

A MULTIPLE CASE STUDY OF THE CHILDREN AND FAMILIES IN
THE INFANT DEVELOPMENT PROGRAM OF BRITISH COLUMBIA

by

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ABSTRACT

In this qualitative, retrospective study the experiences of a purposive sample of six families of developmentally at-risk children, between birth and school entry were examined. Children were followed up by consultants in the Infant Development Program of B.C. --a Provincial, early intervention, home-based, family-centred program serving families with developmentally at-risk children ages 0 - 3 years.

Multiple sources of data collection were used including file reviews, focus groups, and individual, semi-structured interviews with participant parents. This researcher anticipated that it would be meaningful for parents to relate to these experiential issues; and that their responses would provide insights to the research questions posed on their specific experiences with early intervention. Member-checks were completed by participants throughout the data collection and coding stages. Thematic content analysis was used to interpret the themes from throughout the focus groups and interviews, followed by a rigorous process of inter-coder reliability.

The findings of the present study raise issues in identification, referral and follow-up for developmentally at-risk children. The findings support the implementation of a primary level intervention system that probes and supports parents and service providers in identifying what are areas that need follow-up – and why and how to address those immediate needs.

TABLE OF CONTENTS

ABSTRACT.....	ii
TABLE OF CONTENTS.....	iii
LIST OF TABLES	vii
ACKNOWLEDGMENTS	viii
Dedication	x
Chapter I: The Problem.....	1
Introduction.....	1
Background and Rationale.....	3
Purpose of the Study	5
Contributions of the Study	7
Meaning of the Study.....	9
Definition of Terms	11
Research Approach	20
Overview of the Study	21
Chapter II: Literature Review	23
Introduction.....	23
Research on Developmentally “At- Risk” Infants and Children	24
Research on Developmental Screening/ Surveillance and Assessment.....	27
The Need for Early Intervention for Developmentally At-risk Children:	
Current Research and Practices	35
Early Intervention Programs in BC	38
Overview of the Infant Development Program of BC.....	40
Research on Families with Developmentally At-risk Children	47
Significance of Literature Review to the Current Study.....	52
Chapter III: Method	54
Introduction.....	54
Paradigm of Science: Post-Positivism	54
Multiple Case Study Approach.....	58

Ethnography	59
Research Design	64
Procedures	65
Participants.....	65
Description of Final Sample (Participant Children and Parents).....	74
Data collection. Stages One and Two	82
Phase 1 File Reviews	86
Phase 2	94
Data Analyses	96
Content Analysis.....	96
Integrity of study.....	97
Dependability and Representation	99
Criteria for Evaluating the Worth of Study.....	101
Validity	101
Issues of Ethics and Rigor and Issues of Representation.....	106
Issues of Representation	107
Issues of Voice.....	108
Summary.....	109
Chapter IV: RESULTS	111
Introduction.....	111
Across-Participants Findings	116
Overview.....	116
Overview.....	125
Organization of Findings by Theme	128
Summary	132
Findings from Focus Group 1	133
Findings from Focus Group 2 and Interview #4 Concluding Question.....	136
Summary of Across-Participant Findings.....	141
Within-Participant Families Findings.....	142
Overview.....	142
Family 3	143
File Reviews. Child A.....	144
File Reviews. Child B	149

Focus Group 1	153
Interview Accounts	159
Closing Comments: Focus Group 2.....	182
Family 3 Summary.....	183
Exemplary Case from Stage Two of Data Collection.....	186
Family 5 File Reviews	186
Interviews.....	192
Summary of Family 5	226
File Reviews and Interview Summaries	230
File Reviews	230
Summary of Family 1 Interview Responses	234
File Reviews	236
Summary of Family 2 Interview Responses	239
File Reviews	241
Summary of Family 4 Interview Responses	245
File Reviews	248
Summary of Family 6	253
Overview	257
Summary of Findings by Research Questions	258
Theme 1: Family Centred Approach and Home Visitation Services.....	258
Specific Research Questions.....	260
Theme 5: Effective Knowledge Translation in Sharing Information and Resources	261
Theme 2: One to One Relationship with Consultant/Therapist.....	264
Theme 3: Inclusion of All Family Members	267
Theme 6: Case Managing and Service Coordination	268
Theme 7: Stressors that Become Barriers.....	272
Summary	276
Chapter V: Discussion	278
Introduction.....	278
Significance of the Study	279
Implications for Practice and Policy	313
Introduction.....	313

Implications for Policy.....	323
Limitations of the Study.....	325
Summary and Conclusions	336
References.....	341
APPENDICES	376
Appendix A: IDP Family Needs Survey.....	377
Appendix B: Closing Information Form.....	381
Appendix C: IDP Post Service Evaluation Questionnaire.....	382
Appendix D: Contact Letter(s) and Consent Form for Participants	383
Appendix E: Central Registry Form	391
Appendix F: IDP Referral and Waitlist Contact and ConsultationForms.....	392
Appendix G: Home Visitation Record, Family Contact Summary and Waitlist and Monitoring Group Summary.....	396
Appendix H: Scripted Questions for Parents Interviews and Focus Group Discussions	399
Appendix I: File Reviews and Comments to Reviewed Files	404
Appendix J: Model of Service for IDP of BC.....	414
Appendix K: Three Tier Response To Intervention Model (RTI).....	415
Appendix L: Ethics Certificate.....	416

LIST OF TABLES

Table 1. Family Demographics.....	76
Table 2. Interview of Parent/Guardian Participation in the Focus Groups, Interviews and File Reviews.....	85
Table 3. Seven Revised Themes; Research Topic and Summing Themes.....	114
Table 4. Families: Services Received and Transitions.....	122
Table 5. Focus Groups and Interviews: Categories and Sub-Categories.....	127

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¹ Note: the names of the staff at the selected Infant Development Program are not included to protect the anonymity of the participant families.

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Dedication

I dedicate this thesis to my family, John, Maria Carolina, and Gwyn Alejandro; to my mother, Yolanda Mirabal de Pighini, and to the families and the consultants in the Infant Developmental Program of BC.

To Tracy Lynn Pedersen, *quien sí sabe que ella existe*

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Chapter I: The Problem

Introduction

Over the past three decades in British Columbia, Canada and the United States, early intervention programs have been in place for children who are at risk for developmental delays or who have identified disabilities (Brynelsen, 1990; Brynelsen, Cummings & Gonzalez, 1993; Goelman, Brynelsen, Pighini, & Kysela, 2005; Marfo, 1995). Researchers have agreed on the positive effects of these programs in infants and young children who are developmentally at-risk (e.g. Butler, Chambers, Goldstein, Harris, Leach, et al., 1999; Guralnick, 1998; Meisels & Shonkoff, 2000). Nevertheless, researchers continue to examine these programs' impact on the developmental outcomes of this diverse population of young children (Coleman, Buysse, & Neitzel, 2006; Hebbeler, Spiker, Bailey, Scarborough, Mallik, et al., 2007; McCollum, 2002). McCollum's (2002) work, in particular, has challenged a common assumption with regards to the effectiveness of early intervention. McCollum specifically questions, "What is it that works, in terms of intervention: Is it the type and nature of program, is it its intensity or its duration?" (p. 5). McCollum's examination of the effectiveness of early intervention guided the research topic of the present study. In this study, the researcher investigated parents' experiences of an early intervention program, the Infant Development Program of BC, on developmentally at-risk infants and children and their families. Along this line of thought, some aspects of interest that were examined included the relationships between the Infant Development Program consultants as service providers and the children and families they have worked with, and, the influence of consultants on the

quality of intervention of the Infant Development Program from the perspective of the Infant Development Program families.

In questioning how early intervention works, researchers have shifted the scope of the research in early intervention. This shift represents a response to a dominant ecological theoretical framework (Bronfenbrenner, 1979, 1986, 2005; Garbarino & Menzel, 2000). Researchers have also started to acknowledge the key role played by children's families in supporting the implementation and continuity of these services (Dunst, Trivette, & Cross, 1986; Dunst, Trivette, & Deal, 1988; Dunst, 2000; Guralnick, 1998; Turnbull, Friesen, & Ramirez, 1998). More recently, in the US, a national longitudinal study has been launched to explore and understand the characteristics of children and their families receiving early intervention services and the communities where these services are provided (Hebbeler et al., 2007; Scarborough, Spike, Sangeeta, Hebbeler, Bailey, et al., 2004).).

The general intention of this study was to examine the paths of children representing the range of developmental differences serviced by British Columbia's 0-3 IDP of BC: the Infant Development Program of BC. The study supports the current research that evaluates the effectiveness of early intervention programs and, at the same time, includes the family context in the study of early intervention. Through a multiple case study approach, this researcher listened to and explored the meanings of the experiences lived by parents of developmentally at-risk children who participated in the Infant Development Program of BC. It was anticipated that parents would describe the events and circumstances surrounding the time of their referral to the Infant Development Program; the time of discharge from the Infant Development

Program, and up to their child's entering into Primary school. Thus, the intent of this study was to offer these parents a voice that would rightfully represent the unique needs of their families within their communities. This chapter provides the background and rationale for this study, as well as its purposes, the definitions of terms used and the study approach.

Background and Rationale

This section begins with an introduction on the characteristics of the early intervention documentation process in BC over the past 30 years, in order to better describe the intent and characteristics of the study. Data gathering in early child development in British Columbia and Canada has generally been inconsistent both at the program and intervention levels. This creates a gap in conducting both longitudinal and retrospective research on developmentally at risk children (Goelman, Synnes, Houbé, Klassen, & Pighini, 2006). In British Columbia, the Infant Development Program's Programs have collected invaluable medical, developmental and family information on approximately 79,000 children since 1972 (Office of the Provincial Advisor, 2004, 2006). This information has been traditionally entered manually and recorded and stored in a variety of files and formats throughout the 73 locations across the province, including programs within the Aboriginal Infant Development Program (Dana Brynelsen, personal communication, July 10, 2008). A Central Registry Database has been in place only since 2002 through the Infant Development Program Office of the Provincial Advisor (Chan, 2007). This database includes family contact information, such as "date and place of birth," timing and places of services, for example, "date of intake," "reason for referral," and assessments conducted, diagnoses

received, hospitalizations and other medical history among many other fields. The database has the information from the time of referral up through the final process of discharge (see Appendixes E and F).

Nevertheless, studies of the Infant Development Program have not been conducted to-date. This study is the first attempt for the Infant Development Program to participate in research that involves the families they have served. This study represents a true example of academic and community partnership and collaboration. Similar to what has been reported in research elsewhere (Tedlock, 2000; Turnbull et al., 1998, among others) this process of collaboration has taken time to come to fruition in terms of developing trust between the researchers and between consultants and other members of the Infant Development Program. Preliminary discussions with both the Infant Development Program Provincial Advisor and with the program coordinator of one of the Infant Development Program programs have been held during the past two years. These discussions were the result of a joint initiative between the agency and university representatives to inquire about the interest and the need to conduct a study that would document the experiences of families in the Infant Development Program. Moreover, an informal discussion was also held with some Infant Development Program consultants who invited a few former “Infant Development Program parents.” These parents had expressed their desire to be contacted for research purposes about their experiences with the Infant Development Program throughout the discharge process a few years earlier (B. Barnes, D. Brynelsen, personal communication, September 23, 2004; November 16, 2004, January 25, 2005).

Purpose of the Study

This consultation process prepared the grounds to initiate a research process inspired by Shonkoff's (2000) integrated perspectives in early intervention. These perspectives, in turn, derive from Bronfenbrenner's ecological framework (1979, 1986, 2005) which includes the perspectives of children's families, the perspectives of professionals working in community agencies/programs, and current neuro-developmental research on child development and how is early intervention experienced. Thus, the study is intended to bring attention to the importance of effective and accessible programs that provide services to at-risk children from birth and into their early school years. The study has the following two overall goals: (1) to collect and integrate health-related and developmental information about children between birth and 3 years of age who have participated in the Infant Development Program and (2) to utilize the perspectives of children's parents about their experiences with the Infant Development Program of BC. It was expected that the information gained from these two questions will provide a better understanding of: (a) the interaction of medical and biological risk factors (Goelman et al., 2006); (b) how children and their families have experienced these factors; and (c) how early intervention program and services utilization helped shape these unique experiences for both children and parents.

Two observations derived from the research literatures on caregiving served as points of departure for this study. Based on their work with caregivers of adults with mental health illnesses, Karuza, Rabinowitz, and Zevon (1986) commented on the importance of the way in which the caregiving help was actually provided rather than

the type of care that was provided “... if positive consequences are to be realized...” (p. 373). The second observation is from Mahoney, Boyce, Fewell, Spiker, and Wheeden (1998) who stress the fact that effective home-based, family-centred early intervention programs’ parents can effectively “complement” the intervention program instead of “supplementing it” (p. 9). With these observations in mind, this researcher examined the nature of the relationships between families (parents and children) and their Infant Development Program service providers, the different roles played by the consultants and how these interact in the nature and quality of service provision of this program, from the parents’ perspectives.

The study addressed the research topic on parents’ perceptions of their experiences with early intervention on (a) early childhood development; (b) parenting; and/or (c) family dynamics in families with a child at-risk for developmental delays or diagnosed with developmental disabilities?” Four specific questions were raised in this study:

- (1) What are the individual experiences of parents of developmentally at-risk children who participated in the IDP of BC in terms of their child current developmental needs?
- (2) What are the individual experiences of parents of developmentally at-risk children who participated in the IDP of BC in terms of access to resources and programs?
- (3) In what ways do the experiences described in a) and b) relate to the current preschool/school demands on these parents?

- (4) In what ways do the experiences described in (1) and (2) relate to the demands from other family members, and to financial/work pressures?

Contributions of the Study

This study contributes to the existing literature by expanding the target population beyond children with developmental disabilities, by including a retrospective component to the study, and by conducting the study within a qualitative research framework.

The main strength of the study is drawn by complementing and expanding the current research in early intervention by focusing on families' unique experiences while they participate in the Infant Development Program. This is a qualitative and retrospective study that contributes to the existing research on early intervention by attempting to gain a better understanding of the experiences of parents with developmentally at-risk children. Families of developmentally at-risk children requiring early intervention services, as a research topic, have not received the necessary attention thus far. For example, the relatively narrow range of topics addressed in previous and current research looks at the developmental outcomes and interventions for at-risk children. It has included growth (Ehrenkranz, Younes, Lemons, Fanaroff, Donovan, et al., 1999; Hack, Schluchter, Cartar, Rahman, Cuttler, et al., 2003), health and quality of life (Stjernqvist & Svenningsen, 1999; Tideman, Bjerre, & Forslund, 2001), and the overall patterns of skills performance in these children (Anderson, Doyle, & The Victorian Infant Collaborative Study Group, 2003; Breslau, Paneth & Lucia, 2005; Grunau, Whitfield, & Davis, 2002; Grunau, Whitfield, & Fay, 2004; Stroganova, Posikera, & Pisarevskii, 2005). Of these studies,

only a few include and acknowledge the ecological context of the child and the family (Klassen, Landgraf, Lee, Barer, Raina, et al., 2003; Schiariti, Houbé, Lisonkova, Klassen, & Lee, 2007; Taylor, Minich, & Hack, 2001). Another focal point of the early intervention literature has been the effectiveness of intervention programs and strategies for young children with diagnosed developmental disabilities. The focus of this research has been on current program and strategies (Boavida, Espe-Sherwindt, & Borges, 2000; Butler et al., 1999), as well as descriptive and critical meta-analyses of elements and strategies of past and current early intervention programs (Farran, 2000; Guralnick, 1997; McCollum, 2002, among others).

