cancer were asked to define their idea of "a good parent" (Hinds et al., 2009). Some definitions that emerged were: a parent who makes sure the child is healthy, a parent who sets a good example for their child, and a parent who makes unselfish decisions. According to Masten and Coatsworth (1998), parents may derive their definitions of success for their child based on popular notions of the culture and society in which they live (Masten & Coatsworth, 1998). Specifically, Masten and Coatsworth (1998) said:

> How do we know that a child is doing well? Evaluations of how a child is doing in life generally reflect expectations based on pooled knowledge about child development that are culturally transmitted from one generation to the next. The expectations and concerns of parents, teachers, and others important to the lives of children will reflect these expectations, as will popular culture (e.g., the milestones noted in baby books) (p.2).

5.1.2 Who is my child?

Parents were trying to understand who their child was in relation to the disability, that is, whether or not disability was separate from their child's personality traits or character. Parents' recognition of their children's characteristics and personality traits is similar to findings in studies by Kearney and Griffin (2001), Resch et al. (2010), and Shearn and Todd (2000), where parents speak of the positive impact of their disabled child's personal attributes. However, the finding that parents try to understand their child in relation to the disability seems to be somewhat unique as does the possibility that their understanding may have some bearing on their choice of EI goals and activities.

5.1.3 Never Still

The finding that families are proactive and are always on the move resonates with ecocultural theory's premise that families make intentional and proactive adjustments to the ecological and cultural forces that surround their families (Gallimore et al., 1989; Weisner et al., 2005). The families in this study were constantly in the state of "doing," in particular as it related to making decisions about EI.

5.1.4 The source of motivation

Sources of motivation could be intrinsic, such as personal values and beliefs, or external sources, such as societal and cultural expectations and norms. The source of motivation could partly explain how parents make decisions as to whether and how they pursue EI. Ecocultural principles support that the creation of family routines is influenced by the proximal and distal ecologies that surround a family, including the social and cultural norms of the society in which they live. Likewise, a routine is created that is meaningful to the family in terms of their values, goals, and beliefs (Gallimore et al., 1989; Weisner et al., 2005). The narratives of the families were underpinned by what drove their decisions, perceptions, and understanding of their life situations. Sources of extrinsic motivation such as societal and cultural expectations and norms, as well as sources of intrinsic motivation like personal values and beliefs, are discussed in section 5.4.

5.2 What are parents dealing with on a day-to-day basis?

5.2.1 Societal expectations and perceptions

It is not a new finding that parents of young children have various roles and work-care responsibilities to juggle and are hard-pressed for time (Duxbury & Higgins, 2001; Freedman et al., 1995; MacBride-King & Bachmann; 1999; Shearn &Todd, 1997; Thompson, 1998). The analysis also revealed that parents dealt with societal and cultural demands and constraints related to EI and disability, specifically, societal expectations or perceptions and issues related to their child's health care and school systems.

Some parents reported feeling as though they were treated differently in society because of the awkward questions and stares they received from strangers, or because they felt as though they faced judgments about their child's disability and/or odd behaviours. An unknown diagnosis or the lack of a supportive community for some of these parents added to the feeling of being isolated or being an outsider. These findings are comparable to findings documented in a study by Shearn and Todd (2000), in which mothers reported that they felt as though they had come to acquire a special identity which located them on the margins of society. The experience of social isolation has also been documented by Kearney and Griffin (2001), who reported that parents experienced feelings of isolation and rejection as a result of their dealings with society's messages of negativity and hopelessness about their child's disability.

The experience of being an outsider was also true for the parents of a disabled child who were relatively new immigrants. These parents had to deal with the challenges of dealing with complex health care and school systems, and society at large, as well as, the challenges of adjusting to a new environment and culture. One of the two immigrant parents in this study felt that she was sometimes at a disadvantage in the health care system because of her ethnicity. She also expressed that she felt like an outsider despite having moved to the country more than 10 years before. The other immigrant parent did not feel any discrimination in the society or health care system. However, both participants described the difficulties of adjusting to a new culture. Fazil, Bywaters, Ali, Wallace, and Singh (2002) conducted a study with Pakistani and Bangladeshi families in the UK and reported that these immigrant families had significant difficulties in accessing services and experienced institutionalized discrimination on some level.

Some parents felt that they somehow did not fit the societal expectation of being a “good parent” because they were unable to handle their child’s peculiar behaviours, especially in public. In addition they often felt that they could not handle all the responsibilities of childcare in the manner that they thought was ideal. This expectation of being a “good mother” is also described by Shearn and Todd (2000), albeit in the context of maternal employment. The mothers in Shearn and Todd’s study (2000) talked about providing the best care for their child by forgoing employment to put their child’s needs ahead of their own and thus fit society’s idealized notion of a “good mother.”

5.2.2 Dealing with health care and school systems

Some of the tasks on which parents spent substantial amounts of time were: seeking and fighting for services, coordinating services, researching information, and advocating for their children. Parents talked of spending hours on the phone, or face-to-face with service providers and social workers, demanding services that they felt their child was entitled to. The process of fighting for services by parents is not new and has been described by authors Darrah et al. (2002), Woodgate et al. (2008), and Traustadottir (1991). Parents in this study reported that the onus was on them to find and access services for their children. Similarly, parents in a study by Ray (2002) reported that they spent an extraordinary amount of time searching for information, people, and services, mostly in a trial-and-error fashion or by word of mouth. Accessing services required many phone inquiries and meetings. This finding is also supported by the speculation, by authors Mackean et al. (2005) and Breen (2011), that the system has completely shifted the responsibility of coordinating and accessing services over to parents in the name of parent autonomy.

Parents described feeling lost, confused, and overwhelmed over what steps to take in order to obtain appropriate services for their children. The difficulties that parents experienced is akin to what parents experienced with regular home programs as reported by Novak (2011). Parents in Novak’s study advised professionals not to “leave them hanging” or without support after the goals had been set. They also felt that there was a need for professionals to coordinate services among themselves and work together. Likewise, parents in the present study also felt that their own personal time and energy could be put to better use rather than seeking and obtaining services. They felt that this was the responsibility of the services.

Parents, especially those who were working, seemed to spend substantial amounts of time trying to find appropriate formal child care for their children with special needs. The main challenges were high costs of childcare, accessibility, and finding childcare that would accept their child with a disability. The difficulty in finding childcare for parents of children with disabilities was also reported by Booth-La Force and Kelly (2004). These authors found that regardless of the age of the child with a disability, finding quality childcare was the most problematic issue for the parents. The cost of childcare, distance to childcare, and transportation issues were the next most frequent problems that parents experienced, particularly when the child was about 15 months of age.

5.3 How do parents juggle these responsibilities?

5.3.1 Accommodations in career

The first objective of this study was to understand the accommodations that families made to balance the various demands of everyday living, including EI. Parents described accommodations in terms of adjustments, trade-offs, and innovative strategies, mainly in the areas of their career, home, families, personal well-being, and in their child’s health-care and school systems. Parents, particularly mothers, made adjustments in their career, either by changing their work schedules, moving from full-time to part-time schedules, switching careers, or simply deciding to give up work altogether in order to manage many responsibilities. This finding is consistent with similar findings in studies by Freedman et al. (1995) and Shearn and Todd (2000).