In the research, the developmental outcomes of high-risk infants and young children (Allen, 2002; Aylward, 2002; Bhutta, Cleaves, Casey, Cradock, & Anand, 2002; To, Caderette, & Liu, 2001) have also been examined. This research has been made possible as the number of surviving high-risk infants has increased over the years, thanks to advanced and improved treatment provided by neonatal intensive care units (Synnes, 1994; Goelman, Synnes, Houbé, Klassen, Lisonkova, et al., 2008); Vergara & Bigsby, 2004). Very few studies have examined the developmental outcomes of at-risk infants and children receiving early intervention services within the qualitative tradition (e.g., Turnbull, Friesen, & Ramirez, 1998). Further, even within the quantitative tradition, only a small proportion of studies have followed up children over a long term period, either longitudinally or retrospectively, due to the limitation of sample selection and attrition within the data collection process inherent in studies examining the development of at-risk children (Ehrenkranz et al., 1999; Hack et al., 2003; Tideman et al., 2001; Wolke & Meyer, 1999). A dearth of studies

exists in the research literature that focuses on specific family issues. This study intends to complement and expand upon the few examples of studies in this area such as Dunst, Trivette, and Cross (1986); Dunst, Trivette, and Jodry (1997); McWilliam and Bailey (1993); Poston, Turnbull, Park, Mannam et al., (2003), and more recently, Margalit and Al-Yagon (2007), and Santos and McCollum (2007). Chapter 2 of this study will provide a more in-depth review of these studies.

This qualitative study complements the existing quantitative research-on “at risk” (for developmental delays) and “developmental disabilities” in the field of early intervention, emphasizing factors such as interpretation, empathy, narration, and context interpretation of the realities of these children and their families (Daly, 2007). As previously highlighted, this qualitative study goes beyond the measuring of at-risk children’s specific developmental skills and abilities. This is in marked contrast to the predominantly quantitative-based early intervention research cited in the literature review of the study, including Vohr and Msall (2004) and Wadsby, Sydsjö, and Göran, (2001). Hence, this multiple case study delves into the lives of specific families, as they grow and change and as they cope with different situations and confront their individual realities within their unique journey of parenting a child who is at risk for developmental delays or diagnosed with developmental disabilities.

Meaning of the Study

This study is of particular interest to me. As a former Infant Development Program Consultant, I worked with families of at-risk children almost 10 years ago and experienced part of their journey. During this time, I tried to meet some of their ongoing needs through consultation, support, and advocacy. I dealt with issues related

to their children's development, for example, interpreting assessments; accessing resources and services such as financial aid; and transitioning to preschool or daycare programs as the time for discharge at age 3 approached. Later on, in my next professional role as a Resource Teacher, I served students who required additional assistance in their Primary grades in academic, behaviour, and work habit skills. Several of these students shared a common history of pre- peri- and/or post-natal risk, including prematurity, low birth-weight, and for a few of them, medical complications that had persisted throughout their preschool years. My job also included case management for students with global developmental delays and special academic needs that required the orchestration of different services through the school board system.

My work experiences in both professional settings had something in common, beyond the fact that in both jobs I was working with children with developmental and/or learning needs. No continuity in case management was available for these children and families that would connect, or link, all of these programs and services. As an infant development consultant, my role as a service provider and coordinator for children and parents ended after the families' discharge when they transitioned to preschool or daycare and received or not additional special preschool or therapeutic services support. In my next role as a resource teacher working with children who were 5 years old and older, I had little or no knowledge of either the children's past health related experiences or the services they had received. Even for the children who had received their "special needs" designations while in preschool or daycare, the information that was available through their files mainly focused on their present and

immediate past level of services, and on their present developmental performance.

Only parents could have provided additional information. Given the school setting and parents' tight schedules only basic information was usually shared. I perceived that something was incomplete, and unfinished, at both ends of these children and parents' paths. This sense of incompleteness was a barrier that prevented me, as a service provider, to fully grasp the needs of the children and of their parents, and the riches that they brought with them at this stage of their lives.

I was thus inspired by these past professional experiences to take a first step in trying to "connect the dots" of these children's paths, from the time of their birth and into their school ages. Listening to children's parents' voices about their experiences for the past three to seven years provided me with the opportunity to examine what the links were --as they reminisced about their children's experiences after birth, during their IDP years, preschool, daycare and/or school, as well as their experiences in additional support programs.

Definition of Terms

Many of the definitions in this section are drawn from *The early intervention dictionary: A multidisciplinary guide to terminology*, edited by J.G. Coleman (2006). This book provides a comprehensive source of definitions for terms in the early intervention and early childhood special education fields.

Assessment

This study refers to Coleman's (2006) definition of assessment as the combination of informal (or screening) and formal (using standardized tools) procedures that appraise the child's developmental abilities. This study refers to

standardized and screening assessment tools. Examples of standardized tools mentioned in the present study include the Gessell Developmental Schedules (Gessell, Ilg, & Ames, 1974), and the Battelle Inventory of Developmental Skills (Glascoe & Byrne, 1993). Examples of screening tools include the Ages and Stages Questionnaires (ASQ) (Bricker & Squires, 1999) and The Ounce (Meisels, Dombro, Marsden, & Weston, 2003).

At-risk

“At risk children” are those, who as a result of medical, biological, or environmental factors are more likely than typical [or non-risk] children to have developmental delays and school difficulties. Some of the medical complications include low and very low birth weight, premature birth, and other medical complications that most likely would have required specialized neonatal treatment (Goelman et al., 2006). Environmental factors include living in poverty, parental negligence, and/or being exposed to abuse, among others (Office of the Provincial Advisor, 2004, 2006).

Development

The study uses Coleman’s (2006) definition of development: “The lifelong process through which an individual acquires increasingly complex abilities” (p. 111). The proposal refers to *typical* development, that is, the behaviours and skills within the expected time frames (p. 417), and to *atypical* development, where unusual or abnormal behaviours are observed in the child (p. 37). Common examples of developmental milestone behaviours that signal *typical* developmental patterns include smiling, walking, and talking. *Atypical* development encompasses children with

“exceptionalities.” This term, in turn, includes children with “developmental delays” leading to physical and/or intellectual disabilities (Hanson, 2004), as well as children who have specific learning or language difficulties (Botting, 2004; Fuchs & Young, 2006). Although children who are identified as gifted learners are also deemed “exceptional” (Robinson, Zigler, & Gallagher, 2000), these children are not included within the description of “atypical” development in the study.

Developmental delays

The study uses the term “developmental delays” in reference to “infants and toddlers who are not achieving new skills in the typical time frame” (Coleman, 2006, p. 111). Some of these children with one or more moderately to severe delays in physical, motor, and/or cognitive, language, behaviour, and/or emotional development may be later identified with developmental disabilities (see below). Delays in most areas of development are referred to as ‘global developmental delays’ (p. 169). Revisions of the PI 94-192 (1991, 1997, & 2004) have added the “developmental delays” as “... a classification category for children ages three to nine years of age...that are generally associated with chronic health/medical conditions.” For example, epilepsy or heart congenital anomalies are usually identified between the first five years of life (Horowitz et al., 2007, p. 7).

Disability

A limitation in a functional activity or in a socially defined role or task is defined as a disability (Bradsher, 1996).

Developmental disabilities

Coleman (2006) refers to “developmental disabilities” as any physical or

mental condition before the age of 22 that impairs the cognitive, language or motor functioning of an individual, including autism, mental retardation, cerebral palsy or a neurological disorder. Developmental disabilities are generally linked to moderate to severe pre-, peri-, or post- natal medical, health, and or developmental conditions, and are described according to their intensity and severity. Given the level of compromised neuro-developmental functions due to these conditions, these disabilities are usually – but not always- identified within the first year of the child’s life; e.g. the more severe the condition, the higher the impact on the child’s development (intensity); therefore, the earlier will be the time for their identification (Hebbeler et al., 2007).

Learning disability

A learning disability is defined as a neurological disorder affecting the brain in one or more of the psychological processes involved in understanding or using information –e.g. language, spoken or written-- despite the individual exhibiting average or above average intelligence. Learning may be impacted because of *specific* difficulties with reading, writing, speaking, spelling, or doing mathematical calculations –and might involve dyslexia and or attention deficits (Horowitz et al., 2007; The Advocacy Institute, 2006). Recent research has uncovered that many children who are identified with learning disabilities were reported with mild to moderate delays in one or two areas of development between the ages of 0 and 3 by parents or caregivers (Glascoe, 1997; Horowitz et al., 2007).

Disorder

The study uses Coleman’s definition of disorder, that is, “an abnormality or disruption of a normal function, such as speech; e.g. speech disorder” (2006, p. 119).

Early intervention

In this study, the term “early intervention” will refer to programs that provide *secondary* intervention services, in contrast to programs that offer preventative services (Goelman et al., 2005). IDP of BCs (at a secondary level of intervention) attempt to promote child health and well-being, enhance emerging child competencies, minimize developmental delays, remediate existing or emerging disabilities, prevent functional deterioration, promote adaptive parenting, and promote overall family functioning resilience and adaptation (Meisels & Shonkoff, 2000). IDP of BCs serve infants, toddlers, and their families between the ages of 0 to 3. In British Columbia and elsewhere in Canada, these programs are provided at no cost for the families.

Early interventionists

Coleman (2006) describes early interventionists as infant educators or trained professionals who assess and/or plan and implement a program that addresses the infant or young children’s developmental needs (p. 130). In this study, consultants and therapists serving children less than three years of age would be considered “early interventionists.” Early interventionists include professionals such as generalists in child development, as well as physiotherapists, occupational therapist, speech and language therapists, and vision and hearing specialists, among others.

Families

In this study, “family” refers to “kin” --living or not within the same household and not necessarily bound by marriage or biological ties (Rothausen, 1999). This definition acknowledges the diversity in the composition of families. Within this open conception of family, the study incorporates Turnbull et al.’s definition that describes

the family group as conformed by two or more people carrying out family responsibilities, and united or not by marriage or blood ties (1998, p. 5). Diversity in family composition refers to the recognition of traditional and non-traditional forms of family, including, a) the “nuclear” family (two parents and children); b) the “extended” family (uncles, aunts, and grandparents, among other family members); and c) “non traditional” family units, including gay and lesbian families. The Infant Development Program includes these forms of family composition within their referral and record tracking system (Infant Development Program Manual, 2004). The study intends to give preference to families where the *parents* (biological or adoptive) are also the primary caregivers of the child over foster families, where the child is under provisional care and under the official custody of the government.

Grey Area

Although the concept of “grey area” is not a widely used term in the research literature, it is used in the study to describe “young children who show early signs of struggling to learn in the absence of pronounced pediatric disorders; namely those children with early signs of learning disabilities” (Horowitz et al., 2007, p. 7).

Inclusion/Inclusive Systems and Programs

The term inclusion/inclusive systems and programs refers to the full enrollment and participation of children with special needs in preschool, school or community-based programs (Coleman, 2006, p. 202). Inclusive programs are accountable for providing specialized and individualized support for the unique needs of each one of the participating children.

Individualized Educational Plan or IEP

An individualized educational program or IEP is designed for children with identified special needs. This program is revised every year with the parents and preschool/school teaching/administrative staff (BC Ministry of Education, 2000a).

Incidence

Coleman refers to the term incidence as “the frequency or occurrence of a case (e.g., a disease or a disorder) in a given time” (2006, p. 203).

Low, high incidence

In the case of developmental disabilities, the higher the severity and intensity of the condition(s), the lower the incidence of the disability; hence the use of the term “low incidence” to refer to developmental conditions and/or disorders that are severe to profound (severity) and that affect several areas of development (intensity). Low incidence conditions occur in less than 1% and no more than 3% of the population under age 22; for example, cerebral palsy, some pervasive developmental disorders, and neurological disorders (Bradsher, 1996; Coleman et al., 2006; Hebbeler et al., 2007; Kierans, Kramer, McGill, Wilkins, Liston, et al., 2000). Conversely, “high incidence” refers to conditions/disabilities that are more subtle, with lower level of intensity and mild to moderate in the developmental degree of impact. High incidence conditions are generally apparent only after age 5 and during the school years and are present in 5-10% of school-aged children (for example, learning disabilities, attention deficit (hyperactive) disorder, mild cognitive delays, and mild sensorial impairments, such as vision and hearing (Coleman et al., 2006; Hebbeler et al., 2007, Kierans et al. 2000; The Advocacy Institute, 2006).

Low, Very Low and Extremely Low Birthweight

In the current neonatology and the early intervention literature cited in this study, “Low birthweight” refers to infants born under 2500g; “Very Low Birthweight” refers to infants born under 1500g; and “Extremely Low Birthweight” refers to infants born under 800g (e.g. Goelman et al., 2006, 2008).

Prematurity

Prematurity refers to infants born under 37 weeks of gestation. (It is important to note that infants born at term - 37 to 41 weeks of gestation - but who weigh under 2500g are considered to be “small for gestational age” (SGA) and generally require medical intervention (Vergara & Bigsby, 2004, among others).

Corrected age for prematurity. For the purposes of screening and assessments, IDP Consultants calculate the corrected age for premature infants and young children (birth to age three) by subtracting the actual date of birth from the expected due date of birth (YYYY/MM) (IDP Manual, 2004).

Remedial Services

This is a broad terms used within the educational context to encompass a range of instructional services used to meet the needs of school-aged children with learning disabilities, following –or not—early intervention services (Fuchs & Young, 2006). Remedial services encompass specialized support provided not only in the basic academic areas of learning (reading, writing, and mathematics), but also in study skills/work study habits, and in cognitive functions such as memory, visual, and auditory processing, and others.

Screening

This proposal uses Gilliam, Meisels, and Mayes' (2005) description of developmental screening as a simple method that may identify young children who may be at risk for problems in their health, development, or other areas of functioning." The authors caution that screening practices are not only simple in their training and administration, but also deceptive in that the process requires careful and sound attention to its content and administration procedures in order for it to be an effective tool (p. 73).

Universal screening includes the whole population of children of a specific health or administrative region, with or without established or suspected at-risk conditions before, during or after birth.

Targetted screening aims at children with established developmental risk conditions. Established risk conditions are those that have been confirmed to have an impact on the developmental outcomes of children; each administrative or health region specifically defines their criteria that allows children and families to receive targetted screening services within that region (Coleman et al., 2006; Committee on Children with Disabilities, 2006; Hebbeler et al., 2007).

Special Needs

The term special needs refers to the child who requires individualized educational support and/or specialized medical intervention to assist in the acquisition of basic developmental and/or academic skills (Coleman, 2006, p. 376).

Syndrome:

Syndrome is a group of traits, generally genetically linked, that, occurring

together, describe a particular disease or disorder –whether or not all the traits or signs are not exhibited (Coleman, 2006, p. 392). Examples of syndromes in this study include: “Down’s syndrome” and “Fetal Alcohol Syndrome” as conditions linked to developmental disabilities.

Universal Surveillance

Universal surveillance refers to the ongoing follow-up of infants and young children from birth to school entry through the use of developmental screening techniques. Bremberg and Lindstrom (1997), Frankenburg (2003), and Gilliam et al. (2005) have examined the practice of universal surveillance and have evaluated the effectiveness of specific assessment tools to identify specific developmental delays in infants and toddlers who otherwise would not receive the attention they require according to their developmental and learning needs.

Research Approach

The study was conceived as a multiple case study (Creswell, 1998; Stake, 2000) of six families, within the tradition of post-positivist ethnographic research (Lincoln & Guba, 2000; Miller, Hengst, & Wang, 2005). This tradition of research is one that anticipates the re-creation of the experiences of participant parents, from the very early years of their child and to the school years. Information and responses from participants were retrieved through multiple data collection sources (Lincoln & Guba, 2000) including file reviews, focus groups discussions, and individual interviews. Focus groups and interviews were transcribed using a combination of verbatim and summarized transcriptions (Quinn-Patton, 1987) that were coded into relevant categories and themes (Holsti, 1969; Krippendorff, 2004; Roberts, 1997).