Bernheimer and Weisner (2007) also documented moderate to high accommodation intensity in the subsistence domain for almost 40% of the participant families. The present study shows that EI affected parents’ career-related decisions. It seemed as though various facets of EI, such as centre-based therapy, consultations and appointments, home therapy with the aide, and transportation to and from appointments, took time out of what is considered a regular work day. As a result, families ended up compromising on their careers to accommodate EI, which in turn seemed to have repercussions on their income. Giving up a career or job was especially hard for those who were in the lower income bracket. One participant who was a single mother talked about not working at all because it was impossible to find work that was flexible enough to allow her to attend the numerous medical and therapy appointments for her son. Similarly, mothers in the study by Shearn and Todd (2000) reported that the demands of caring for their children with intellectual disabilities limited their scope for employment, as they could only take up a job that had a flexible time structure which would allow them to prioritize their child's care demands. Mothers found that the nature of their schedule was largely inconsistent with the temporal discipline of general employment practices.

Some mothers in this study valued work greatly but chose to stay at home not only to supervise interventions but also because of the lack of formal or informal child care. This is consistent with findings by Shearn and Todd (2000) that though mothers valued employment, pursuing work ultimately brought little or no financial gain to their families because of the cost of child care.

5.3.2 Accommodations at home

The finding that parents adjusted household tasks to make time for EI services is supported by similar findings by Thompson (1998). Mother carers in Thompson’s study adjusted personal and family routines in order to seek, obtain, and regularly monitor EI services for their children. Accommodations in household tasks or domestic workload, in response to a child’s needs, were also reported by Bernheimer and Weisner (2007). The parents in the present study described in detail how they pushed back routine tasks like laundry, cooking, or cleaning to the end of the day or sometimes decided to put off these tasks altogether to make time for appointments or home therapy with their child’s aide. This adjustment of routine tasks is similar to the “temporal unfolding” used by mothers of children with ADHD, described in a study by Segal (2000). These mothers put off routine or personal tasks till a later time in order to make time for their child. Mothers in Segal’s study reported using this strategy to encourage their child’s emerging self care skills. However, in the present study, parents reported pushing back routines in relation to EI-related tasks and activities.

Time-saving strategies that parents used, such as multitasking and what they described as “finding windows of time” , are similar to Segal’s (2000) descriptions of “enfolding occupations.” Parents also reported splitting chores with spouses as well as assigning certain tasks to their other children in order to save on time and perform other tasks that were higher on their priority lists. This strategy has been recorded but labelled differently by different scholars. According to the ecocultural approach, the division of tasks between spouses and the assignment of tasks to other children fall under the accommodation domains of “Marital Roles” and “Childcare Tasks”, respectively (Bernheimer & Keogh., 1995; Gallimore et al., 1993). Segal used the term “unfolding by inclusion” (2000) to describe the act of delegating tasks to other individuals in order to make time for different priorities. The parents in this study were proactive in making time in their routine to include EI if they thought it to be a priority.

In addition to making numerous adjustments in household tasks parents reported that they often felt frustrated at not being able to fulfill routine household tasks. They expressed that they struggled to find time to balance various responsibilities. Research has long documented similar reports by parents, from earlier studies by Hinojosa and Anderson (1991) to more recent studies such as that by Wiart et al. (2010): parents explained that they could not “do it all,” that is, manage to balance all the responsibilities in their daily routine including fulfilling therapy goals.

5.3.3 Accommodations in family and personal wellbeing

In terms of personal wellbeing, parents, mothers in particular, often reported sacrificing sleep and health in order to make time to fulfill routine tasks as well as EI. This mirrors findings from the study by Shearn and Todd (2000). Mothers in Shearn and Todd’s study (2000) found that there was a shortage of time to fulfill tasks or that the routine (including EI) schedule was incompatible with their own personal schedules. As a result mothers generally felt that they should sacrifice their own needs and desires to those of their families.

The long standing assumption that a child’s disability has negative effects on the marital relationship has been widely documented in past decades and strongly challenged in recent years by scholars and parents alike (Risdal & Singer, 2004). Marital strain in parents of children with disability has been cited by Resch et al. (2010) and Trudgeon and Carr (2007). One of the findings of this study was that parents made time for care-giving responsibilities, such as their child's therapy, at the expense of time spent with their spouses and children. This finding is in agreement with the findings of the UK-based study by Trudgeon and Carr (2007). The parents in Trudgeon and Carr's study (2007) explained that some of the costs associated with implementing an EIBI program were the health of their marital relationships and the time they spent with the siblings of their child with disability. Although parents in the current study did not mention that EI directly affected their family relationships, they alluded to it by explaining that they were too tired for family time or time with their partner at the end of a day full of work and care-giving responsibilities. Care-giving responsibilities generally included appointments and therapy for their child.

Some parents also felt that their other children were sometimes "traded-off" as a result of the special focus on their child with special needs. Trudgeon and Carr (2007) found that parents involved in a rigorous intervention program often do not have enough time to spend with the siblings of their child with disability. Parents in the present study did not necessarily feel like they spent less time with their other children. They did feel, however, that the focus of attention was their child with disabilities. For example, activities, although not always EI related, were more focused on the developmental needs of their child with disability. Siblings' preferences for an activity tended to be given less importance if it did not benefit or involve the child with disability. Parents in this study often felt guilty about the decreased focus on their typically developing children.

5.3.4 Health system and therapy-related accommodations and strategies

The finding that parents in this study spent substantial amounts of time coordinating and fighting for services for their children was discussed earlier in this chapter. An interesting finding was that parents described strategies to manage perceptions of professionals in order to obtain funding for the services their child required. Ray (2002) documented how parents of a child with disability "worked the system," or tested different investigative, management, advocacy, negotiation, and lobbying skills when faced with limitations and the lack of coordination of the health and social service systems. Ray calls some parent strategies, for coordinating services, ingenious. For example, one mother invited all her son's therapists to a luncheon at her home in order to have them meet each other. Parents in Ray's study (2002) developed extensive and sophisticated management and advocacy skills to make sure that their children were getting the services they required.

In terms of therapy-related accommodations, parents described using everyday activities to fulfill therapy goals. This finding is similar to the findings by Schaaf, Toth-Cohen, Johnson, Outten, and Benevides (2011) that parents of children with autism used strategies in their typical routine to teach their child, to provide a variety of learning experiences, and to increase family participation. Kellegrew also documented the use of daily routines by mothers to encourage their children's self-care occupations (Kellegrew, 1998; Kellegrew, 2000). Mothers in Kellegrew's study (1998) made small adjustments in the home routines that shaped the types of opportunities for skill development offered to their children. The finding that parents adopted the mindset that "everything is therapy" in order to fit EI into their routine can be likened to findings by Thompson (1998). Thompson (1998) reported that mothers in her study made the statement "We make it [therapy] fit," to explain that they managed to implement therapy into their routines despite the difficulties they experienced in trying to manage the demands and responsibilities of everyday. The strategies that mothers in Thompson's study used to make therapy "fit" were not further explored, however. Families in the present study used every opportunity that presented itself, whether at home or on an outing, to fulfill a therapy goal. Parents tried to make a deliberate effort to keep therapy foremost on their minds at all times.

5.3.5 Using social support

Most parents in this study sought various avenues of social support from friends, family, and the community to help aid them in managing their daily routines, which included EI-related responsibilities. Boyd (2002) and Resch et al. (2010) have reported that parents seek social support to cope with stress caused by raising children with disabilities. The use of social support as an accommodation has been documented by proponents of ecocultural theory (Bernheimer & Weisner, 2007; Gallimore et al., 1989) and supports the finding in this study that parents are proactive in finding support through community, friends, and family to help them manage daily responsibilities including implementation of EI. Parents reported that they tried to find and connect with people of their own communities or people who were like-minded to help them with childcare and/or transport or simply to relax with and socialize.

5.3.6 Positive attitudes and beliefs

The finding in this study that parents adhered to positive attitudes about their children is consistent with findings in studies by Kearney and Griffin (2001) and Resch et al. (2010). Kearney and Griffin (2001) found that despite the difficulties parents face, and negative attitudes that society has toward families of children with disabilities, parents maintained hope and a belief in their child. Parents in that study spoke of their children with love, optimism, and pride, and also talked about being inspired by their children. Parents in the present study developed new meanings of success from their experiences with their child and chose to use daily situations, challenging or otherwise, as “teachable moments” or life lessons. Kearney and Griffin (2001) also write that the parents in their study constructed meanings and developed new perspectives from their experiences and challenges. The finding that parents derived hope and strength from their spiritual convictions or life philosophies is supported by very similar findings reported by Poston and Turnbull (2004) in their qualitative study on the role of spirituality and religion in quality of family life in families of children with disabilities. Participants in Poston and Turnbull’s study (2004) found that their spiritual beliefs helped improve and contributed to the overall quality of family life. Having faith helped parents make sense of their child’s disability. For some parents, their faith helped them view their child as a blessing from God, while others viewed their child’s disability as a test of their faith. Overall, Poston and Turnbull, (2004) found that spiritual beliefs and participation in religious communities helped families achieve a sense of purpose in their lives and a sense of strength. In the context of balancing responsibilities and maintaining a daily routine, families in this study adopted positive attitudes, spiritual beliefs, and life philosophies as strategies to manage their roles and responsibilities on a day-to-day basis.

5.4 What influences EI implementation?

The second objective of this study was to understand the values, goals, beliefs, resources, and constraints that influenced parents’ implementation of EI.

5.4.1 Values, goals, beliefs

Parents used certain phrases or mottos that represented their beliefs. They also spoke of their goals and values. One finding in this study was that these beliefs, goals, and values influenced parent decisions about EI implementation. Parents accessed and implemented EI within the routine not only according to how they prioritized routine tasks but also according to whether EI-related tasks were in agreement with their values, goals, and beliefs. This finding is supported by the ecocultural principle that the creation of a routine is partly based on a family's values and goals (Weisner et al., 2005). Kellegrew (2000) also found that mothers built their daily routine based upon their goals and their perceptions of future expectations for their children.

One of the beliefs that parents held was that they were the experts on their child. The finding related to this belief was two-fold. Firstly, parents seemed more motivated and inclined to participate and be involved in their child's therapy when they perceived that their opinions were valued. A similar finding was reported by Ingber and Dromi (2010) in their study regarding the actual-versus-desired family-centred-practice experience of mothers of children with hearing loss. Mothers in that study felt strongly motivated to participate in their child's therapy programs when practitioners took time to listen to their opinions and collaborate with them.

The second part of the finding related to parent expertise in this study, was that parents made EI-related decisions by negotiating between the belief in their own expertise and that of the therapists. This particular finding is unique and not mentioned elsewhere; however, Thompson (1998) reports that some mothers in her study felt that the therapist was the expert and left therapy-related decisions to them, whereas other mothers preferred to be very involved in the therapy sessions. MacKean et al. (2005) also report that families in their study highly valued professional expertise and opinions. Most of the parents in the present study believed and acknowledged that therapists and other medical professionals had the best medical expertise. Even so, parents held strongly that they (the parent) ultimately had the best knowledge about their children's needs. Many parents in the present study also felt that their expertise was sometimes overridden by professional expertise. Lea (2006) documented similar reports of adolescent mothers of children with disability who were part of EI programs. These mothers reported that their opinions were sometimes not valued and hence they did not feel respected, mainly because of they were looked upon as young and inexperienced as mothers. The belief that the parent is the expert is part of the philosophy of the current family-centred practice (Breen, 2011; Hanna & Rodger, 2002). Scholars also believe that parent expertise can contribute to community health solutions and advocacy for children with disabilities. They have found, however, that individual expertise is often not recognized unless it is backed by a larger organization or support group (Law, King, Stewart & King, 2001).

The second finding related to values, beliefs and goals was that parents were more likely to implement an intervention based on whether they perceived it to be effective for their child. This finding is supported by similar findings documented by many scholars, including Hinojosa and Anderson (1991); Novak, Cusik, and Lannin (2009); Schreiber et al. (1995); and Segal and Beyer (2006). Generally, parents seemed more motivated to pursue an intervention despite all odds when they were able to see progress in their children's development and believed that their children were achieving therapeutic goals.

Some parents did not implement therapist recommendations as frequently as prescribed or chose not to make a particular recommendation a priority because they felt that their own goals or priorities were different. This is similar to findings by Cohn et al. (2000), Thompson (1998), and Wiart et al. (2010). The findings of the study by Cohn et al. (2000) showed that whereas therapists chose to focus on sensory skills for children with autism, parents described success for their children in terms of daily occupations and social participation rather than sensory skills per se. Wiart et al. (2010) found that therapy goals set by practitioners in a child's school setting did not necessarily match family priorities. Wiart et al. (2010), also reported that parents in their study seemed to experience a disconnect between their preferences and values and the intervention approach of their child's therapist.

The finding that societal and cultural perceptions or values influenced the implementation of early intervention by parents agrees with the findings of Kearney and Griffin (2001) and the writings of Landsman (2005). Kearney and Griffin (2001) found that the sorrow that parents experienced with regards to their child's disability was derived from external sources, that is, societal perceptions of disability. Kearney and Griffin (2001) described parents being inundated by negative messages of hopelessness from society, of which professionals are a part. Landsman (2005) found that mothers sought to improve their children's opportunities in mainstream society by using the tools necessary to "fix" their children. According to Landsman, a mother who may not necessarily possess that belief intrinsically may still give in to societal perceptions and norms simply to move her child out of the category of "disabled," a category that the society or culture places on the child. The mother does this to ensure that her child is not denied an opportunity to reach his or her full potential. Likewise, some parents in the present study said that they chose to make "everything therapy" because they believed that “everything is therapy” and that this was necessary for their children. Some parents explained that this idea had been “engrained” into their thinking. Seligman and Darling (2007) write that despite the advances in the social model of disability, which looks at disability as a result of social barriers, many parents of children with disabilities adhere to the medical model of disability and focus on treatments and interventions to improve their children’s ability to function in society. On the other hand, Seligman and Darling (2007) write that, while numerous earlier studies describe steps that parents take to find services to make their children “normal,” parents report that they often seek services with the intention of being a good parent and improving the quality of life for their child rather than trying to “cure” them. This suggests that the intrinsic motive for parents to access therapy is to give their children a better quality of life, while the need to “normalize” their children may be derived from extrinsic sources such as society or culture.

5.4.2 Resources and Constraints

The final set of findings presented in this study had to do with resources and constraints that determined EI implementation by parents. The constraints that parents reported were: complexity of the intervention regime and its adaptability to the routine, lack of time and energy, and difficulties accessing services.

Families did not implement a therapist recommendation if they felt that it was too difficult or too frequent. The fact that the complexity, intensity, and prescribed frequency of an exercise regime can play a role in whether a parent implements therapist recommendations has been documented by authors Hinojosa (1990), Hinojosa and Anderson (1991), and Segal and Beyer (2006). Another factor that acted as either a resource or constraint with many of the parents in this study was the adaptability of the therapy program to a family’s routine. Some parents chose therapy goals that could be implemented on the go with their children. Some parents made changes in the therapeutic activity to suit their routine or children’s likes but tried to adhere to the original goal. This finding is in agreement with the findings of Hinojosa and Anderson’s study (1991) that mothers selected interventions that were “doable” in their routine and in the context of other home activities.