In this study I employed predominantly thematic content analysis to interpret the coded responses from participant parents (Berg, 2001; Holsti, 1969; Krippendorff, 2004; Roberts, 1997). In order to ensure the rigor of the study, a process of inter-coder reliability was followed. Participants were consulted through member-checks throughout the data collection, data-analyses, and interpretation of the findings to ensure the validity of the findings. The findings of the study were representative across the themes identified, examining both the commonalities across the different families' descriptions, and the unique or individual themes that emerge within each one of the participating families. The unique nature and characteristics of this study as being the product of an academic and community partnership situates the study within a collaborative and participatory research approach. Within the context of this approach, the community program involved with the study had a consultative and advising role in the development of the study and the completion of the study (Daly, 2007; Tedlock, 2000; and, Turnbull et al., 1998). The next two chapters of this study consist of a review of the literature, and a more detailed description of the proposed method and procedures.

Overview of the Study

The purpose of this qualitative, multiple case study was to gain a deeper understanding of the impact of early intervention services on children at-risk for developmental delays or diagnosed with developmental disabilities. The study aimed at capturing parents/caregivers' experiences with the Infant Development Program (IDP) of BC from the time of their children's birth and until the years following their discharge from this program. This was accomplished through the use of multiple

methods of data collection, including: (1) focus groups and semi-structured interviews with the 10 parents and 1 grandmother comprising the parent sample and (2) file reviews of the 7 children in the 6 participant families. Chapter 2 presents a review of the literature concerning parents/caregivers' experiences with the early intervention services received through the IDP of BC. Chapter 3 presents the interpretative framework of this study that is situated within the ethnographic tradition of inquiry. This is followed by a description of the participant children and parents, and the method and procedures for data collection and analyses. Chapter 4 presents and explains the findings of the study based on their corresponding data analyses. Chapter 5 expands on these results with regards to their implications for program practices, training and policy in early intervention services, and recommendations for future research.

Chapter II: Literature Review

Introduction

Developmentally at-risk infants and children constitute a diverse group, with unique needs that partly depend on whether or not they have an established developmental condition during their early years. An established condition is one that compromises their health and one or more developmental domains. At the same time, the needs of developmentally at-risk children also depend on the nature of this condition (Coleman et al., 2006; Committee on Children with Disabilities, 2001). The higher the degrees of intensity and severity of the condition, the higher the probabilities these children have in obtaining early intervention. Hebbeler al.'s (2007) recent report on a national longitudinal study on early intervention has identified the risk factor categories utilized in the process of referral of children between birth and age three. According to this study, developmentally at-risk infants and toddlers are referred for early intervention services based on one or more of the following risk categories: health-related, substance abuse, sensory impairments, neuromotor disabilities, muscle-skeletal conditions, motor delays, physical delays, language delays, and/or social/environmental concerns (p. 2-9). In the case of preschool children, cognitive and/or adaptive delays, speech and language impairments, social, behavioural, and emotional concerns are added to the list of risk factors (Horowitz et al., 2007). While approximately 50% of children meet two of the criteria for developmental risks identified by Hebbeler et al. (2007), almost 25% meet the criteria for over six of the total of risk factors (pp. 2-8).

This chapter will first provide an in-depth review of the literature highlighting

the overall outcomes of developmentally at-risk children. This review will be followed by a description of screening and assessment practices currently used for the early identification of these children's needs. Next, the chapter will review the characteristics and effectiveness of the different models of early intervention programs that respond to and address the above listed risk factors for these children. The last section of the chapter reviews the literature on families with developmentally at-risk children receiving early intervention services.

Research on Developmentally "At-Risk" Infants and Children

Research focusing on the health, developmental outcomes, and overall well-being of children "at risk" for developmental disabilities has been conducted in British Columbia (Chelsea, Lisonkova & Synnes, 2004; Grunau et al., 2002; Houbé, Lisonkova, Klassen, Synnes, Lee, et al., 2004; Klassen et al., 2003; Schiariti et al., 2007; Whitfield, Grunau, & Holsti, 1997), elsewhere in Canada (Chan et al., 2001; Chudley, Conry, Cook, Looock, Rosales, & Leblanc, 2005); Saigal, Hoult, Streiner, Soskopf, & Rosenbaum, 2001; Synnes et al., 1994), and in Europe (Saigal et al., 2003; Stroganova et al., 2005; Walther, den Ogden & Verloove-Vanhorick, 2000; Wolke & Meyer, 1999). Examples of "at-risk" factors include anomalies that are present at birth, complications of treatments required in the newborn period, as well as other environmental and/or concomitant risk factors (Goelman et al., 2006). Many of these children are survivors of neonatal intensive care (NICU) treatments (Allen, 2002; Chan et al., 2001; Chelsea, Lisonkova, & Synnes, 2004; Rescnick et al., 1998; Synnes et al., 1994; Synnes, Lefevre, & Cake, 2005; Synnes et al., 2006; Vergara & Bigsby, 2004). Children exposed to these health and medical complications may end up with

specific developmental and learning disabilities. Some of these disabilities may only be evident in the later preschool years, while other ones are generally “hidden” until the elementary school years (Butler et al., 1999; Horwood, Mogridge, & Darlow, 1998; Klebanov, Brooks-Gunn, & McCormick, 1994; Rescnick et al., 1998; Stroganova et al., 2004; Whitfield et al., 1997).

Recent preliminary findings from a population-based study that compares the health trajectories of children born in BC between the years 1996 and 1997 indicate that 25% of live born children in BC hospitals received specialized neonatal attention in Neonatal Intensive Care Units (NICU’S) due to premature birth and low to very low birth weight. An additional 5% of these children required extra more intensive medical intervention. This percentage includes 2% of children either born very premature and with extremely low birth weight, or born “small for their gestational age” (SGA) (Goelman et al., 2007; Goelman et al., 2008). Major circulatory and/or respiratory complications may impact on the central nervous system. These may include intra-ventricular hemorrhage and/or respiratory distress syndrome that are associated with very premature birth and to very to extremely low birth weight (Donovue, 2002; Escobar, Littenberg, & Petiti, 1991; Sankaran, 2002; Schiariti et al., 2007; Synnes et al., 2001; Vohr, 2003). Longitudinal studies have reported global developmental delays and specific developmental disabilities for a significant proportion of former “NICU” treated children, adolescents, and adults, who survived these and other major complications soon after birth (Chelsea et al., 2004; Vohr et al., 2003; Vohr & Msall, 2004; Vohr et al., 2000). The findings of longitudinal studies are supported by Hebbeler et al.’s (2007) recent report. Hebbeler and colleagues confirmed that 38% of

the children referred to early intervention services between birth and three years received neonatal intensive care treatment associated with premature birth and low birth weight.

Follow-up for developmentally at-risk infants and children in British Columbia. In British Columbia, Neonatal Follow-Up Clinics provide multidisciplinary diagnostic services for preterm infants treated in NICU's. Only a small percentage of extremely "at-risk" children, including those with gestational age under 25 weeks and with birth weight <800g, or those infants considered "small for gestational age," are systematically followed up by the Provincial Neonatal Follow-up Program (NFUP) after their discharge from the NICU's (Chan et al, 2001; Goelman et al., 2006; Synnes, Lefevre, & Cake, 2006). These children are seen by a multidisciplinary team through comprehensive, multi-disciplinary medical and developmental assessments scheduled between the ages of 1 and 5 years old. This team includes professionals trained in developmental psychology, in the pediatric medical and health sciences, and in social work. These assessments comprise physical check-ups, neuro-pediatric evaluations, psychological tests, hearing and vision screening, and speech and language batteries, among other components (Synnes et al., 1994; Synnes, Lisonkova, Houbé, Klassen, & Lee, 2004; Goelman & The CHILD Collaborative, in press). Based on the results of their ongoing assessments, the NFUP team provides guidelines to parents and other professionals regarding the developmental follow-up of these children (Goelman & The CHILD Collaborative, in press).

A proportion of the children with very low to extremely low birthweight have

medical conditions that may continue or intensify throughout their first second and/or third year of life (Goelman et al., 2007; Schiariti et al., 2007). These children are more likely to be identified later on as children in need for early intervention support.

Community intervention services provide on-going developmental support for infants and young children and their families in BC; however, almost all intervention services terminate upon school entry. In addition, education policy, budgets, and staffing prohibit on-going provision of remedial services to all but the most disabled school-age former preterm infants (Goelman et al., 2006). For those at-risk children born in British Columbia who are followed up throughout their school entry years, a referral process takes place to service them through either early intervention programs or to specific pediatric therapies like physiotherapy and occupational therapy, according to Fuchs and Hungerford's report (2005). A description of developmental assessment practices in British Columbia will be presented later on in this chapter.

Research on Developmental Screening/ Surveillance and Assessment

Researchers and practitioners in the early intervention field concur on the need for early identification of special needs and/or at-risk factors that have been known to impact on the development of young children (Goelman et al., 2007; Guralnick, 1999; Meisels & Shonkoff, 2000). Moreover, researchers and practitioners agree on the importance of incorporating different levels of assessment into this ongoing screening and surveillance process that reflects an ecological framework. These current developmental assessment models include the family context as well as other environmental and psychosocial context factors, as mentioned earlier in this chapter (Coleman et al., 2006; Hebbeler et al., 2007; Krauss, 2000; Sroufe, Egeland, Carlson,

and Collins, 2005). Nonetheless, the discussion continues around the effectiveness of developmental screening and surveillance, and in particular, to the examination of universal vs. targeted screening and surveillance practices –similar to the screening and surveillance practices described in the previous section with regards to British Columbia’s Neonatal Follow-up (NFUP) Program.

Attention to targeted screening and surveillance practices came as a result of systematic early intervention research conducted in the 1980’s and 1990’s (Farran, 2000; Guralnick, 1999; Meisels & Provence, 1996). This research identified the major biological and environmental risk factors that impact upon the developmental outcomes of infants and young children; hence the use of term “established” for developmental risks, conditions, or disabilities (Spiker, Hebbeler, & Mallik, 2005). Established risk conditions include chromosomal abnormalities such as Down’s syndrome; congenital anomalies, such as spina bifida; substance abuse, such as FAS and/or premature birth associated with extremely low birth weight, among others (Connor & Stresissguth, 1996; Chudley et al., 2005; Hebbeler et al., 2007; Vohr & Msall, 2004). This research responded to changes in legislation in US’ PL 94-192 and Part C (Early Intervention Services for Infants and Toddlers) of the Individuals with Disabilities Educational Act (IDEA). These revised legislations addressed the issues of accuracy and fairness in the assessment and service provision for children with identified developmental risks and disabilities (McLean, 2004). Recommendations from these legislative revisions were also followed by some provinces in Canada, including BC (Brynnelsen et al., 1993; Goelman et al., 2005).

As a result of this research, assessment tools over the past three decades have

gradually been refined to identify the different and unique skills of children with diverse developmental and learning needs. Some of the changes in the components of the developmental assessment process include the incorporation of less traditional forms of assessment. For example, these include use of parent-reported measures such as surveys, questionnaires, and interviews (Glascoe, 1997, 2000; Klassen et al., 2003; Lynch & Hanson, 2004) as well as anecdotal recording and observations collected by early intervention service providers and preschool and daycare teachers. Therefore, these tools can better determine the actual performance of children with established health and developmental conditions ranging between moderate to profound in their intensity of severity and degree of impact with a higher of accuracy than previously could be determined with more traditional assessment tools (Bailey, 2004b; McLean & Crais, 2004). This higher accuracy of the revised developmental assessment tools was the result of incorporating non-biasing elements such as the assessment of non-verbal language skills. Tools are also conceived from a perspective of cultural diversity, and reflect cultural differences that help to portray a fair and accurate portrait of the children's skills and the needs of their families (McLean & Crais, 2004; Crais, Poston Roy, & Free, 2006). The development of such tools follow the work of John Ogbu and collaborators about cultural expectations related to performance in minority students in U.S. schools (Ogbu, 1981; 1987). These changes in the selection of assessment components and tools are currently impacting on the emerging models of assessment and intervention (Coleman et al., 2006; Hebbeler et al., 2007).

The evolution of developmental assessment tools for the purposes of screening and assessment has brought increased benefits in the identification and follow-up to

children with established conditions of developmental risk. The current assessment tools can identify the areas in need for special support, given the intensity and severity of these children's developmental conditions, with the likelihood of a health-related or neuro-developmental disorder and/or sensory impairments being associated with their developmental conditions (Frankenburg, 2002; Meisels & Provence, 1986). Following the completion of a systematic process of developmental screening and assessment for most of the children with established risk conditions, a "special needs" designation would entitle these children and their families to receive specialized services (Gilliam et al., 2005; Hebbeler et al., 2007; Meisels & Shonkoff, 2000).

This is not necessarily the case for other developmentally at-risk children whose subtle difficulties are not readily identified by current assessment tools (Frankenburg, 2002; Gilliam et al., 2005; Glascoe, 1997, 2000). Hence, current research has very recently shifted its focus from diagnosis, intensity and severity to issues of sensitivity, specificity, and reliability of the tools utilized by clinicians and practitioners. The purpose of this shift is to determine which tools can actually help clinicians and other service providers to identify developmental delays and disabilities for this group of children in the "grey area" of development during their first three years of life (Ford & Dahinten, 2005; Glascoe, 1997, 2000; Horowitz et al., 2007). Two initiatives support this shift in conceptual thinking about early intervention. One is the "Recognition and Response" system, described by Coleman et al. as "an early intervening system for young children at-risk for learning disabilities" (2006, p.1). The second initiative is the "Response to Intervention" (RTI) model which derives from the "Recognition and Response" system, and is an integral component of Part C

of the IDEA Act. The RTI model is based on work conducted by Deno (1985), and by Berman (1985) (as cited in Coleman et al., 2006, p. 10).

Both the “Recognition and Response” system and the “Response to Intervention” model rely on a multi-level tier of services. These services operate within an ecological framework represented in a pyramid with the family at its base. The “Recognition and Response” system deals with the processes of screening and surveillance. The system promotes universal screening and surveillance processes so that all children and not just the ones with established risk, health, or developmental conditions can be followed up according to their unique needs (Hebbeler et al., 2007). Early interventionists working with the “Recognition and Response” system acknowledge the transitory nature of some of the more subtle developmental conditions identified between birth and age three years. The structure of this system includes pathways to access ongoing treatment and intervention for those conditions with different degrees of severity and levels of impact that will last during the child’s lifetime (Coleman et al., 2006). As such, the system integrates a variety of formal and informal tools and utilizes different forms of assessment that include the perspectives of families and the reports of service providers documenting changes in the children’s overall developmental outcomes over time –and the issues and needs expressed by families serviced (Coleman et al., 2006, pp. 23-24). The role of the Response to Intervention (RTI) model (see Appendix K) would be to implement the recommendations derived from the findings identified throughout the Recognition and Response early intervention system. The system places a central role families; however, multi- or interdisciplinary teams coordinating intervention services are

usually case managed by a professional (for example, a pediatrician) and continues to be centre or agency-based. Nevertheless, current reports on early intervention service provisions continue to identify home visits as the predominant model of early intervention services for families with children from birth to age years (Committee on Children with Disabilities, 2005; Hebbeler et al., 2007). While both of the “Recognition and Response” and “Response to Intervention” initiatives are currently being implemented in the US; other countries and regions are examining similar systems and models to address the urgent need of early identification of children at-risk for more specific developmental delays or learning disabilities (BC Ministry of Child and Family Development, 2007a; Committee on Special Needs Children, 2007; Pretis, 2007). Hebbeler et al.’s (2007) previously cited recent report of the “National Longitudinal Study of Early Intervention” has, in fact, documented parents’ ratings of early intervention services. Out of the participating 3,338 families, 99% of the interviewed parents had a highly positive attitude about their first encounters with early intervention service providers in either home or centre settings. In addition, most parents feel listened to by early intervention service providers (pp. 2-5).

The status of special needs services in British Columbia: Assessment practices.