The lack of time and energy was a constraint for families, especially when both parents were working; they would be too fatigued at the end of a day to carry out therapy, even if the therapy program itself was not too rigorous or complex. Gajdosik and

Campbell (1991), Tetreault et al. (2003), and Thompson (1998), among others, report similar findings where the many responsibilities of everyday may leave no time for families to pursue therapy.

Another constraint that parents faced was the difficulty of maneuvering through their children’s health and education systems in order to access necessary services. Parents found this complex and time-consuming. Many parents also felt that this task should not be their responsibility but that of the service providers. This finding is related to the finding, reported in an earlier section, that parents assumed the responsibility of strategically navigating their children’s health care and educational systems in order to find and implement services for their children in the daily routine. Parents sometimes felt that it would be better either not to pursue services or wait until later to do so. These findings are consistent with findings by Brotherson and Goldstein (1992), who found that the lack of coordination between services and the complexities of the health system were a constraint on the time of parents with a young child with disability. Resch et al. (2010) also documented that a principal stressor for parents was related to accessing services and information. Parents found it hard to navigate through a complex human service system involving health care providers. Likewise, the parents in the study by MacKean et al. (2005) found it to be a daunting task to have to fight for access to services and advocate for their children.

Previous research has documented that parents are more motivated toward an intervention program when they perceive their therapists to be supportive of family goals and routines and show genuine interest in family needs. Parents highly value therapists with these characteristics (Novak, 2009; MacKean et al., 2005; Thompson, 1998). Likewise, parents in this study who had a supportive aide or therapist were also more interested in following through with therapist recommendations despite the challenges that they faced in the system. Parents felt that the therapist who showed genuine interest in the family and who seemed to care for their children also helped the family navigate through the complex health care and school systems. The support of these professionals was a resource for the parents. Parents in this study greatly appreciated not only the knowledge that a supportive therapist brought to the therapist-parent relationship, but also the respect and attention they gave to parents’ opinions. This is consistent with the findings by MacKean et al. (2005) that parents valued caring, compassionate, and knowledgeable therapists who respected parents and strove to work collaboratively with these parents to develop a plan that would best meet the needs of the child and his family.

Another resource that families used was the social support they got from family, friends, and the community. Although most of the time this support was not directly related to the implementation of therapy, it contributed by giving respite and thus making time for parents to transport their child to and from therapy while family members or friends looked after their other children. Resch et al. (2010) found that a lack of family supports often left parents feeling frustrated.

Parents also found formal respite services to be of great value. They also found training and parent resources to be helpful in teaching them strategies to manage their concerns about their child in their daily routine. Some parents felt that the respite they received was not enough or that parent resources were hard to access because of distance or lack of transport. This finding is also consistent with findings by Doig et al. (2009) and Resch et al. (2010). Parents in the study by Doig et al. (2009) found accessing and obtaining respite services to be a frustrating and time-consuming task because of the numerous requirements that parents had to meet to qualify for the services. Resch et al. (2010) also found that parents viewed counselling and respite services as a form of support and that they valued these services but found them hard to access because of their limited availability.

5.5 Scope and limitations

The scope of this study allowed me to explore the experiences of parents of children with developmental disability who were 6 years of age or younger and who were accessing EI services within the Alberta health care and educational systems. I was also able to identify and explore in depth a range of issues related to family accommodations, innovative strategies and tradeoffs as well as some of the factors that influenced parents' decisions to implement EI strategies.

One of the main limitations within the scope of the aims of my research was that the participants were purposively sampled and recruited from primarily urban and suburban areas thus ruling out the experience of families in rural settings. Also, the perspectives of first nation families were not taken into account. Another limitation was that there was a lack of diversity in the study sample in terms of the time of the child's diagnosis: All the participants had already been accessing the EI systems for a year or more at the time of the interviews.

The extent to which families made accommodations strategies and tradeoffs as well as the percentage of families who employed each strategy was not investigated. In the same manner, how much each factor influenced families to make EI related decisions was not measured. However, it was outside the scope and aims of the study to investigate these items.

5.6 Implications for policy and practice and suggestions for future research

In this section, I discuss briefly the implications of this study for practice and policy and make a few recommendations for each implication. The families in this study received their services within a complex system that included government agencies and school and health care systems. Parents addressed many issues they faced before and after they were connected to this system. The key issues that were identified from the findings of this study have the following implications for practice and policy.

1. Finding ways to decrease time and energy demands on families.
2. Considering parent expertise.
3. Increasing the span of resources: support, respite, information.
4. Being aware of how services are presented while keeping in mind that parents constantly negotiate their social, cultural and material surroundings and their values, beliefs and goals.

5.6.1 Decreasing time and energy demands

Key issues at the time of diagnosis and before families are connected with the services

- Parents receive limited information from health practitioners about available services
- Parents conduct extensive searches through media like the internet and the newspaper for information about options for services

What can be done:

- Having a third party such as an agency or service that works exclusively to assist parents in accessing the service system. For example a worker or representative of the agency will; meet with parents and explain service options that are best suited to the family; connect them with the most appropriate service by helping them fill out necessary paper work and make necessary phone calls.

Key issues after families are connected with services

- Families are responsible to coordinate between themselves, the funding agencies , the service providers and the school system
- Parents spend a lot of time: on the phone with funding agencies convincing them that they need funding for specialized services and supplies; writing letters/ fighting with school boards to keep child in a school that they think is appropriate.
- Parents make a number of tradeoffs and accommodations to make time for therapy related tasks and home programs

What can be done:

- Just as suggested earlier, a third person, who is well informed of the family's needs and child's diagnosis, can be introduced to coordinate the services, agencies and school system: They would make the needed phone calls, fill out paper work, inform families about policy changes or what should be done when needs of the family change, for example during transition periods.
- Another solution to the lack of coordination between services would be to integrate all the systems (funding agency, health care, and school systems) that the family is involved in. This kind of single delivery system could potentially save time and energy for families as there needs to be only one detailed and holistic assessment of family needs rather than separate assessments by each agency, a single intake process, and there will be no overlap of goals and interventions between services. Families could also avoid having to take on the responsibility of coordinating services.
- An assessment tool like the ecocultural family interview (Weisner, 2002) or an adaptation of the same can be adopted by practitioners and funding agencies alike in order to be able to accurately gauge the needs of families. This would avoid the need for families to fight for services or struggle to acquire needed funding.

- Likewise, assessing the routine using a tool like the ecocultural family interview can also open up the possibilities of “embedding” interventions. For example, practitioners can analyse the following to evaluate if components of the intended intervention goals are already part of a family’s routine: daily routine tasks (e.g., meal time, bed time, transport, self-care routines), school or extracurricular activities that the child is already involved in, and parent and child leisure activities or hobbies. An analysis of routines can also reveal the innovative strategies that parents already use. Dunst and colleagues (2006) have found that the use of everyday activity settings as sources of learning opportunities for children yields more positive outcomes in different domains of functioning. In contrast, when an intervention strategy is implemented within an activity setting there is a higher probability for negative or no effect on parent wellbeing, competence, and progress in child behaviour. Using what is already part of a regular routine as a therapy goal puts parents a place of expertise, makes use of their existing skill sets, and possibly avoids additional demands from EI in an already busy family routine.

5.6.2 Considering parent expertise

Key issue:

- In keeping with FCP, practitioners may ask parents about their goals and priorities. However, parents in this study still talked about a mismatch in priorities.