In the current health and educational systems in British Columbia, Canada, it is the labeling of specific diagnostic medical and/or developmental conditions that allows for children to qualify for funding so that they can apply for and eventually receive individualized support services during their preschool and school years (BC Ministry of Education, 2000b). In British Columbia, children with moderate to severe health or medical conditions, who may also exhibit developmental delays of moderate, severe,

or profound degree of intensity, are the same children who may be eligible for diagnostic assessment, systematic follow-up, and referrals to intervention and therapy-based programs from the time of their diagnosis, through their toddler and preschool years and onto their school years (Goelman et al., 2006). Funding for these children requires their being officially labelled with “special needs” under one or more established high or low incidence categories that meet specific clinical or professional criteria pre-established by the BC Ministries of Health and/or Education. Examples of these categories include chronic health conditions and pervasive developmental disorders, conduct disorders, or learning disabilities (BC Ministry of Education, 2000b). The age range for the identification of these conditions varies, as it has been documented by Hebbeler et al. (2007). While moderate to severe health and developmental conditions will probably receive attention between birth and age 3 years (Goelman et al., 2006; Office of the Provincial Advisor, 2006), mild to moderate health and/or developmental conditions would not receive support until a final diagnosis or an established developmental risk is confirmed. In BC, the Provincial Supported Child Development Program will provide developmental support services for children between the ages of 3 and 12 years, within these guidelines of identification and diagnosis (BC Ministry of Child and Family Development, 2007a).

The BC model of early intervention and remedial services provision is guided by specific criteria that stem from two models. One is the medical model of services where a medical specialist must provide a health or developmentally-linked diagnosis of an established condition (Committee on Children with Disabilities, 2005). The diagnosed or established conditions are expected to meet the Province’s criteria for

funding. The second one refers to the use of the discrepancy criteria between skills and performance to determine differential diagnoses regarding cognitive abilities; for example, cognitive delays and general and specific learning disabilities (Coleman et al., 2006; The Advocacy Institute, 2006). Therefore, in order to receive early intervention services in BC, children must be assessed with specific tools that will demonstrate their performance being at least two standard deviations below the norm; show a significant difference between verbal and performance scales that indicate a discrepancy between the student's intellectual aptitude and their actual academic skills; and/or reveal sensorial and/or physical and/or motor impairments that compromise their independent functioning at home and/or at school. Special needs funding entitles young children and their families to access pediatric therapies like physiotherapy- and occupational therapy; speech and language therapy; and behavioural intervention therapies (BC Ministry of Children and Family Development, 2007a). During the preschool years, these children may apply for placement at "inclusive" preschool and/or daycares, and have their individual needs met through the required adaptations and accommodations to the learning and physical environment specified in an individualized program (BC Ministry of Child and Family Development, 2007a). As they enter school, "remedial" services that target the specific developmental and learning needs of these children are intended to continue within the context of inclusive classrooms and schools. The expectation for children is that they will be assigned with support staff who can effectively work under the guidance of a specialized teacher, and in conjunction with parents, the classroom teacher, and school administrators, following the prescribed outcomes indicated in the

child's "Individualized Educational Program (IEP)" (BC Ministry of Education, 2000a; Learning Assistance Teaching Association of BC, 2002). The next section describes the characteristics of early intervention practices that are intended to address the diverse needs of developmentally at-risk infants and young children and their families, and presents current research reports on the effectiveness of such practices.

The Need for Early Intervention for Developmentally At-risk Children: Current Research and Practices

Findings of numerous studies in early intervention in BC and elsewhere in Canada, the US, and the Netherlands have confirmed the need for early intervention programs that target infants and children either identified with disabilities or at-risk for developmental delays, and their families (Bhutta et al., 2002; Butler et al., 1999; Guralnick 1997, 1998; Meisels & Shonkoff, 2000; Zero to Three and Ounce of Prevention Fund, 2000; Walther et al., 2000; Whitfield et al., 1997; Wolke & Meyer, 1999, among others). To date, developmentally at-risk infants and toddlers referred to early intervention services represent over 2 % of the North American (Canada and the US) population under age 3 (Cossette, 2002; Hebbeler et al., 2007). A wide range of developmental differences exist among these children. Criteria of "severity" and "intensity" are generally used to describe suspected delays, or identified disabilities, already exemplified in the "Definition of Terms" section. Children born with severe to profound conditions that impact on their health and overall areas of development will generally end up with a medical and/or a developmentally-linked diagnosis within their first year of life (Allen & Alexander, 1999; Bailey, Skinner & Warren, 2005) with some of the diagnoses even being detected prenatally (Wald, George, Smith,

Densem, Petterson et al., 1996). As previously mentioned, Hebbeler (2007) and collaborators (have used biological, environmental, and psychosocial risk factors as criteria to determine the level of early intervention services that the infant and/or young child might need, and these can be used to anticipate some of the paths that the children and their families could follow. For example, a child with an established health condition or with a diagnosed disability will most likely be involved with multiple levels of intervention since birth, through a multi- or interdisciplinary team providing ongoing assessments.

These processes of assessment, diagnosis and access to specialized services are similar for children with moderate to severe delays in one or more areas of development. Given the high level of severity and degree of intensity of their conditions, it is very likely that these children will be identified with special needs by the age of three if consistently followed-up with developmental assessment tools (Allen & Alexander, 1999; Bailey et al., 2005; Baird et al., 2001; Bremberg & Lindstrom, 1997; Gilliam et al., 2005; McLean, 2004). Recently reported findings from Hebbeler et al.'s (2007) national longitudinal study on early intervention services have confirmed these reports. While the prevalence of severe to profound developmental disabilities corresponds to approximately 3% of the 0-3 child population (in comparison with up to 11% children with unspecified developmental delays), the specific group of children with severe to profound disabilities accesses early intervention services at approximately seven months of age. Children with developmental delays are only identified by 16 months of age (pp. 2-9). These statistics reporting the time of referral for early intervention services closely

correspond to those of the Infant Development Program of BC (Office of the Provincial Advisor, 2006). The first group of at risk children for severe to profound disabilities represent up to 35% of the referrals between 6 – 12 months of age; the second group of children with moderate to severe developmental delays account, instead, for approximately 20% of the referrals, and they are mostly referred between 12-18 months of age (Office of the Provincial Advisor, 2006).

In addition, within the classification of developmentally “at-risk” young children referred to early intervention programs, some of these infants and toddlers may exhibit difficulties that are also identified or at least “flagged” by the age of 3 years old (Bailey et al., 2005; Frankengurg, 2002; Gilliam et al., 2005; Glascoe, 1997). However, young children can be found whose developmental and/or learning differences might be subtle enough that they are not identified by early screening and assessment tools, until they are older and well into their school years (Frankengurg, 2002; Gilliam et al., 2005; Glascoe & Dworkin, 1993; Horowitz et al, 2007; McLean, 2004). This broad “at-risk” category constitutes approximately 30% of the Infant Development Program of BC’s referrals received each year (Office of the Provincial Advisor, 2005, 2006), and corresponds with Hebbeler et al.’s (2007) proportion of at-risk infants and young children referred to early intervention services (p. 2-2).

Current referrals conducted by community-based professionals such as family physicians to early intervention programs, including the Infant Development Program of BC, tend to target either those children with diagnosed developmental delays, or those who have been identified by hospitals following neonatal treatment for moderate to severe complications requiring medial follow-up, as previously described. Research

in early intervention programs indicates that most professionals working in early intervention are specifically trained in the development of young children with special needs (McLean, 2004; Zero to Three and Ounce of Prevention Fund, 2000). Few early intervention professionals, however, have been introduced in the use of screening tools with high sensitivity and specificity (Glascoe, 1997; Horowitz et al., 2007); such tools would allow early interventionists to identify more subtle developmental conditions (Ford & Dahinten, 2005). In terms of service delivery, these professionals are trained to play several roles according to the child's developmental profile and needs. For example, they may monitor families with children considered to be in the broader category of "at risk for developmental delays" through periodic telephone calls, and/or using quick screening tools such as the Ages and Stages Questionnaire (Bricker & Squires, 1999; Squires, Potter, & Bricker, 1999) and the Nipissing District Developmental Screen (Nipissing District Developmental Screen Property Association, 2002). In the case of children with identified "developmental delays" or with diagnosed "developmental disabilities" and their families, these professionals will, instead, provide ongoing support in the form of regular home visitation sessions that may be periodically followed up with formal assessments (Bailey, 2004a; Zero to Three and Ounce of Prevention Fund, 2000). A specific example of these levels of services is provided later on in this section.

Early Intervention Programs in BC

Funding for early intervention services at a preventative or primary prevention level in British Columbia has been in place under the mandate of the 1999 Government of Canada's National Children's Agenda, an agreement conducted in

partnership with territorial and provincial governments (Government of Canada, 2001, 2002). Following the Agenda's priorities on the needs of young children and families, a federal/provincial/territorial Early Childhood Development Agreement was announced with four key foci: promoting healthy pregnancy, birth, and infancy; improving parenting and family supports; strengthening early childhood development, learning, and care; and the strengthening of community supports. Funding was, thus, provided for programs if they would a) focus on early intervention and prevention; b) value diversity in terms of the children's abilities, ethnicity, and language; c) provide community support to the families and children; and d) provide a cross-sectoral form of service delivery from different professions and disciplines (Goelman et al., 2005, p. 440).

In British Columbia, secondary level intervention programs are, instead, represented in different agencies and programs, including the Infant Development Program of BC, the Supported Child Development Program of BC, and the Child Development Centres, as well as multi-disciplinary based agencies; for example, the Centre for Ability and the Alan Cashmore Centre. Of these agencies, only the Infant Development Program of BC provides Province-wide, home-based, and family-centred early intervention services from birth to age 3 (Brynelsen, et al., 1993). The Supported Child Development Program provides in-centre and in-home consultation with staff, teachers and parents of children with identified special needs (www.scdp.ca). The BC Centre for Ability provides assessment and either in-centre or in-home direct therapy services for children ages birth to 6 years old with identified special needs (www.centreforability.ca). In contrast to the IDP where self-referrals are

accepted, families need a referral from a professional working with the child and family; for example, infant consultant, teacher, physician, or social worker, among others, stating the special needs status (or in process) of the referred child in order to gain access for these programs. In British Columbia, the IDP Program is the only one of its kind to provide services since birth. The early intervention and special needs support programs listed above, including child development centres, or CDCs, provide therapeutic oriented services, and/or assist families in supporting children ages 3 and older (Fuchs & Hungerford, 2005). These programs are not included within the family-centred approach and home-based service delivery model categories.

Overview of the Infant Development Program of BC²

Early intervention support in British Columbia has proven successful in reaching and serving developmentally at risk children and their families for over the past 30 years (Goelman et al., 2005). Extensive documentation has occurred regarding individual programs' activities (Brynelsen, 1990; Brynelsen et al., 1993; Goelman et al., 2005). The Infant Development Program of BC specifically targets the developmental needs of young children and their families (Goelman et al., 2005). This is one of the few programs in BC led by a Provincial Advisor, The Office of the Provincial Advisor provides guidelines and ongoing training for all programs across the Province, while, at the same time, supports the individuality of each program within their community and region. Since 2002, the Office of the Provincial Advisor of the Infant Development Program of BC works in conjunction with the Aboriginal Infant Development Program Provincial Advisor (Office of the Advisor, Aboriginal

² The Infant Development Program of BC: www.idpofbc.ca

Infant Development Program of B.C., 2004, 2006). As a secondary early intervention program, the Infant Development Program monitors the development of children birth to age 3 years who are at risk for developmental delays, or who have been identified developmental disabilities. The program provides assessment and follow-up services for these children and their families (Goelman et al., 2005). The Infant Development Program follows provincial guidelines for the operation of the regional infant development programs throughout the province. As mentioned in the first chapter of this study, the program is based on theoretical developmental principles that stress the importance of the early years, that can alleviate the impact of delay or disability through early intervention, and that the family unit is essential to the healthy development of the child (Brynelsen, 1990; Brynelsen et al., 1993). The Provincial Advisors are accountable to the Provincial Steering Committee and to the BC Ministry of Children and Family Development (Goelman et al., 2005; Office of the Provincial Advisor, 2004, 2006). Since its inception in 1972, the program has assisted over 79 000 families in British Columbia (Office of the Provincial Advisor, 2006). The program has also provided extensive documentation regarding individual programs' activities and resources (Infant Development Program, 2004), with detailed biennial programs' statistics collected over the past 20 years (Office of the Provincial Advisor, Infant Development Program of BC, 1983, 1994, 2002, 2004, 2006). Programs and services have continued to expand in different provinces since the 1970's and throughout the 1980's (Marfo, 1991, 1995; Office of the Provincial Advisor, Infant Development Program of BC, 2006). The early intervention model of services implemented by the Infant Development Program of BC has been described by

Goelman et al. (2005). A chart with the IDP model of services is presented in Appendix J.

For the purposes of the study, it is important to highlight the two different levels of early intervention services that are provided by the Infant Development Program: the home visitation and the monitoring level of services. The decision regarding which level of services is required by each family is made in conjunction with the parents at the early stages of referral to the Infant Development Program through the completion of the “Family Needs Survey” (see Appendix A). This study seeks to target participants that have been served by the Infant Development Program of BC in either the home-visitation or the monitoring level of services. The home-visitation services targets those children who have been referred to the program because of one of the following reasons: (a) compromised developmental conditions or disabilities, (b) developmental delays observed, or (c) identified risks that may lead to developmental delays. The home visitation sessions are booked with the parents in an interval of three to five weeks and last approximately one hour. The Infant Development Program Consultants and the parent(s) meet to share information and experiences on a variety of issues related to the development and well-being of the child, as listed in the “Family Needs Survey” (see Appendix A). Depending on the child’s unique needs, a physiotherapy consultant and/or other professionals involved in the developmental follow-up of the child; for example, “Deaf and Hard of Hearing” consultants, may also be present and/or regularly involved with Infant Development Program home visitations. Home visitation summaries with recommendations and follow-up plans and activities are recorded and filed, with copies given to parents after

each visits. These filed summaries constitute one of the recorded documents that the study will access within the data collection process, through the file reviews. On the home-visitation level, the study seeks to recruit families with the following characteristics: families with children either identified with “global developmental delays” within their first year of life and subsequently referred to the Infant Development Program; and families with children exposed to moderate to severe risk factors at birth; these children usually end up identified with developmental disabilities, or “specific developmental delays” by age 3 years.

The home-visitation level of intervention is different from the “monitoring” intervention level in both the frequency and the intensity of contacts and follow-ups between the family and the Infant Development Program consultant. The “monitoring” level of services consists of regular follow-up to families via “telephone visits” and/or through on-site consultations. These are recorded with memos labelled “Telephone Visit Records” (see Appendix G) that list and describe the current needs of the families. Occasional home visits are made, most often to complete an informal screening or to discuss assessment and/or transition plans. The “monitoring” level of services is provided for children and families also referred to the Infant Development Program under the “at-risk” category between birth and age 3. The difference with families with children with established or identified developmental delays, is that the “at-risk” children are not diagnosed with a medical and/or developmental condition by the time they leave the Infant Development Program at age 3. Many of these children are described as “catching up to norm” before age 3 and are discharged from the program early on (Office of the Provincial Advisor, 2004, 2006). As they grow older

(age 5 and over), a number of the children in this specific “at-risk” category may require further assessment to rule-out specific learning and/on behavioural needs that in turn require specialized intervention during their preschool years (Gilliam et al., 2005; Horowitz et al., 2007).

Research supporting the Infant Development Program’s family-centred model.

Current research has reported how the family-centred model of services empowers families with children developmentally at-risk in terms of encouraging parents to actively participate in the decision making process and planning activities for their children. At the same time, studies that have evaluated the effectiveness of early intervention programs report a strong commitment from early intervention services that operate under family focused models (Dunst, et al., 1986; Dunst, Jenkins, & Trivette, 1988; Karuza et al., 1988; Turnbull & Turnbull, 1985, 1993, 1995, 2001). Ramey, Krauss, and Simeonsson (1989), as well as Ramey and Ramey (1998), have, in fact, highlighted the mutual influence of families (parents, caregivers and siblings) on early intervention service providers and vice versa.

The early intervention model of services embraced by the Infant Development Program of BC follows Dunst et al.’s (1988) theoretical framework of family-centred model for early intervention services (Infant Development Program, 2004). Dunst et al. (1988) have stressed how the needs of the family and not the imposed direction of the consultant or therapist assigned to each family must guide the intervention program for each child. The framework has been conceived within an ecological model that acknowledges the many levels of influence within the child, family, and community (Bronfenbrenner, 1979, 1986, 2005). Implementing this framework within

a home-visitation model of services, in turn, supports the Infant Development Program program's intention of promoting and enhancing healthy attachment patterns between parents or caregivers and their children and of supporting parents' sense of self-efficacy. This theoretical framework that originally draws from both attachment (Bowlby, 1973) and self-efficacy theories (Bandura, 1973, as cited in Forman & Sigel, 1979), is discussed in depth in Olds (2004) and in Olds and collaborators' longitudinal study about nurses' home pre- and post –natal visitation program (Olds, Eckenrode, Henderson, Kitzman, Powers, et al., 2007). The study followed mothers of infants and young children considered to be at-risk for environmental reasons (poverty, single mothers, and/or with perceived little or no self-confidence in their psychological resources). The findings of the study confirmed significant, long-term positive effects of the home visitation process on the health and well-being of children who were sustained until adulthood. Specific benefits in terms of the children's developmental outcomes were reported for those cases where mothers reported little or no self-confidence in their own psychological resources. These findings are supported by related studies (Kitzman, 2004; Olds et al., 2007; Wadsby et al., 2001) and reported in other publications, including policy reports focusing on the effectiveness of home-based services in the early childhood years, and the continuity of early child development services for targeted or at-risk populations (Drummond, Weir, & Kysela, 2002; King & Meyer, 2006; Santos, 2005, among others).

Child-focused services. In contrast to family-centred services, child-focused early intervention services continue to operate following a more traditional orientation towards services that originate in the medical model of care (Guralnick, 2005; Zelman,

1996). Although child-focused services may include a home-visitation component, their working model is oriented towards addressing the needs of the child as the identified “client” or patient physically attending a program where services, usually of therapeutic nature, are provided and guided under the leadership of professional expertise (Committee on Children with Disabilities, 2005). These therapeutic-guided practices are reflected in the more traditional early intervention practices where a multi- or inter-disciplinary team focuses on the child’s development and invites the family to participate in the implementation of a service intervention plan, usually to comply with mandated government or agency service provision guidelines. Such is the case of the Individualized Family Services Plan³ (McLean, Wolery, & Bailey, 2004a).

This professional leadership may be also identified within educational, non-therapeutical programs providing early intervention services for young, preschool children, and that rely on early childhood educators’ leadership (OECD, 2004). Doherty, Friendly, and Beach (2005) have used the term “pre-primary curriculum” practices to describe preschool programs that operate through the structuring of detailed goals and outcomes that determine or influence planned or curriculum decisions about what and how children learn, and what they are expected to learn, under a school “readiness” model. Within the child-centre approach, the more traditional pre-primary curriculum model contrasts with the social-pedagogic model also implemented in early childhood educational settings. This model acknowledges the context of family and community as major influences in the child’s development, works with trained practitioners who are highly reflective on their practices and place less stress on the accomplishment of goals; and rely on ongoing observation that may

³ See Appendix A for an example of an IDP Individual Family Services Plan.

include developmental screening if advisable (Bertrand, 2007, p. 4).

In summary, current research continues to support the delivery of highly specialized and individualized early intervention services for developmentally at-risk children; at the same time, researchers investigating service delivery practices for children and families have found compelling evidence about the effectiveness of family-centred early intervention service models, over services that are primarily child-focused. The last section of this chapter takes a look at literature concerning families of at-risk children in order to add context to the previously cited family-centred early intervention research.

Research on Families with Developmentally At-risk Children

Current qualitative research exploring the lives of families has discussed the implications of ontological assumptions about human development on this work. These assumptions include the acknowledgement of ecological contexts and time as central elements in the understanding of individual families (Bronfenbrenner, 1979, 1986, 2005; Daly, 2007, among others). Pratt and Fiese (2004) as cited in Daly (2007) have described how the family is central to the ecological context, and it serves as an intermediary between individual and the wider cultural contexts. Families provide a place for children to learn, and try to maintain a delicate balance between the individual priorities of their members, and the collective family history (Miller et al., 2005). Within the family life cycle, each transition represents a central focus in the development of both the individual and the collective family. A retrospective approach is important in the study of families, as it allows the researcher to examine and understand family transitions; that is, how families change over time (Daly, 2007).

Individual members in families grow biologically, they also need to adapt to external contexts and events, such as historical events, cultural norms, and social structures. Thus, families change in both the socially defined events they enact, the roles they play, and the identities they represent over time (Giele & Elder, 1998, p. 22).

Through their own testimonials, parents of developmentally at-risk children have given strength to this ecological perspective (Turnbull, 1985; Turnbull et al., 1998; Turnbull & Turnbull, 2001). In *Growing up Together*, Jane Schulz (Turnbull & Turnbull, 1985) candidly analyzes her roles, attitudes, needs, and concerns as a parent of a child with cognitive and developmental delays. Schulz effectively describes how family life and the needs of parents of children and adults with disabilities are generally the same as the needs of any other family. The difference lies in the fact that parents of children with special needs lack clear precedents, for each stage that their child and family embarks on, and have limited alternatives in comparison to the rest of the families (p. 5). Schulz takes a look at the ongoing changes and transitions that are typically expected in families, through the lens of the transitions with her other children, as they grow up towards full independence. Conversely, the process of supporting a child with a disability to become an independent adult is described by Schulz as an ongoing struggle that goes beyond the expected challenges of parenting. Schulz characterizes this process as one rooted in a deep awareness of the child's needs, demands, and self-examination of abilities and limitations; anguish throughout each major transition lived, and acceptance of shattered dreams, of limitations, of social exclusion –and confronting even ostracism from the surrounding community. Schulz's vivid account and plea for a full participation of both parents and children

with disabilities in major decisions relating to children and adults with disabilities is also echoed by other parents (Turnbull et al., 1985, 1993, 2001). Their voices resonate in researchers' work that has identified similar experiences and processes in parents of developmentally at-risk children (Crnic, Friedrich, & Greenberg, 1983; Krauss, 1992, 1994; and, McCubbin & Patterson, 1981, as cited in Krauss, 2000, p. 293).

Krauss (2000) presents an example that illustrates family interactions from the perspectives of the roles of caregivers. Krauss introduces McCubbin and Patterson's (2000) model of coping, through the authors' work with aging families, and how do caregivers cope with stressors (p. 293). McCubbin and Patterson utilize a four component model (the ABCX model). This model describes the characteristics of stressors, labelled (A). (B) represents the meaning the stressor has for each family; (C) stands for the resources available for the caregiver to cope with the identified stressor; and, (X) refers to the individual qualities of adaptations of the caregivers. A more specific perspective on stress and coping among families with developmentally at-risk children is presented by Santos and McCollum (2007). Their research is cited and further discussed by Margalit and Al-Yagon (2007). Santos and McCollum compared levels of stress between families with children who had specific (or established) disabilities such as Down's syndrome, versus those families with children who had non-specific disabilities, for example, developmental delays. These authors found no significant difference between the reported levels of stress between either of the two groups of families. Differences in the perceived levels of stress and in coping strategies for families with developmentally at-risk children were identified, however, in families with different beliefs and attitudes towards their children's disability

(Margalit & Al-Yagon, 2007). Families rating higher in levels of “hope” appeared to report lower levels of stress and accessed more coping resources than the rest of the families. Margalit and Al-Yagon’s work was framed within Snyder’s (2002) hope theory and referred to Antonovsky’s (1987) “salutogenic” model. Snyder’s hope theory refers to the capacity of individuals to self-motivate in pursuing certain pathways, in order to successfully reach their desired goals. Antonovsky’s salutogenic model focuses on explaining the origin of health, rather than explaining the causes of disease, and looks at the continuum and not at the dichotomy between health and disease (Margalit & Al-Yagon, 2007).

Similarly to these authors, Pearlin, Mullan, Semple, and Skaff (1990, as cited in Krauss, 2000, p. 293) have developed a conceptual model that examines the roles of care providers within the context of caregiving. These authors identify a relationship between stressors and coping strategies in families with developmentally at-risk children. The authors specifically raise the issue of the need for researchers and practitioners to look at the caregiver’s characteristics and how these influence the dynamics and consequences of caregiving (p. 293). Kelly, Booth-LaForce, and Spieker (2005) have also examined the issues of stress and coping strategies in families in looking at the importance for researchers to recognize the families’ own resources when implementing an early intervention program. Researchers including Bailey and Powell (2005); Crnic et al. (1983); Dunst et al., (1988); Ramey et al., (1989); Sroufe et al. (2005); and Seltzer and Krauss (1994), among others, have used a different lens in their research concerned with families and early intervention as they examine the context of caregiving from the parents’ perspective. These authors

identify some of the factors that affect the adaptation of parents to the task of rearing a developmentally at-risk child. For example, Sroufe et al. (2005) examined the multiple influences of caregiving that impacted children with challenging temperamental traits and who were identified with attention and learning difficulties during their school years. Many of these children were considered to be at-risk due to environmental influences like poverty. Sroufe (2005) and collaborators particularly focused their work on what they have termed the “organizational perspective of development.” These authors examined the caregiver-infant dyad and the influences exerted by both members of the dyad in shaping their first relationships –together with the external influence of environmental and psychosocial factors (pp. 39-40). A second example refers to Bailey and Powell’s (2005) work on listening to the needs of families. These authors report how families have identified key informational issues that are relevant for them as the recipients of early intervention services. These issues include accessing specific information related to the developmental needs of their child; obtaining strategies to relate to other members of the family; and being able to communicate their needs and issues to other people about how their experiences of living with a child with unique developmental needs influence their lives. Other work conducted by McWilliams (2005) and Kelly et al. (2005) report similar findings from families with developmentally at-risk children. These examples illustrate issues other than developmental outcomes that need to be taken into account by early intervention programs in their ongoing evaluation and implementation of their services with families.

Significance of Literature Review to the Current Study

This study contributes to the current literature in response to a shift in the focus of research. Moving away from the perspective of a child-centred ‘developmental outcomes’ model, research has turned towards a family-centred model, and more recently, on to an exploration of integrated systems models that influence policy decisions on inclusive and universal early intervention service provision (Halfon, Uyeda, & Inkelas, 2004; Shonkoff, 2000, 2004). The Response to Intervention (RTI) model (see Appendix K) is a very recent example, as it provides a framework for the creation of programs that target a wide range of at-risk children and that address their unique needs (Coleman et al., 2006; Hebbeler, 2007; The Advocacy Institute, 2006). Through the power of parents’ voices, this study contributes to the understanding of “what works” about programs currently available in British Columbia for developmentally at-risk children, echoing McCollum (2002, p.5). At the same time, and as previously mentioned, the effectiveness of early intervention was more recently examined by Hebbeler et al.’s (2007) report. This information is relevant and highly informative to similar programs elsewhere in Canada and North America. It’s practicality and efficacy consists in pointing at, describing, and analyzing issues around the different models of service delivery for families with children with established risks and children with suspected risk who end up as ‘unlabelled’ preschool children. Even more so, the study also suggests the need for an in-depth revision of the models guiding service delivery, at a time when parents and community voices are gaining strength (Committee on Children with Disabilities, 2001; Glascoe, 1997, 2000; Mahoney et al, 1998; Shonkoff, 2004). These voices are

taking advantage of successful academic and community partnerships and collaborations, such as the one represented in this study to integrate efforts in addressing the developmental needs of young, at-risk children and their families from a universal and holistic perspective (Coleman et al., 2006; Goelman, Brynelsen, & Pighini, 2007; Goelman & The CHILD Collaborative, in press).

Chapter III: Method

Introduction

Researchers in early intervention for developmentally at-risk children recognize the need to frame their investigation within an ecological framework that includes the family and community contexts of children –a framework that was absent in previous quantitatively based studies (Garbarino & Menzel, 2000; Guralnick, 2005; Scarborough et al., 2004; Shonkoff, 2000). As such, authors of recent studies in early intervention have incorporated some of the qualitative methods of inquiry used in the social sciences literature (Hirschberg, 1996; McWilliam & Bailey, 2000; Scarborough, 2004). At the same time, and using this same broader ecological framework supporting the study of early intervention, qualitative researchers are interested in understanding the changing realities of families and their ongoing transitions, as well as the different meanings of these realities (Daly, 2007; Denzin & Lincoln, 2000; Lincoln & Guba, 2000). This chapter will explain the research design and procedures of the study, with a previous description of the epistemological assumptions and the tradition of inquiry guiding its method.

Paradigm of Science: Post-Positivism

This ethnographic study was supported by the post-positivist paradigm that places emphasis on the discovery and verification of theories. Post-positivism relies on the use of multiple methods that assist the researcher in attempting to capture as many aspects of reality as possible (Denzin & Lincoln, 2000, p. 9). Unlike positivist assumptions that position the researcher as the “knower” of external reality, post-positivist epistemological assumptions believe that researchers can only represent an

approximation of reality. While positivist researchers state hypotheses that need to be verified, post-positivist researchers replace the absolute certainty, or “verification.” Therefore, more than one perspective of reality might be experienced by participants (Denzin & Lincoln, 2000). These assumptions converge with the intention of this study to describe the experiences of parents of developmentally at-risk children. Researchers conducting inquiries that follow post-positivistic assumptions recognize that conflicts might exist between the participants’ representation of their realities and the researcher’s point of view. This conflict needs to be acknowledged because it means that data and theories would be intertwined, and that pre-existing theories may provide specific meaning(s) to the data collected. In sum, no such thing as theory-free (or value free) data exists, as post-positivism is rooted in the objectivist practices of induction (Daly, 2007, p. 48). This is still an aspect of controversy among researchers following the post-positivistic paradigm, as it adds to the ongoing debate between the conventional (foundational) positivist/positivist and the less traditional (non-foundational) constructivist/post-modernist paradigms (Lincoln & Guba, 2000). In addition and as already documented by Strauss and Corbin (1998, as cited in Daly, 2007, p. 48), the debate over the post-positivism paradigm representing more of a quantitative method of analysis has been present for several decades. In contrast to positivism, post-positivism has been conceptualized as a “less rigorous” form of scientific positivistic practice that includes reports of participant observation (Denzin & Lincoln, 2000, p. 9). Nevertheless, the post-positivistic paradigm continues to rely heavily on issues of internal and external validity as it seeks to approach the “external” truth.

In the post-positivist paradigm, scientific rigor is supported by the use of triangulation procedures, a procedure described later on in this chapter. Hence, relying on a multiplicity of data is important because this data is expected to confirm the information collected through various sources. Even if the multiple sources of information include (and rely on) the participants' voices, the post-positivist researcher remains in "control" of the information. Member-checks with participants verified the accuracy of the information collected and interpreted. This verification ensured the rigor of the study. In turn, maintaining this scientific rigor ensured the building of the "edifice of knowledge" about the researched issues. In the final sections of this chapter, I will discuss more in depth other issues of rigor, including verification.