What can be done:

- Parent expertise must be respected and considered when developing a successful intervention program. Some questions that a practitioner needs to consider are: Does a recommendation encourage parent skills and expertise? Are parent strategies considered? Is there anything they might like to do differently? Has the parent been asked what they think of the recommendation and how practical it is for them?

5.6.3 Increasing resources

Key issues

- Families feel as though they do not have enough respite

- Inadequate contact and support from family support services

What can be done:

- Once connections are established, the funding agency and service providers must provide constant support by maintaining ongoing contact with parents to assess whether there are any difficulties with service provision. Funding agencies need to inform parents about policy changes. They must assist parents through transitions between service providers and funding periods by once again providing the necessary information and assessing routines.
- Also family support services need to consider an increase in respite funding to parents.

5.6.4 Awareness of how services are presented:

Key issue:

- Parents of children with disabilities often feel overwhelmed by the demands of their everyday routine, including EI.

What can be done:

- Apart from managing the practical tasks of the everyday routine, parents who accommodate EI spend a lot of time and energy thinking about and negotiating the demands of their society, culture, and the meanings they associate with these demands. Parents in this study revealed that interventions are "engrained" into their thinking as something they have to do, even if it isn't necessarily their top priority. Practitioners should therefore consider how recommendations are presented: Are the suggestions of value to parents? Are they compatible with what parents think is culturally acceptable? Are they presented in manner that puts parents at ease or are parents likely to perceive the recommendations as a burden?

5.7 Conclusion

From the findings of this study, one can conclude, first, that there is a disconnect between the health system's intention (to provide care that is family-centred) and families' actual experiences (that intervention entails significant costs). Second, the finding that the demands of care-giving, including the implementation of EI, can entail significant costs for families reinforces the notion that the care demands of disability (including EI implementation) rather than the disability per se, may be a burden on parents and families. Third, the family of a child with disability, like every other family, has the central adaptive challenge of creating and sustaining a meaningful routine. The difficulty these families face, which differs from that of a family with a typically developing child, is to balance the additional demands of EI in a daily routine. Finally, family stories are important. Families are, without a doubt, interested in the outcomes of their children, just as are the professionals who work with them. However, implementing EI is part of a complex process of juggling demands for these families. Through their stories, families are telling us that this process is as important as the final outcome. This knowledge of the real-world experience of families of young children with disabilities can effect a positive change in the way interventions are developed.

REFERENCES

Allan, C., O'Donnell, M., & Peetz, D. (1999). More tasks, less secure, working harder: Three dimensions of labour utilisation. *The Journal of Industrial Relations, 41*(4), 519-535.

Bazyk, S. (1989). Changes in attitudes and beliefs regarding parent participation and home programs: An update. *The American Journal of Occupational Therapy, 43*(11), 723-728.

Becker, M. H., & Maiman, L. A. (1975). Sociobehavioural determinants of compliance with health and medical care recommendations. *Medical Care, 13*(1), 10-24.

Bernard, A. W., Malone, M., Kman, N. E., Caterino, J. M., & Khandelwal, S. (2011). Medical student professionalism narratives: A thematic analysis and interdisciplinary comparative investigation. *Emergency Medicine, 11*, 1-8.

Bernheimer, L., & Keogh, B. K. (1995). Weaving interventions into the fabric of everyday life: An approach to family assessment. *Topics in Early Childhood Special Education, 15*(4), 415-19p.

Bernheimer, L. P., & Keogh, B. K. (1995). Weaving interventions into the fabric of everyday life: An approach to family assessment. *Topics in Early Childhood Special Education, 15*(4), 415-433.

Bernheimer, L. P., & Weisner, T. S. (2007). "Let me just tell you what I do all day..." the family story at the center of intervention research and practice. *Infants & Young Children, 20*(3), 192-201.

Bleakley, A. (2005). Stories as data, data as stories: Making sense of narrative inquiry in clinical education. *Medical Education, 39*, 534-540.

Booth-LaForce, C., Kelly, J.F. (2004). Childcare patterns and issues for families of preschool children with disabilities. *Infants & Young Children*, *17*(1), 5-16.

Boyd, B. A. (2002). Examining the relationship between stress and lack of social support in mothers of children with autism. *Focus on Autism and Other Developmental Disabilities, 17*(4), 208-215.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101.

Breen, L. J. (2011). Early childhood service delivery for families living with disability: Disabling families through problematic implicit ideology. *Early Childhood Australia,*

Brotherson, M. J., & Goldstein, B. L. (1992). Time as a resource and constraint for parents of young children with disabilities: Implications for early intervention services. *Topics in Early Childhood Special Education*, *12*(4), 508-527.

Brown, G. (2004). Family-centered care, mothers occupations of caregiving and home therapy. In M. Biblis, P. Waltner & J. H. Martin (Eds.), *Mothering Occupations: Challenge, agency, and participation* (pp. 346-370). United States of America: F. A. Davis Company.

Bruner, J. (1991). The narrative construction of reality. *Critical Inquiry, 18*, 1-21.

Campbell, I., & Charlesworth, S. (2004). *Key work and family trends in Australia*

Clandinin, D. J. (2006). Narrative inquiry: A methodology for studying lived experience. *Research in Music Education, 27*, 44-53.

Clandinin, D. J., & Connelly, F. M. (2000). *Narrative inquiry, experience and story in qualitative research*. San Francisco: John Wiley and Sons, Inc.

Cohn, E., Miller, L. J., & TickleDegen, L. (2000). Parental hopes for therapy outcomes: Children with sensory modulation disorders. *The American Journal of Occupational Therapy, 54*(1), 36-43.

Coyne, I. T. (1997). Sampling in qualitative research. Purposeful and theoretical sampling; merging or clear boundaries? *Journal of Advanced Nursing, 26*, 623-630.

Crowe, T. K. (1993). Time use of mothers with young children: The impact of a child's disability. *Developmental Medicine and Child Neurology, 35*, 621-630.

Crowe, T. K., & Florez, S. I. (2006). Time use of mothers with school-age children: A continuing impact of a child's disability. *American Journal of Occupational Therapy, 60*(2), 194-203.

Darrah, J., Magill-Evans, J., & Adkins, R. (2002). How well are we doing? Families of adolescents or young adults with cerebral palsy share their perceptions of service delivery. *Disability and Rehabilitation, 24*(10), 542-549.

DeGrace, B. W. (2004). The everyday occupation of families with children with autism. *The American Journal of Occupational Therapy, 58*(5), 543-550.

Doig, J. L., McLennan, J. D., & Urichuk, L. (2009). 'Jumping through hoops': Parents' experiences with seeking respite care for children with special needs. *Child: Care, Health and Development, 35*(2), 234-242.

Dunst, C. J. (1997). Conceptual and empirical foundations of family centred practice. In R. J. Ilback, C. T. Cobb & H. M. Joseph Jr. (Eds.), *Integrated services for children and families: Opportunities for psychological practice.* (pp. 75-91)

Dunst, C. J., Bruder, M. B., Trivette, C. M., & Hamby, D. W. (2006 a). Everyday activity settings, natural learning environments, and early intervention practices. *Journal of Policy and Practice in Intellectual Disabilities, 3*(1), 3-10.

Duxbury, L., & Higgins, C. (2001). *Work-life balance in the millenneum: Where are we? Where do we need to go?* No. 7314. Canadian Policy Research Networks.

Fazil, Q., Bywaters, Z. A., Wallace, L., & Singh, G. (2002). Disadvantage and discrimination compounded: The experience of Pakistani and Bangladeshi parents of disabled children in the UK. *Disability & Society, 17*(3), 237-253.

Floersch, J., Longhofer, J. L., Kranke, D., & Townsend, l. (2010). Integrating thematic, grounded theory and narrative analysis: A case study of adolescent psychotropic treatment. *Qualitative Social Work, 9*(3), 407-425.

Fossey, E., Harvey, C., McDermott, F., & Davidson, L. (2002). Understanding and evaluating qualitative research. *Australian and New Zealand Journal of Psychiatry, 36*, 717-732.

Freedman, R. I., Litchfield, L. C., & Warfield, M. E. (1995). Balancing work and family: Perspectives of parents of children with developmental disabilities. *Families in Society: The Journal of Contemporary Human Services,* , 507-514.

Gajdosik, C. G., & Campbell, S. K. (1991). Effects of weekly review, socioeconomic status and maternal belief on mothers' compliance with their disabled children's home exercise program. *Physical and Occupational Therapy in Pediatrics, 11*(2), 47-65.

Gallimore, R., Weisner, T. S., Bernheimer, L. P., Guthrie, D., & Nihira, K. (1993). Family responses to young children with developmental delays: Accommodation activity in ecological and cultural context. *American Journal of Mental Retardation, 98*, 185-206.

Gallimore, R., Weisner, T. S., Kaufman, S. Z., & Bernheimer, L. P. (1989). The social construction of ecocultural niches: Family accommodation of developmentally delayed children. *American Journal on Mental Retardation, 94*(3), 216-230.

Gannoni, A. F., & Shute, R. H. (2009). Parental and child perspectives on adaptation to childhood chronic illness: A qualitative study. *Clinical Child Psychology and Psychiatry*, *15*(1), 39-53.

Green, S. E. (2007). "We're tired, not sad":Benefits and burdens of mothering a child with a disability. *Social Science & Medicine*, *64*, 150-163.

Guralnick, M. J. (2005). Early intervention for children with intellectual disabilities: Current knowledge and future prospects. *Journal of Applied Research in Intellectual Disabilities, 18*, 313-324.

Guralnick, M. J. (1998). Effectiveness of early intervention for vulnerable children: A developmental perspective. *American Journal of Mental Retardation, 102*(4), 319-345.

Hanna, K., & Rodger, S. (2002). Towards family-centred practice in paediatric occupational therapy: A review of the literature on parent-therapist collaboration. *Australian Occupational Therapy Journal*, *49*(1), 14-24.

Hinds, P. S., Oakes, L. L., Hicks, J., Powell, B., Srivastava, D. K., Spunt, S. L., et al. (2009). “Trying to be a good parent” as defined by interviews with parents who made phase I, terminal care, and resuscitation decisions for their children. *Journal of Clinical Oncology, 27*(35), 5979-5985.

Hines, S., & Bennet, F. (1996). Effectiveness of early intervention for children with down syndrome. *Mental Retardation and Developmental Disabilities, 2*, 96-101.

Hinojosa, J. (1990). How mothers of preschool children with cerebral palsy perceive occupational and physical therapist and their influence on family life. *The Occupational Therapy Journal of Research, 10*(3), 144-160.

Hinojosa, J., & Anderson, J. (1991). Mothers' perceptions of home treatment programs for their preschool children with cerebral palsy. *The American Journal of Occupational Therapy, 45*(3), 273-279.

Human Rights and Equal Opportunity Commission. (2007). *It's about time: Women, men, work and family. Executive summary*. Sydney, Australia: GPO.

Ingber, S., & Dromi, E. (2010). Actual versus desired family-centred practice in early intervention for children with hearing loss. *Journal of Deaf Studies and Deaf Education, 15*(1), 59-71.

Kearney, P. M., & Griffin, T. (2001). Between joy and sorrow: Being a parent of a child with developmental disability. *Journal of Advanced Nursing, 34*(5), 582-592.

Kellegrew, D. H. (1998). Creating opportunities for occupation: An intervention to promote the self-care independence of young children with special needs.. *American Journal of Occupational Therapy, 52*(6), 457-465.

Kellegrew, D. H. (2000). Constructing daily routines: A qualitative examination of mothers with young children with disabilities. *The American Journal of Occupational Therapy, 54*(3), 252-259.

Keogh, B. K., Gallimore, R., & Weisner, T. S. (1997). A sociocultural perspective on learning and learning disabilities. *Learning Disabilities Research and Practice, 12*(2), 107-113.

Ketelaar, M., Vermeer, A., Helders, P. J. M., & Hart, H. (1998). Parental participation in intervention programs for children with cerebral palsy. *Topics in Early Childhood Special Education, 18*(2), 108-117.

Kramp, M. K. (2004). Exploring life and experience through narrative inquiry. In K. de Marrais, & S. D. Lapan (Eds.), *Foundations for research: Methods in education and the social sciences* (pp. 103-121) Mahwah, NJ: Erlbaum.

Kruskal, M. O., Thomasgard, M. C., & Shonkoff, J. P. (1989). Early intervention for vulnerable infants and their families: An emerging agenda. *Semin Perinatol, 13*, 506-512.

Lalvani, P. (2008). Mothers of children with down syndrome: Constructing the sociocultural meaning of disability. *Intellectual and Developmental Disabilities, 46*(6), 436-445.

Landsman, G. (2005). Mothers and models of disability. *Journal of Medical Humanities, 26*(2/3), 121-139.

LaRochelle-Cote, S., & Dionne, C. (2009). Family work patterns. *Perspectives, Statistics Canada no. 75 001 X,* , 15-26.

Law, M., & King, G. (1993). Parent compliance with therapeutic interventions for children with cerebral palsy. *Developmental Medicine and Child Neurology,* (35), 983-990.

Law, M., King, S., Stewart, D., & King, G. (2001). The perceived effects of parent-led support groups for parents of children with disabilities. *Physical and Occupational Therapy in Pediatrics, 21*(2/3), 21-48.

Lea, D. (2006). 'You don't know me like that': Patterns of disconnect between adolescent mothers of children with disabilities and their early interventionists. *Journal of Early Intervention, 28*(4), 264-282.

Leiter, V., Krauss, M. W., Anderson, B., & Wells, N. (2004). The consequences of caring effects of mothering a child with special needs. *Journal of Family Issues, 25*(3), 379-403.

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry* (1st Ed.). Beverly Hills, California: Sage Publications.

MacBride-King, J. L., & Bachmann, K. (1999). *Is work-life balance still an issue for Canadians and their employers? you bet it is!*The Conference Board of Canada.

MacKean, G. L., Thurston, W. E., & Scott, C. M. (2005). Bridging the divide between families and health professionals’ perspectives on family-centred care. *Health Expectations*, *8*(1), 74-85.

Majnemer, A. (1998). Benefits of early intervention for children with developmental disabilities. *Seminars in Pediatric Neurology, 5*(1), 62-69.

Marshall, K. (2009). The family work week. *Perspectives, Statistics Canada no. 75 001 X,* , 5-13.

Masten, A. S., & Coatsworth, J. D. (1998). The development of competence in favorable and unfavorable environments: Lessons from research on successful children. *American Psychologist*, *53*(2), 205-220.

Mayo, N. E. (1981). The effect of a home visit on parental compliance with a home program. *Physical Therapy, 61*(1), 27-32.

McConnell, D., Brietkreuz, R., Sobsey, D., Rempel, G., Ray, L., & Hughson, A. (2008). *Striking the balance: Sustainable family care for children with disabilities*

Neely-Barnes, S., & Marcenko, M. (2005). Predicting impact of childhood disability on families: Results from the 1995 national health interview survey disability supplement. *Mental Retardation*, *42*(4), 284-293.