As an epistemological posture, post-positivism is radically different from those postures in less traditional forms of inquiry mentioned earlier in this section, like constructivism. The non-traditional forms are based on epistemological assumptions that state that there is no universal or approximate external reality, and that knowledge and knower cannot be dissociated in an internal/external dualism (Lincoln & Guba, 2000). The non-traditional stances invite participants' voices in order to find consensus, and to escape the marginalization that they have been subjected to in the past. Researchers unite their voices with the participants' voices and take an active advocacy role. In contrast, the post-positivist researcher does not become an active advocate for social or political causes, but becomes, in Heron and Reason's (1997) terms a "transformative intellectual" (p. 16) or as a translator of knowledge. The post-positivist researcher reports findings and delineates recommendations for change (to

other academics, to community agencies, to policy makers) based on the verification of what Heron and Reason (1997) have termed “non-falsified” hypotheses (p. 16). In trying to find some convergence between the different epistemological stances, authors Lincoln and Guba (2000) cite previous discussions from Guba and Lincoln (1981, 1982, 1989, and 1994) as well as Lincoln and Guba (1985). These discussions debate how it is possible for the epistemological assumptions underlying this post-positivist paradigm to find commensurability between positivist/post-positivist paradigms that would allow mixed strategies to be implemented. However, these authors acknowledge that commensurability is just a “chimera” between the foundational and non-foundational paradigms (Lincoln & Guba, 2000, p. 185). Within the context of the proposed multiple case study, however, the possibility exists for using mixed strategies of inquiry mentioned earlier in this chapter.

A final topic on the debate on the post-positivist paradigm among non-foundational stances refers to the attempts made to allow for the use of combining quantitative data and descriptive statistics in reporting the findings, within the tradition of qualitative inquiry (Silverman, 2006). The rationale behind this conciliatory position is one that stresses the use and interpretation of the data, instead of focusing on the (quantitative) nature of the data (Lincoln & Guba, 2000; Rosenberg, Schnurr & Oxman, 1990). This study relied on the interpretation of the data and focused on qualitative content analyses methods of data analyses. Nonetheless, counting the frequencies of categories during the preliminary analyses of Stage One participants’ coded responses added to the rigor of this study, by providing this researcher with accurate information in reference to how often and under which particular topics

specific categories were identified.

Multiple Case Study Approach

The multiple case study approach allowed for an in-depth analysis of the participant parents' perspectives of their varied experiences (Creswell, 1998, 2003). For example, given their previous involvement with the IDP of BC, its participant parents were expected to have experienced one or more of the processes of referral, identification, and diagnosis with their children between birth and age 3, at the time of their discharge from the program. A similar process would have happened later on, when transitioning to preschool, daycare, or school. A consistent process of member-checks followed throughout the study to ensure that, together with the researcher's voice, the participants' voices were accurately represented (Lincoln & Guba, 1985, 2000). The chapter includes an in-depth description of this process further along.

Stake identifies three purposes for case studies: intrinsic, instrumental and collective (2000). Two of these purposes, instrumental, and collective, guided this multiple case study. The instrumental process refers to the ways in which this research provided specific insights into issues related to the early intervention service delivery models examined throughout the parents' former participation with the Provincial Infant Development Program of BC. The underlying collective purpose relates to how the study investigated issues anticipated to be common for parents of developmentally at-risk children, as a "population." Participant parents in the study were included in the "collective" category of "parents of developmentally at-risk children." The sharing of similar needs, issues, worries, concerns, and activities gave a unique voice to his distinct group of participant parents. This distinct voice resonated in the different

“communities” where they belong; for example, the community of parents, the community of parents of developmentally at-risk children, and the community at large. The present study is situated within the ethnographic tradition of inquiry, described in the section that follows.

Ethnography

As a tradition of enquiry, ethnography seeks to provide a meaningful context to experiences such as “events,” “encounters” and “understandings” (Tedlock, 2000, p. 163). At the same time, the researcher, in conjunction with the participants, try to understand and interpret the meaning of the parents’ experiences (Tedlock, 2000). Hence, social issues surrounding the complex culture(s) of “developmentally at-risk” children would be identified, for example, barriers, accessibility, and inclusion, among others (Miller et al., 2005). More specifically, the researcher would explore the overarching contexts and activities in which experiences and social issues are embedded for parents with developmentally at-risk children. This means paying attention to the parents’ informal belief systems (or “folk theories”) related to, for example, child development, child rearing, and accessing early intervention support services. In the ethnographic tradition, these beliefs are perceived as collectively shared, as it would be the case of this group of parents. Therefore, they inform and rationalize these experiences and activities (Miller et al., 2005, p. 222).

Through the proposed multiple case study approach, this researcher looked at the experiences of participant parents from a historical background and was bound by a specific period. In his book *Qualitative Methods for Family Studies and Human Development*, Daly (2007) has identified how research with families must include the

contexts of time and place, as well as the timing of events, among other ontological assumptions. As such, the study included the physical setting where events occurred for the participating families. Other contexts were taken into consideration, for example the social and economic contexts, following Stake's (2000) suggestions (p. 438).

In order to acknowledge and represent these different contexts on the participant parents' experiences, the data collection process included multiple sources (Donne-Wamboldt, 1992; Lincoln & Guba, 2000); for example, semi-structured interviews and focus groups, for the pilot stage of the data collection. These sources are listed and described in the Procedures section of the study. The use of these particular methods of data collection draws attention towards the rationale and purpose for choosing certain methods over others within the ethnographic tradition of inquiry. Authors including Schwandt (2000) and Gubrium and Holstein (2000) have elaborated in depth on the ways that methodologies and epistemological paradigms converge. More specifically, and within the constructivist and phenomenological stances, Gubrium & Holstein use the encompassing term of "ethnomethodologies."

By conducting a multiple case study through the use of interviews, as well as focus or discussion groups, the researcher provided parents with opportunities to share aspects of their changing realities in both one-to-one and group contexts (Daly, 2007). More specifically, semi-structured interviews allowed participants to include comments reflecting their values and beliefs while sharing their experiences. Byrne (2004, as cited in Silverman, 2006, p. 114) refers to the interaction between interviewee and respondent (or participant) as a process that takes into account the

other; for example, who the other is, what the other person is presumed to know (p.118). The level of depth reached through open-ended or semi-structured interviews is not reached through the use of other methods of data collection, for example structured interviews, surveys, or questionnaires. These methods, situated within the positivist model of interviews, are more concerned with reliable facts and depend on standardized questions. Conversely, semi-structured interviews and focus groups methods of data collection fall within the “emotionalist” or “constructionist” models of interviews (Silverman, 2006). These models of interviews strive to give a voice to participants whose experiences have not been fully represented in the past (Byrne, 2004, as cited in Silverman, 2006, p. 114). The present study, epistemologically defined in the post-positivist stance, and situated within the ethnographic tradition, was inspired by the guiding principles of the “emotionalist” models of interviewing. Rather than limiting participant respondents to express facts, this model allows respondents to generate information that gives authentic insight into their experiences (Silverman, 2006, p.118). Within the post-positivist stance researchers attempt to report a close approximation to reality. Therefore, although they do not co-construct reality with participants through these interactions (Denzin & Lincoln, 2000), researchers are not bound by strict, standardized methods of data collection. The guidance of the emotionalist model of interviews allowed this researcher to encourage participant parents to share their experiences, not only as a recollection of facts and events, but also as a representation or narrative, personal accounts about their experiences (Baker, 1982, as cited in Silverman, 2006, p.118). At the same time, this researcher made every effort to maintain the ethnographic principle of remaining as

“invisible” as possible throughout interviews, by limiting personal comments that could manipulate participant respondents’ comments and interventions (Silverman, 2006).

Miller (2000, as cited in Daly, 2000, p. 67) acknowledges and incorporates the relationships between participants and their contexts within their families as being extremely important for the researcher to be familiarized with when conducting qualitative research. Inspired by the ethnographic tradition, Miller (2000) and other authors like Pratt and Fiese (2004, as cited in Daly, 2007, p. 67), and Giele and Elder (1998, as cited in Daly, 2007, p. 68), depict families as intermediaries between the individual and the broader cultural contexts –that is, between the individual and collective histories. Giele and Elder (1998) have also highlighted the changing nature of families and the ongoing transitions lived by family members. These authors describe how families not only move from one stage to the next, but also change in their roles and identities throughout the years. It is anticipated that semi-structured interviews and focus groups to be completed in the study will capture some of the complexity of the changing nature of families. This can be facilitated through the sharing of different aspects and components of the participants’ realities. At the same time, the combination of “text and talk” (Peräkylä, 2005; Silverman, 2006) allowed for these different lenses to be brought into the data collection process. The combination of sources of information included textual sources such as file reviews (see Appendix I), as well as other “talk” sources such as member-checks with participants and additional member-checks with IDP of BC consultants. The use of multiple sources of data collection, or data triangulation, is further explored further along in this chapter.

Participation in interviews and focus group discussions elicited participant parents to share their experiences about the time spent with the IDP of BC, as well as their transitions to other programs after they left the program. The detailed process of sharing their experiences encouraged participant parents to unfold a series of events as they went back in time in their memories and accounts. As anticipated, participant parents recalled the early years of their children's lives, and referred to family life events at each stage. This process ended up capturing two types of events: The first one, termed "epiphanies," refers to unusual or unexpected events (Denzin, 2001). Schutz (1971), as cited in Daly, 2007, p. 66) refers to "epiphanies" as "problematic." The second type of event has been described as "mundane reality," and it refers to the more unremarkable events that constitute the daily life (Driver & Gottman, 2004, as cited in Daly, 2007, p. 66). These authors point out the importance of examining the social and emotional aspects of these 'unremarkable' events. The "mundane reality," they state, provides a background in the understanding of other major components that are represented in the "epiphanies" (Driver & Gottman, 2004, as cited in Daly, 2007, p. 66). Examples of these two types of events are examined in the Results chapter of this study.

Participatory nature of study. Although the researcher's position follows a post-positivist epistemological stance where the researcher remains "in control" of the information to be examined (Lincoln & Guba, 2000), the way the study was conducted represents a true example of academic and community partnership and collaboration. Similar to what has been reported in research elsewhere (Kemmis & McTaggart, 2000; Tedlock, 2000; Turnbull, Friesen, & Ramirez, 1997) this process of collaboration has

taken time to come to fruition. A key element in this collaboration has been the development of a high sense of trust between the researcher and participants, the consultants, and other members of the IDP of BC. Background for this collaborative relationship is provided in the literature review of this study (Goelman et al., 2005), and it is further illustrated in the Procedures section that follows.

Research Design

Overview and rationale. This is a qualitative and retrospective study. This researcher used a multiple case study approach involving six participant families served by the IDP of BC. According to Stake (2000), the case study is not conceived as a “methodological choice,” but a “choice of what is to be studied” (p. 435). This approach is defined by the interest in the case, and not by the methods of inquiry (p. 435); for example, in this proposed study, the experiences of the families of developmentally at-risk children represent the “case.”

The study addressed the research topic on parents’ perceptions of their experiences with early intervention on (a) early childhood development; (b) parenting; and/or (c) family dynamics in families with a child at-risk for developmental delays or diagnosed with developmental disabilities. Four specific questions were raised:

- (1) What are the individual experiences of parents of developmentally at-risk children who participated in the Infant Development Program in terms of their child’s current developmental needs?
- (2) What are the individual experiences of parents of developmentally at-risk children who participated in the Infant Development Program in terms of access to resources and programs?

- (3) In what ways do these individual experiences described in 1) and 2) relate to the current preschool/school demands on these parents?
- (4) In what ways do these individual experiences described in 1) and 2) relate to the demands from other family members and to financial/work pressures?

Procedures

Participants

Description of Sample. This multiple case study purposefully targeted a sample of families (Berg, 2007) of parents and children who had participated in the IDP of BC program between the children's birth and age three years. Previous discussions with this researcher's supervisor and representatives from the IDP of BC (e.g. Provincial Advisor, Steering Committee Program Coordinator and consultants), cited earlier on in this study, guided this researcher in defining the criteria in the selection process of a purposive sample (Patton, 2002, as cited in Glesne, 2006, p. 35), to be described next. The selection and recruitment of participants, and the data collection procedures were completed in two stages. Stage One, or the pilot stage conducted between April 2005 and October 2006, followed by Stage Two, or the research project stage, between October 2007 and March 2008. The purpose of having two stages of data collection was to present a more comprehensive portrayal of the experiences of families receiving early intervention support in British Columbia. This would highlight the different characteristics of families served by the IDP of BC in terms of their children's individual needs and of the services accessed through the program. The rationale behind this decision is associated with having two sets of criteria for

inclusion of the targetted sample, including (1) children with established risks and with diagnoses of developmental disabilities by the time of their discharge from the IDP at age 3 years old; and, (2) children with suspected risks and with no diagnoses of developmental disabilities by the time of IDP discharge. A detailed description of the sample, and the criteria for inclusion and exclusion is presented further along in this chapter. This study is of participatory nature, and, therefore, both adult and children are referred to as “participants,” as opposed to “subjects.” The justification for sample size and the description of participants are described next.

Justification of Sample Size. The study met Creswell’s criteria (1998, 2003) in that the number of participant parents was small enough that it allowed for in-depth analysis. At the same time, the small size allowed the researchers to highlight each family’s unique characteristics. Although all six families shared common features that are displayed on Table 1, individual differences were noted in: (a) the composition and demographics of the six participating families; (b) the nature of their referral process into the IDP of BC; (c) the service provision levels received by families; and (d) the different stages lived by each family. Five of the families had already been discharged by the IDP of BC, and their children had moved towards daycare/preschool, and were in transition or were already participating in elementary school programs. In contrast, one of the families in Stage Once (Family 4) was still completing the discharge program of the IDP of BC at the time of data collection. In addition, the study followed the specified sampling criteria related to the requirements of content analysis, the data analysis method employed in this study.

In content analysis, the theory of sampling is extended from populations of

individuals to sampling of texts. Text sampling must be large enough to address and respond to the research questions and minimize bias when coded, analyzed, and validated; at the same time, the text sample size must be manageable in size (Holsti, 1969; Krippendorff, 2004). In this study, the samples of texts derive from the contents of the following documents: (1) Individual file reviews conducted by the researchers, followed up by an individual file revision session with the participant families; (2) eighteen- to 21 individual, semi-structured interviews; and, (3) two focus groups with participant parents (for families in Stage One only). The data analysis section reveals further details of this process, later on in this study. This number of itemized activities of data collection between the researcher and the participants is summarized in qualitative research as the number of “interactions.” When using a case study approach, an in-depth analysis of the participants’ experiences is required for the purpose of the study. In this study, it is the number of interactions with the participant parents, rather than the number of families (Silverman, 2006), that help meet the sampling requirements. A minimum of 26 and a maximum of 29 interactions took place between the researchers and the participants throughout the above described data collection activities in Stages One and Two, averaging to 27.5 interactions. This total number of interactions meets the minimum required number of interactions for data analysis in case studies of four to five interactions with each participant (M. Buchanan, personal communication, March 23, 2006; Silverman, 2006). This process is described in the Data Collection section of this chapter.