Nelson, C. A. (2000). The neurological bases of early intervention. In J. P. Shonkoff, & S. J. Meisels (Eds.), *Handbook of early intervention* (Second ed., pp. 204-277). Cambridge: Cambridge University Press.

Novak, I., Cusik, A., & Lannin, N. (2009). Occupational therapy home programs for cerebral palsy: Double-blind, randomized, controlled trial. *Pediatrics, 124*(606-614)

Novak, I. (2011). Parent experience of implementing effective home programs. *Physical and Occupational Therapy in Pediatrics, 31*(2), 198-213.

Olshansky, S. (1962). Chronic sorrow: A response to having a mentally defective child. *Social Casework, 43,* 190-193.

Ozonoff, S., & Cathcart, K. (1998). Effectiveness of a home program intervention for young children with autism. *Journal of Autism and Developmental Disorders, 28*(1), 25-32.

Plant, K. M., & Sanders, M. R. (2007). Predictors of care-giver stress in families of preschool-aged children with developmental disabilities. *Journal of Intellectial Disability Research, 51*(2), 109-124.

Polkinghorne, D. E. (1988). *Narrative knowing and the human sciences*. United States of America: State University of New York Press.

Poston, D., & Turnbull, A. P. (2004). Spirituality and religion in family quality of life for families of children with disabilities. *Education and Training in Developmental Disabilities, 39*(2), 95-108.

Ray, L. (2002). Parenting and childhood chronicity: Making visible the invisible work. *Journal of Pediatric Nursing, 17*(6), 424-438.

Resch, J. A., Mireles, G., Benz, M. R., Grenwelge, C., Peterson, R., & Zhang , D. (2010). Giving parents a voice: A qualitative study of the challenges experienced by parents of children with disabilities. *Rehabilitation Psychology, 55*(2), 139-150.

Riley, T., & Hawe, P. (2005). Researching practice: The methodological case for narrative inquiry. *Health Education Research, 20*(2), 226-236.

Risdal, D., & Singer, H. S. (2004). Marital adjustment in parents of children with disabilities: A historical review and meta-analysis. *Research and Practice for Persons with Severe Disabilities, 29*(2), 95-103.

Rone-Adams, S. A., Stern, D. F., & Walker, V. (2004). Stress and compliance with a home exercise program among caregivers of children with disabilities. *Pediatric Physical Therapy, 16*(3), 140-148.

Rubin, H. J., & Rubin, I. S. (2005). *Qualitative interviewing: The art of hearing data* (Second edition ed.). United States: Sage Publications.

Sallows, G. O., & Graupner, T. D. (2005). Intensive behavioral treatment for children with autism: Four-year outcome and predictors. *American Journal of Mental Retardation, 110*(6), 417-438.

Schaaf, R. C., Toth-Cohen, S., Johnson, S. T., Outten, G., & Benevides, T. W. (2011). The everyday routines of families of children with autism: Examining the impact of sensory processing difficulties on the family. *Autism, 15*(3), 373-389.

Schreiber, J. M., Effgen, S. K., & Palisano, R. J. (1995). Effectiveness of parental collaboration on compliance with a home program. *Pediatric Physical Therapy, 7,* 59-64.

Segal, R. (2000). Adaptive strategies of mothers with children with attention deficit hyperactivity disorder: Enfolding and unfolding occupations. *American Journal of Occupational Therapy, 54*(3), 300-306.

Segal, R., & Beyer, C. (2006). Integration and application of a home treatment program: A study of parents and occupational therapists. *The American Journal of Occupational Therapy, 60*(5), 500-510.

Shearn, J., & Todd, S. (1997). Parental work: An account of the day-to-day activities of parents of adults with learning disabilities. *1997, 41*(4), 285-301.

Shearn, J., & Todd, S. (2000). Maternal employment and family responsibilities: The perspectives of mothers of children with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 13*, 109-131.

Shonkoff, J. P., & Hauser-Cram, P. (1987). Early intervention for disabled infants and their families: A quantitative analysis. *Pediatrics, 80*, 650-658.

Skinner, D., & Weisner, T. (2007). Sociocultural studies of families of children with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews, 13*, 302-312.

Smith, T., Groen, A. D., & Wynn, J. W. (2000). Randomized trial of intensive early intervention for children with pervasive developmental disorder. *American Journal on Mental Retardation, 105*(4), 269-285.

Solnit, A. J., & Stark, M. H. (1961). Mourning and the birth of a defective child. *The Psychoanalytic Study of the Child, 16*, 523-537.

Statistics Canada. (2008). *Participation and activity limitation survey 2006: Families of children with disabilities in Canada* No. Catalogue no. 89-628-X — No. 009).Statistics Canada.

Stiles, W. B. (1999). Evaluating qualitative research. *Evidence Based Mental Health, 2*, 99-101.

Super, C. M., & Harkness, S. (1986). The developmental niche: A conceptualization at the interface of child and culture. *International Journal of Behavioural Development, 9*, 545-569.

Tetreault, S., Parrot, A., & Trahan, J. (2003). Home activity programs in families with children presenting with global developmental delays: Evaluation and parental perceptions. *International Journal of Rehabilitation Research, 26*(3), 165-173.

Thompson, K. M. (1998). Early intervention services in daily family life:Mothers' perceptions of 'ideal' versus 'actual' service provision. *Occupational Therapy International, 5*(3), 206-221.

Todd, S. (2004). *Improving work-life balance – what are other countries doing?* Human Resources and Skills Development Canada.

Traustadottir, R. (1991). Mothers who care: Gender, disability and family life. *Journal of Family Issues, 12*(2), 211.

Trudgeon, C., & Carr, D. (2007). The impacts of home-based early behavioural intervention programmes on families of children with autism. *Journal of Applied Research in Intellectual Disabilities, 20*(4), 285-296.

Vanier Family and Work Institute (1997). *Executive summary. The 1997 national study of the changing workforce*. Families and Work Institute.

Weisner, T. S. (1984). Ecocultural niches of middle childhood: A cross-cultural perspective. In A. Collins (Ed.), *Development during middle childhood* (pp. 335-369). Washington D.C: National Academy Press.

Weisner, T. S. (2002). Ecocultural understanding of children's developmental pathways. *Human Development, 45*, 275-281.

Weisner, T. S., Matheson, C., Coots, J., & Bernheimer, L. P. (2005). Sustainability of daily routines as a family outcome. *Learning in cultural context family peers and school* (pp. 41-73). Springer US.

Wiart, L., Ray, L., Darrah, J., & Magill-Evans, J. (2010). Parents' perspectives on occupational therapy and physical therapy goals for children with cerebral palsy. *Disability and Rehabilitation, 32*(3), 248-258.

Woodgate, R. L., Ateah, C., & Secco, L. (2008). Living in a world of our own: The experience of parents who have a child with autism. *Qualitative Health Research, 18*(8), 1075-1083.

Zeanah, C. H., & McDonough, S. (1989). Clinical approaches to families in early intervention. *Semin Perinatol, 13*, 513-522.

Appendix A - Information sheet/Advanced notice for participation

Early Intervention and Sustainability of Family routines

Advanced Notice for Participation

Address

Dated

Dear {name},

You are invited to participate in a research project titled' Early Intervention and Sustainability of Family Routines. The focus of this study is to examine and describe the ways in which families of children with disability, balance their daily routines and the demands of Early Intervention. This study is being conducted by Miriam Parakkal, a graduate research student at the University of Alberta, and is part of a larger project undertaken by researchers Drs. David McConnell, and Rhonda Breitkreuz, (also from the University of Alberta) with funding from the Alberta Child, Family and Community Research, and supported by Alberta Children and Youth Services, and the Alberta Association for Community Living.

Participation in this study involves an interview, with the researcher, where you will be asked about your daily routine, and how you manage the tasks related to taking care of your child and the responsibilities of home and family.

You will receive a consent form in the mail in one week.

One of the outcomes of this study will be its contribution to a web-accessible 'booklet' of strategies that families identify as useful in juggling the changing and often competing demands of work and family and care for a child with disabilities. Upon completion of the project, a summary of the research findings will be sent to every participating family.

If you have any questions about the study at this time please contact Miriam Parakkal on (780)-710-5546. We hope you will consider participating in this important project. Your views are important to us.

Yours sincerely,

David McConnell

Appendix B - Participant letter and consent form

Sustainable family care for children with disabilities

Researchers: Dr David McConnell (phone 780 492 7475)
Dr Rhonda Breitkreuz (phone 780 492 5997)

Dear Parent,

You are invited to participate in a research project titled "Sustainable family care for children with disabilities". The focus of this project is on understanding how parent-carers juggle multiple roles and responsibilities, and the resources they need to keep their family life running. This three year project is being undertaken by University of Alberta researchers, Dr David McConnell and Dr Rhonda Breitkreuz, in partnership with the Alberta Association for Community Living. The study is funded by the Alberta Centre for Child, Family and Community Research, and the Social Sciences and Humanities Research Council of Canada.

Participation in this project involves completing a questionnaire annually for the next three years. Please find the questionnaire enclosed with this letter. Once we have received all of the completed questionnaires, some parent-carers will also be invited to participate in an interview and in a web-based discussion forum. The questionnaire should be completed by the parent who usually does most of the caregiving. The questionnaire includes questions about your family's health and wellbeing, the challenges and rewards involved in caregiving, and the strategies and resources you need to keep your family life running. This questionnaire should take around 40 minutes to fill out.

You can complete this questionnaire yourself or, if you prefer, we could complete it together over the phone. Please note that you may find some of these questions uncomfortable. We hope you will answer every question, but the amount of information you provide is up to you. Should you become upset, you may contact the Alberta Association for Community Living on phone 780 451 3055. Once we have received your questionnaire we will remove any information that identifies you, including the attached consent form, and store it in a separate and safe place. That means that no one, not even the researchers, will know that the information you share with us came from you.

Your participation in this study is voluntary. This means that you don't have to take part. If you agree to participate, you can change your mind and withdraw at any time, without having to give a reason and without prejudice. Whether you participate in this project or not, the services you and your family are receiving will not be affected in any way. If you choose to participate, any information you share will be kept strictly confidential unless release is required by law, and will be used only for the purpose of the research project. Only the researchers will have access to your information, and this will be stored in a safe place. All of the information we collect will be stored in a locked filing cabinet for a period of seven years by Dr McConnell in the Faculty of Rehabilitation Medicine. Further, any report or other publication that comes out of this study will not identify you by name.

If you are willing to participate in this important project, please:

1. Complete the attached consent form.
2. Complete the questionnaire enclosed with this letter. And,
3. Return the completed consent form and questionnaire to the researchers in the postage paid envelope provided.

One outcome from this study will be a web-accessible ‘booklet’ of strategies that families identify as useful in juggling the changing and often competing demands of work and family and care for a child with disabilities. Upon completion of this project we will also send every participating family a summary of the research findings. In addition, each participant who completes the questionnaire will receive a cheque in the amount of $30.00. This is to acknowledge and provide some reimbursement for the time that families invest in this project. If you have any questions about this project at this, or any other time, please contact either Dr David McConnell on (780) 492 7475, or Dr Rhonda Breitkreuz on (780) 492-5997.

We hope you will participate in this important project. Your views are important to us.

Yours sincerely,

DB McConnell

David McConnell, PhD

If you have any concerns about the ethical conduct of this research you may contact the University of Alberta, Health Ethics Board on 780-492-0302.

Participant Consent Form

Sustainable family care for children with disabilities

Researchers: Dr David McConnell (phone 780 492 7475)

Dr Rhonda Breitkreuz (phone 780 492 5997)

	Yes	No
Do you understand that you have been asked to participate in a research study?	☐	☐
Have you read and received a copy of the attached information sheet?	☐	☐
Do you understand that participation is voluntary?	☐	☐
Do you understand that you are free to withdraw at any time, without having to give a reason and without affecting your future services?	☐	☐
Has the issue of confidentiality been explained to you?	☐	☐
Do you understand who will have access to your information?	☐	☐
Do you understand that you can contact the researchers at any time if you have any questions or concerns?	☐	☐

I agree to take part in this study: YES ☐ NO ☐

Signature of research participant: ______________________

(Printed name) ______________________

Date: ______________________

Signature of witness: ……………………………………………………

I believe that the person signing this form understands what is involved in this study and voluntarily agrees to participate.

Signature of researcher: DB McConnell Date

Dr. David McConnell

Appendix C - Interview protocol

Introduction

The focus of this interview is on family life. That is, how parent-carers and families manage to juggle all the demands on their time and energy, and how they juggle the interests and needs of different family member….. To get us started, I wonder if you…

A. **Can tell me about yesterday**?

- How did it begin?
- Was yesterday a typical day, if not 'typical' would you describe that as well?(explore)
- Was yesterday a 'good day' or a 'tough day'?(Explore either)

(More than just an itinerary/schedule, we will delve into the 'why's' and 'how's' of the nuances of the routine that the parent/caregiver gives us)

B. **Can you tell me a little more about your family and what's involved in keeping your family life running?**

- Can you tell me a little about the kids? What are the most important things we need to understand about them?
- What's it like to care for (Child's name)? What are some of the challenges? What are some of the challenges? What are some of the rewards?
- What are the things that have to get done in a day (Transportation, keeping appointments, home programs/exercises prescribed by a health professional .Activities/interests of other children in the family, domestic and childcare workload, other commitments etc)
- Who pitches in? Who takes responsibility and for what tasks??
- Who makes decisions about what gets done and how?

C. **What are the different roles or responsibilities that you and your family are juggling?**

What roles, responsibilities, or activities are you juggling?

- Childcare?
- Housekeeping?
- Transport/taxi?
- Work
- Elder care

- Involvement in community organisations or groups
- Other (explore)

D. **How are you managing to keep 'the balls in the air' so to speak? That is, how do you and your family juggle/balance the many different demands on your time and energy?**

(Look into secrets/strategies that families have learnt? supports, relationships with the services, are services responsive to their needs, priorities and requests, do they have any influence on how services are provided?)

E. **Can you tell me about the trade-offs or compromises you or your family have had to make in trying to keep family life running**?

- Are there any interests/activities that you (or any family member) have had to cut back on?
- Have you (&/or your partner) had to adjust your expectations/hopes/dreams in any way?
- Have there been any opportunities (e.g. career) that you or any family member has had to turn down? Could you tell me a bit more or give me one or two examples?
- Do you think the family routines 'works' for everyone in your family? How do you go about meeting everyone's wants and needs?

F. **Are there any responsibilities/roles that you're worried you might drop (using the analogy of a juggler)?**

- If there was one that you had to drop, what would it be?
- How long do you think you can keep 'all the balls in the air'?
- Is there anything threatening your ability to keep those balls in the air?
- What's ahead for your family? Hurdles? Rewards?

G. **To wrap up, can you tell me what you like to do for yourself? Like, how do you treat yourself? Or what would a treat be for you?**