Criteria for inclusion/exclusion. Criteria for inclusion were defined by the following: (a) the children’s date of birth between the years of 1997 and 2004, with

expected dates of discharge from the program between the years 2000-2007; and (b) the service level provided for children and families in the IDP of BC corresponding to home visits for children with diagnosed or suspected developmental delays and monitoring and telephone consultation for children in the “at risk” category. Both levels of service would have combined overall developmental and physiotherapy consultation and assessment services on an as-needed basis. These levels of service are described in the literature review of the study and further documented through file reviews and through the series of interviews. The final sample included children in two levels of service: (1) for children in the Stage One of data collection, regular bi-monthly to monthly home visit level of services. Children in Stage One were referred to the IDP of BC under the developmental delays or health/developmental risk categories. These children ended up having a medical and/or developmental diagnosis or an educational label by the time of their discharge from the IDP of BC, and they were later on identified as requiring developmental and special education needs. (2) For children in Stage Two of data collection, monitoring consultations (varying between monthly, quarterly, and semi-yearly visits) held in the program’s “waitlist groups.” Children in Stage Two were referred to the IDP of BC under the ‘at-risk’ category and were discharged by age 3 without a specific diagnosis or special needs category. The rationale behind the criteria for selection of children in Stage Two responded to the necessity to include children referred to the IDP of BC in the ‘at-risk’ category and who could be considered in the ‘grey area,’ as described in the literature review of this study. According to Gilliam et al. (2005), the need exists for screening and surveillance for “at-risk” children with no identifiable delays or special needs by

age 3. Due to the risk factors at birth, these children could exhibit indicators of specific learning, behavioural, social-emotional, and motor difficulties between ages 3 – 5 years that would eventually have them require some kind of special assistance in the Elementary years. (3) The geographic location of the IDP of BC associated with the participating family was a specific large urban area within BC's Lower Mainland Region. (4) The participant parents who met the above-described criteria were fluent in oral and written English in order to be in full capacity to decide to participate in this study. (Note: Since this is the first study of its kind in partnership with IDP, recruitment of non-English speaking families will be a target of a future study. The later study will allow the researcher to better capture and reflect the diversity of IDP families in BC's Lower Mainland Region. Families who have participated in one of the IDP Lower Mainland Region Programs, but who did not meet the above criteria for inclusion were not contacted for this study.) (5) The parents who agreed to participate in this study expressed their full consent for the following: (a) Allow researchers to contact them to partake in the different activities that comprised the data collection. Activities included two focus groups and three to five semi-structured interviews with the researchers for participant parents in Stage One, and three to five semi-structured interviews for participant parents in Stage Two. (b) Allow researchers to review their children's files kept in the IDP of BC participating program's office; and, (c) participate in member-check sessions to review the transcribed interviews; to revise the reviewed files; and, to provide final feedback on the coded interviews (see Appendix D). Criteria for exclusion included the following: (1) families who had not received services from the specific IDP program selected in this study; (2) families

who were not residing in British Columbia's Lower Mainland at the time of the data collection; (3) families who did not speak and understand English; (4) families whose children were not born between 1999-2003; (5) families whose children were in foster care at the time of data collection; and (6) families who received IDP levels of services that did not include a home visitation or a monitoring/waitlist groups component (according to the criteria for inclusion for Stage One and Stage 2 families).

Recruitment of Participants and Ethics. This multiple case study is the first of its kind with the IDP of BC of BC. Therefore, recruitment practices for Stages One and Two of the data collection process required working partnership and collaboration with the IDP of BC Provincial Advisor, the coordinator of the participating IDP of BC at the selected site location, and other members of the IDP of BC Steering Committee. This Committee includes representatives of agencies that are directly involved with the IDP of BC. The recruitment of participants was preceded by a series of preliminary meetings with these representatives between January and July of 2004. These meetings provided the researchers with guidelines that were instrumental in designing both the final recruitment process and the overall logistics in the study. The recruitment process for Stage One was conducted throughout February and April, 2005. In order to preserve confidentiality of potential participant parents, recruitment was led and conducted by the Coordinator of the specific IDP program, at the selected site location. The following section describes the rigorous ethics process followed throughout the recruitment of participants.

The ethics approval process comprised two separate sets of approvals during Stage One of data collection. The first one consisted of obtaining the consent and

approval from the agencies representing the IDP of BC Advisory Board, from the Office of the IDP of BC Provincial Advisor and from the selected IDP of BC. This consent allowed this researcher to conduct a study that would involve contacting up to 28 families who had participated in the IDP of BC between the years of 1997 (year of intake) and 2003 (year of discharge). These families had expressed their interest in being contacted for a follow-up study through the IDP of BC Post-Evaluation Questionnaire throughout the discharge process. Upon obtaining the expressed written consent from the above-mentioned agencies and programs for the researchers to contact the interested families by mail, the researcher proceeded with the second set of ethics approval through the Office of Research Studies at the University of British Columbia. Consent was obtained to contact by mail the families previously identified by the IDP of BC coordinator as families who had agreed to be re-contacted after being discharged from the IDP of BC. This permission for contact had been indicated in their IDP of BC Post-Service Evaluation Questionnaire (see Appendix A). The letter sent to these families invited them to participate in this study. The description of the study followed the criteria for inclusion previously outlined. During the second step of the consent process for Stage One of data collection, the IDP of BC Coordinator from the participating IDP of BC coordinated and supervised two mail-outs of consent packages within a period of 15 days between the first and the second mail-out. The consent packages sent to parents in each of the targeted families consisted of the following documents: (1) an introductory letter from the IDP of BC Provincial Advisor; (2) a letter from this researcher and her thesis supervisor explaining the nature and characteristics of the study; and, (3) consent forms for

parents that required participants to indicate either their consent or dissent in participating in the study.

Parents were asked to sign whether they agreed or not to participate in the study and to mail back either response to the Researchers in self-addressed and stamped envelopes included in the package (see Appendix D). Signed consent forms were obtained from eight parents in four out of 28 families contacted by mail. Of the remaining 24 families, two declined participation (over the telephone, not in writing) to the Program Coordinator. These parents expressed their concerns with not being available to commit to the study because of family commitments. The remaining 22 families did not respond. There were no letters returned in the mail. Participant parents gave explicit consent for researchers to examine their child's IDP of BC file and to be contacted by researchers to participate in two 90 minutes focus group sessions, and in three to five semi-structured interview sessions, each one expected to last, approximately, 30 to 45 minutes (see Appendix H).

Ethics renewal and approval was obtained to conduct the Stage Two of the data collection. The criteria for inclusion in Stage Two were described in the previous section. The recruitment process followed similar steps as the ones outlined for Stage One. Selected families (e.g., those who had attended the program's "waitlist monitoring" consultation sessions and did not receive home visits) were sent a package also containing a revised set of introductory letters and consent forms. It is important to know that in contrast to Stage One families, Stage Two families had not completed the Post Evaluation Questionnaire. The Program Coordinator selected the families who were contacted in Stage Two, following the previously outlined criteria.

Between November 2007 and January 2008, two mail outs were sent out to 16 families who had attended the waitlist or monitoring consultations in the IDP of BC between 1997 (intake) and 2006 (discharge). Of the 16 families contacted, two of them accepted to participate, three of them declined, and the remaining 11 did not respond. No letters were returned in the mail, as in Stage One of data collection (B. Barnes, personal communication, February 13, 2008). This was largely associated with the Program Coordinator ensuring that recruitment packages for potential participant parents meeting the criteria for inclusion would only be mailed to families with a confirmed current address and/or with date of discharge from the IDP of BC between 2005 and 2006. The relevance of this information for data collection process refers to the program's statistics reporting an average of 25% families moving within two to three years after discharge, at age 3 years old (IDP of BC Statistics, 2004). These statistics not only focus on families with at-risk children, but also relate to BC family mobility trends reported through the 2001 Census (Statistics Canada). In fact, a document from the ECD Table in BC's Fraser Region reports: "Early childhood is a time of family mobility. 41% of BC's children will move 3 or more times before they get to school" (BC Children's First, 2005, p. 3). The only two participating families in Stage 2 had been discharged in 2006, within two years of their date of discharge. Their acceptance to participate in this study confirmed what was anticipated by the program coordinator, regarding her consideration about contacting former families who had recently been discharged from the program.

It is important to observe that for both Stages One and Two of data collection, the children in the participating families were not directly involved in any of the data

collection activities. All information regarding children was collected through file reviews or through interviews with their parents. The contents of file reviews, interviews, and focus groups will be further described in the data collection section of this study. A last re-contact was made to one of the families (Family 3) during Stage Two of the data collection in order to conduct a file review of the family's older child (Child A). Throughout the interview process, the participant parent had incorporated data about both of her children. However, this child's file had not been reviewed since Child A did not meet the criterion referring to having received a diagnosis by the discharge time at age 3. This child's parents had referred him to the IDP of BC because of suspected developmental delays, yet the child had not received a diagnosis at the time of discharge. This addition was considered to be important for Stage Two of data collection for two reasons: One, the information about this child would provide the researcher with important information that would allow for data triangulation coming from interviews and focus groups. Two, this information would be regarded as an additional example of the children in the "grey area" category. These children do not generally receive the intervention services they require until their later school years, as previously documented in the literature review of this study (Coleman et al., 2006); Hebbeler et al., 2007; Meisels et al., 2005).

Description of Final Sample (Participant Children and Parents)

The final sample consisted of six families, with a total of 11 participant parents and 7 participant children. The family composition included father-mother structures for families 1, 2, 3, 4, and 5, and had grandmother as the guardian and custodian for the participant child for Family 6. All participant parents were adults over 21 years

old; none of the participants was a senior (60 years old or over). In reference to marital status, all consent forms and files reviewed indicated that participant parents in families 1 – 5 were established couples, and residing together. Participant parents in families 1 through 5 identified themselves as married; Grandmother 6 was a single parent and provided sole consent to participate in the study. It is important to note that information retrieved through interview transcriptions about this family revealed that, although not living in the same household, both the guardian/custodian and the child have regular contact with the child's biological father (see Table 1). Parents in four out of the six participant families were recruited in Stage One of the data collection. These families had received services from the IDP of BC at the home visitation level. The remaining two families were recruited in Stage Two of the data collection and had, instead, participated in the "waitlist monitoring" groups. All families had complied with the rest of the requirements specified in the criteria for inclusion, and had signed consent forms for all the activities previously specified in the Recruitment section of this study. For purposes of confidentiality, the six participating families were identified with one digit number codes: 1, 2, 3, 4, 5, and 6. In order to ensure anonymity for all participating families, the participant's descriptions (children and families) were stripped of personal information that could be linked to any of the participants. Nevertheless, given the small size of the sample as a case study, this researcher acknowledges that full anonymity cannot be guaranteed. Details on family composition and family demographics are summarized in Table 1.

Information retrieved through file reviews, interviews, and file revision sessions with participant parents/guardian confirmed the participant parents in all six families lived together

with their children. Table 1 presents information about parents' education, work and financial status, and languages spoken. Although all 11 parents in the six families gave their consent for participation in this study, two fathers were limited in their availability to partake in each one of the data collection activities. Two participant couples decided that only the mothers would take part in the interviews, focus groups, and file revision sessions (see Table 2). Details on the parents' involvement and participation in each one of these activities are provided in the procedures and data collection sections of this study.

Table 1. Family Demographics

Stage One	Family Members	Participant Children		Siblings (non-participant)		Participant Parents		
		Age	Gender	Age	Gender	Language Spoken	Level of Education	Employment Status
Family 1	F, M					English	Post-secondary / University	F M
	Child	7y 10m	Girl	10y	Boy			FT PT
Family 2	F, M					English, Other - bilingual	Post-secondary	F M
	Child	6y 9m	Girl	None				Both FT
Family 3	F, M					English, Other	Post-secondary / University	F M
	Child A	4y	Boy	None				Both PT, self-employed
	Child B	6y 6m	Boy					

Table 1 (continued)

Stage Two	Family Members	Participant Children		Siblings (non-participant)		Participant Parents			
		Age	Gender	Age	Gender	Language Spoken	Level of Education	Employment Status	
Family 4	F, M					English, Other	Post-secondary / University	F	M
	Child	2y 10m	Boy	7y	Girl			Both PT, and PT self-employed	
Family 5	F, M					English, Other - bilingual	Post-secondary / University	F	M
	Child	5y 1m	Boy	None				N	PT, self-employed
Family 6	GM					English	Post-secondary / University	GM*	
	Child	4y 7m	Boy	1y	Boy			PT	

* Guardian

Table 1 highlights the characteristics of the six families participating in the study. These were retrieved through both file revision and interview sessions. All participating parents/guardian have post-secondary education (college or university degree equivalents). At least one parent/guardian per family is either employed or self-employed, with none of the parents/guardian relying on permanent income assistance. (Note: Participant guardian 6 receives government subsidy for child, as reported in the file revision and interview 3 sessions). Of the 11 participant parents/guardian, five parents spoke a second language other than English, with parents in two of the families (2 and 5) describing themselves as 'bilingual families.' The other languages

spoken by participant parents included Cantonese, Tagalog, Hebrew, and German. In addition, through researcher's observations and comments through interviews, the following information was gathered: (1) Five of the 11 parents who took part in the interviews and/or focus groups were immigrants to Canada; the other six parents were born in Canada, with two of them being first generation Canadian. (2) Ten of the 11 participant parents (in five out of six families) were homeowners. At the time of the data collection, four of the five families resided in either a two-level apartment or a town house (families 1, 3, 4, and 6); Family 5 resided in an apartment (condominium), and Family 6 resided in a two-storey townhouse within a co-operative housing complex. (3) Two of the families had support from extended family members, including child minding as well as help with cooking and driving members of the family. The remaining four families had either occasional or no support available from their extended families, as it will be described later on in the Results section of this study.

Children included five boys and two girls. (Note: In the selection of participant children, this researcher was not focused on having equal numbers of male and female children for the purposes of this study). Information retrieved through the initial file reviews, later through the interviews, and file revision sessions with parents confirmed the dates of births of the children ranging between 1997 and 2003 for both Stages One and Two of data collection. Six out of the seven children resided with their two biological parents (father and mother), while one of them resided with his paternal grandmother (guardian and custodian). Three of the children had older siblings, while the remaining child was an only child. Children in participant families 2 and 5 had no

siblings. In Family 6, the child's full-blooded sibling lives with his adoptive family, as reported during both the file revision session and during interview 3. As previously mentioned, the child in participant Family 6 is in permanent custody with his paternal grandmother, although he is in contact with his biological father. This participant child, his biological father and grandmother (guardian) are also in occasional contact with the child's sibling and his adoptive family. At this point, there is no contact for either of the children with their biological mother who lives out of province.

All children in Stage One of data collection were identified in the IDP of BC files as having special needs in terms of developmental disabilities and with specific health conditions associated that required medical treatment shortly after birth. One of the children's mothers was followed during the last trimester of their pregnancy since there was a suspected congenital condition of her baby. This condition was identified during prenatal testing and later on confirmed with subsequent testing. Additional medical diagnoses and/or developmental conditions were also confirmed between birth and the age of three years according to the reviewed files (see Appendix I). From the remaining children in Stage One, two were identified with a genetic condition soon after birth (Families 2 and 4), and one was identified with developmental disabilities by age 1 year old (Family 3). His older sibling (Child A, in Family 3) was also referred later on to the IDP of BC because of specific developmental delays (his file was reviewed during Stage Two of data collection). Additional information was retrieved later on in during Stage One of the data collection process about the children in this study with dates of birth between the years of 1997 and 1998. This information, to be unfolded in the Results chapter of this study, revealed that these children

received additional diagnoses of other medical conditions between the ages of three and six years. At the time of Stage One of the data collection, the two children with dates of birth between the years 1997 (in Family 1) and 1998 (in Family 2) were attending elementary schools in their neighbourhoods. Child B, in Family 3, with year of birth 2000, attended an inclusive preschool with onsite special needs support. The child in Family 4, with year of birth 2003, was in the final phases of the discharge process with the IDP of BC. At this time, the IDP of BC was completing the transition process to an inclusive preschool with on-site special needs support and help of consultants working for a Provincial agency providing support for children with identified special needs during the preschool and elementary school years. It is important to note that, during Stage One of data collection, Family 3 had only child identified Child B for the purposes of file reviews. Child B was the younger of two siblings. However, information on Child A, Mother and Father 3's older son, also in the IDP, emerged and was documented through focus groups discussions and interviews. Child A's files were reviewed during Stage Two of the data collection. Detailed information about Child A in Family 3 unfolded as the data collection process progressed. Child A was age 2 by the time IDP of BC consultant was referred to the participating family to provide support to their younger child, identified as Child B in this study. This family had voiced their concerns on the development of their oldest child, or Child A to their family physician, but had not received the attention required regarding the needs of their child up to that point. Conversely, Child B, identified as "at risk" at birth, was soon after referred to the IDP of BC by a community health nurse. The family's involvement with the IDP of BC for Child A

resulted in the parents being able to voice their developmental concerns on Child A. The IDP of BC Consultant supported and advocated on behalf of the parents in a referral process for Child A. This child ended up being identified with special needs and referred to the appropriate medical and developmental specialist services after his file was closed with the IDP of BC (by age four years old). This information was confirmed throughout the file revision session in Stage Two of the data collection. The information revealed how intertwined the experiences of Child A, Child B, and their parents were, as it will be described in the results and discussion sections of this study. Child A was identified with developmental delays for Stage One of data collection; although he received no diagnosis by the time of discharge, unlike the remaining children in Stage One, he was referred for special needs preschool services for developmental delays. Child A only received IDP services between ages 2 and 3 years old, unlike other children in Stages One and Two who received home visitation or monitoring services between birth and age 3 years old.

Children in Stage Two of data collection were referred to the IDP of BC under the “at risk” category for developmental delays or disabilities given their pre-, peri-, and /or post-natal history. None of the two children had had a specific diagnosis or medical/developmental condition identified throughout their participation with the IDP of BC according to both file reviews and interview transcriptions. The child in Family 5 had an uneventful pregnancy, but was born pre-term and identified with a condition that brought him to the special care nursery soon after birth, and was later on re-hospitalized with an acquired illness. Immediate follow-up occurred for the child in Family 6 right after birth, given his pre-natal history of his biological mother’s drug

use during the first two trimesters of the pregnancy (see Appendix I).

Six out of the seven children in Stages One and Two of the data collection were referred to the IDP of BC within six months of age. The wait time for children between the date of referral and date of intake by the IDP of BC ranged between one and three months. Several referral sources were available for all children for Stages One and Two of data collection. For Stage One, children with identified health and/or developmental risks, the sources were (1) pediatrician (two children) and (2) community health nurse (two children). For Stage Two, children with suspected risks, the sources were (3) social worker (one child); (4) pediatric physiotherapist at Provincial Children's Hospital (one child). Referral (5) was a self-referral from parents in Stage One after their youngest child; also, a participant in the study was referred to the IDP of BC through the community health nurse.

Data collection. Stages One and Two

Data sources. Data collection in both Stages One and Two used multiple primary and secondary sources of information (Donne-Wamboldt, 1992; Krippendorf, 2004; Rosenberg et al., 1990). Multiple sources of information included the following: (1) File reviews from the children's IDP of BC files; (2) the transcribed versions of approximately 30 individual, semi-structured parent interviews; e.g., three to four interviews with each parent; (3) the transcribed versions of two focus groups with parent participants, one preceding and one following the parent interviews; and, (4) memos and/or theoretical notes (Strauss 1987). These included comments and reflections added by this researcher throughout the completion of any of the above listed activities. For both Stages One and Two the data collection process comprised

three phases.

Phase 1. This phase included the collection of primary and secondary sources of information. Primary sources comprised file reviews, interviews, and focus groups. Secondary sources of data collection included written or digitally recorded memos that were attached to the primary sources of information. Clarification and updated information about the IDP of BC was obtained through periodic meetings held with IDP of BC consultants, with the Program Coordinator and with the Provincial Advisor. Finally, each one of the families completed revisions of the reviewed files with the researcher. The use of secondary sources was instrumental for two reasons. First, for the purposes of data verification within the data triangulation process, it was important to corroborate or to clarify ambiguous or unclear information drawn from the IDP of BC files. Second, in order to gain a deeper understanding of the findings, it was important to add or complement information, and make connections to be used further along in the study for interpretation (and, specifically, for the memos that followed some of the interview sessions). For both Stages One and Two of data collection, the first phase included file reviews from the children's IDP of BC files, followed by three to four semi-structured digitally recorded interviews. Families in Stage One of the data collection (families 1, 2, 3, and 4) had also the first of the two focus groups occurring during the first phase, and the second and final focus group, after the set of interviews were completed. Activities for Stage One (families 1, 2, 3, and 4) were carried out between March and September 2005; whereas activities for Stage Two (families 5, 6 and file reviews for Child A in Family 3) were carried out between January and March 2008. Table 2 provides an overview of the attendance

and participation of parents per family throughout the data collection activities.

Phase 2. The second phase focused on the transcription of the digitally recorded interviews and focus groups, between October 2005 and July 2006, for Stage One, and between March and April 2008, for Stage Two.

Phase 3. The third and last phase focused on the final revision of the transcribed material with participant parents, and was completed, for Stage One, between September and October 2006, and during April 2008 for Stage Two. (Note: An ethics amendment requiring the extension of the project for data collection was submitted and approved after Phases 1 and 2 of the data collection process took longer than first anticipated and delayed Phase 3 of the data collection process.⁴ A detailed description of the activities and the sources of information used during Phases 1 to 3 is presented next).

⁴ This researcher went on two health-related leaves between winter 2005 and spring of 2006.

Table 2. Interview of Parent/Guardian Participation in the Focus Groups,
Interview and File

		Families					
		1	2	3	4	5	6
Data Collection and Post Data Collection Activities' Topics							
Focus Group 1	Meaning of study	X	X	X	X	N/A	N/A
		X	M	M	X		
Focus Group 2	Closing comments	F	X	X	X	N/A	N/A
		X	M	M	X		
Interview Session 1	Early experiences	X	X	X	F	F	N/A
		M	M	M	M	M	GM
Interview Session 2	Transition from EI [0 - 3 Program]	X	X	X	F	F	N/A
		M	M	M	M	M	GM
Interview Session 3	Transition to school	X	X	X	F	F	N/A
		M	M	M	M	M	GM
Interview Session 4	Coping with transitions and changes	X	X	X	N/A	N/A	N/A
		M	M	M			
Post data collection activity 1:File Revision	Verification of summarized file information	X	X	X	F	F	N/A
		M	M	M	M	M	GM
Post data collection activity 2: Member Checks, Session 1	Transcriptions	X	X	X	X	F	N/A
		M	M	M	M	M	GM
Revision Sessions*							

Table 2 highlights overall parental attendance and participation throughout the data collection activities. It also reveals parental figures attending; for example, mother, father, and guardian). For example, Family 5 in Stage Two was the only one with both parents

participating throughout interviews through Stages One and Two of the data collection process. Family 4 in Stage One having both parents participate in two out of the three interviews. A closer look to parental figures' attendance patterns reveals that in families 1, 2, and 3, only mothers participated in the interviews; whereas the grandmother (guardian) participated for Family 6. Focus groups discussions' attendance in Stage One was low due to unforeseen circumstances. In reference to patterns of overall parent attendance, it is important to note that parents' absences were due to unforeseen or unexpected circumstances for parents on both dates for Focus Group 1 and 2. It is also relevant to highlight that the dates had been previously scheduled according to the personal convenience of all participants. In addition, participants received telephone calls confirming their availability for the already pre-scheduled meetings one- to two- days ahead of the focus groups dates. In reviewing the recruitment procedures for data collection, it is also relevant to emphasize that the parent participants had not only given their consent for researchers to examine their children's files reviewed, but that they had also indicated their willingness to participate in interviews and focus groups. Issues related to parent participation throughout the interview process with all the participant parents are brought up in the Discussion chapter of this study.

Phase 1 File Reviews

Procedures. The file review process for the 7 children was conducted at the IDP of BC site by the co-Investigator in this study between March and July, 2005, for Stage One, and between January 2008 and March 2008, for Stage Two. The IDP of BC staff provided this investigator access to the files that were kept locked in the consultants' offices, as well as a working space and access to a computer to enter the anonymized information retrieved from each one of the reviewed files. All of this

information was stripped from individual identifiers. Pseudonyms and random ID-numbers were assigned to the 6 participant families (one ID-number per family), in order to ensure anonymity and to maintain confidentiality. The retrieval of information contained in the fields included in the IDP of BC's Central Registry Codes. These codes categorize and describe the fields used by IDP of BC consultants since the year 2002 to enter the information on each one of the children and families participating in the IDP of BC in the Referral Forms (see Appendix E). These codes have been recently entered to the IDP database system that is a part of a larger database project entitled *The LINK-DSC Database System* (Chan, 2007). The project was previously alluded to in chapter 2 of this proposal.

Content. Each one of the IDP of BC files contained information categorized in fields (see Appendix F). File fields included the following: Demographic information about each child, family composition, dates of referral, intake, and discharge with the IDP of BC, medical, health, and developmental information collected between birth and three years; description of the child and family's involvement with the IDP of BC; for example, therapies, assessments, other referrals, and access to alternative programs, as well as information on the discharge process and transition to other programs and services. This information had been manually recorded and/or copied and entered by IDP consultants in a series of documents contained in each one of the retrieved files. For Stage One of data collection, and for Child A (Family 3) reviewed during Stage Two of data collection, the IDP of BC files contained the following documents (see Appendices A – G): (a) the initial Needs Assessment Questionnaire, where the the family identifies their needs and goals for their child (or children)

together with the consultant; (b) the Home Visit Records, filled monthly or bi-monthly according to the number of home visits with anecdotal recordings by the IDP of BC consultant and/or pediatric physiotherapist supporting the family. The anecdotal comments entered in the Home Visit records highlight some of the IDP of BC consultant's recommendations and strategies shared for each family and their impressions on the home visits accomplishments; telephone communication registries, that contain updates and follow-ups to a previous visit, for example, information about referrals, assessment dates, and liaison with other programs, services and/or resources; (d) copies of medical and/or developmental assessment reports; (e) copies of referral forms to other services; and, (f) summaries or notes from attendance to other programs or groups, for example the parent-infant group or language stimulation/therapy sessions. All of this information was entered and summarized into individual excel template forms, which were later on revised with the participant parents.

In addition to these documents, Stage Two of data collection included notes and reports on the monitoring consultations –with telephone visits preceding or following up. These notes and reports substitute the home visit records and consultations retrieved for participating families in Stage One of the data collection. Each one of the template forms of the reviewed files contained memos, or theoretical notes (Strauss, 1987), that summarized the researchers' impressions on the interactions between each family and the IDP of BC consultant(s), after having completed the review of the individual files, as previously mentioned. These notes provided the researchers with secondary sources of information that, together with the primary sources of information, are later on integrated in the Results and Discussion chapters

of this study. Additional details on information entered in the file review forms will be complemented in a section covering the file revision sessions carried out with the participant parents after the series of interviews were completed (see Appendix I).

Phase 1 Focus Group 1

Procedures. The first focus group was conducted on October 2005 at the IDP of BC site. The aim was to promote for the attending parent participants with an opportunity to engage in an introductory discussion about their perspectives on the nature and purpose of the case study. Having obtained previous written consent from participants, the session was digitally recorded, and later on transcribed. The objectives of the discussion were the following: (a) to engage parents in a discussion about their perspectives on the nature and purpose of the proposed case study; (b) to identify what were the parents' roles in the study; and, (c) to provide parents with an opportunity to raise any issues or doubts about their participation in the study. The researcher had previously contacted the participant parents by telephone and had secured attendance for at least one member of each of the parents in every one of the participant families for a specific weekday, in the evening. Parents were offered two child minding options. The first one was child minding at the site; the second one was reimbursement for child minding at home, as well as bus fares. There was free parking on site. None of the participant parents requested any of the child minding options, nor bus fare reimbursement. The final attendance, however, consisted of two parents from two of the participant families. One of the non-attending participants was suddenly ill that night, whereas the fourth participant had last minute work schedule conflicts. Focus Group 1 was conducted with two participant mothers representing families 2

and 3 (see Table 2).

Contents. The guiding topic for this focus group was “meaning of study.” The session consisted of (a) a brief welcome and introductions; (b) a summarized presentation highlighting the background and rationale behind this study; and (c) the introduction of a guiding outline that listed the goals for the discussion that would be taking place. Following these preliminary activities, the researcher asked the question “In what ways is it meaningful for you to participate in this study?” to participant parents attending this session (see Appendix H). Participants sustained an engaged discussion for approximately 45 minutes. The discussion tried to elaborate on their hopes and expectations concerning their participation in the study, based on their recollection of their experiences with the IDP of BC when their children were under the age of three. The discussion ended with the researcher providing a summary of its main points. The session concluded with a check-in and confirmation with each parent participant on his or her understanding of the procedures for scheduling the interviews coming up in subsequent weeks. It is important to note that the questions posed during the Focus Group 1 with the two participating parents were later on woven into the introduction component of the first interview for the six parents who participated in the interviews, but who did not take part in Focus Group 1 (in both Stages One and Two of the data collection). The rationale supporting this decision was to ensure that each participant would have access to and would be able to reflect upon most topics covered through the data collection. Notwithstanding, the effort to maintain the integrity of the contents, this researcher acknowledges two important differences in these activities. One, the style of the question and answer process derived from

individual interviews would differ from that of the participant group discussion (Fontana & Frey, 2000). Two, in terms of number of participants, there are differences in the discussion format carried out by only two participant parents, in contrast to the discussion that would have taken place with at least four participant parents as originally projected in this study. These circumstances were limiting factors acknowledged in chapter 4 of this study.

Phase 1 Interviews

Procedures: The series of three to four semi-structured interviews focused on parents' experiences while serviced by IDP of BC (see Appendix H). Each interview consisted of three to four questions using "how to" and "in what ways" formats. These formats allowed participant parents to expand on the topic, and at the same time provided some structure to the session (Fontana & Frey, 2000; Lincoln & Guba, 1985). Interviews were scheduled and carried out following each parents' requests for dates, time, and location. Most interviews took place in the parents' own homes. However, two of the participant families chose to hold the interviews in different locations; one, in a community centre near their home, another one in a café close to her work place. As previously stated, children did not take part in any of the interviews. Nonetheless, it is important to inform the presence of children (and in one of the cases, a child's older sibling) with their parents in all interviews and file review session in families 2 and 4, at their parents' request. One of the other families (Family 1) had their participating child and their sibling in a separate area of their home during the final interview session. Although being removed from the interview process, the two children in this family were cognizant of the interview session. Child minding was

available for parents so that they could make arrangements before the scheduling of the interviews; however, parents' preferences were to take care of their own child minding arrangements; for example, sharing with their partners. One family (Family 6) accepted reimbursement for child minding for two out of the three interviews and for the last member check session, during Stage Two of data collection.

Contents. Interview questions elaborated on the queries posed by the study's research questions in trying to learn about the participant parents' experiences. (1) Interview #1: In the first interview, the researcher first summed up the highlights of Focus Group 1 discussion session for participant parents in Stage One. The researcher then proceeded to ask parents information about their recollection on the following events: (a) their child's birth and post-natal experiences; (b) the process of referral to IDP of BC; and, (c) the early experiences with the IDP of BC. As mentioned earlier, the first interviews included a similar introduction to Focus Group 1 for those two parents participating in Stage One interviews who could not attend it and for participant parents in Stage Two. (2) Interview #2: The second interview dealt with the parents and overall family experiences through the discharge process with IDP of BC. This interview expanded on the families' transition to preschool and daycare programs. Experiences would have included their accessing other agencies providing support for families with children at risk for developmental delays during the preschool years. (3) Interview #3: The third interview dealt with the parents' experiences of their children entering school, in either Kindergarten or grade 1, and the support services their children were currently receiving during their Elementary years. Only the three parents with children ages six to eight at the time of the Stage

One data collection participated in this third interview. However, parents in Stage Two commented on issues related to their children transitioning to Kindergarten. (4)

Interview #4: The fourth and last interview for all families in Stages One and Two enquired how had parents dealt –and what were some of their coping strategies— throughout their different experiences and transition processes. Specifically, families where asked to provide examples that would illustrate these processes since their child’s birth, within the realities of parenting a child who was identified as “at risk” for developmental delays. Parents were asked to situate questions within the context of raising a child who had required or might still require of special attention. Parents were also asked to consider issues regarding their raising other children and dealing with job, financial, and other logistic and daily life issues (see Appendix H).

Focus Group 2⁵

The aims of the second and last focus group discussion were to engage parents in a discussion about their experiences in having participated in the interviews and to provide a closure to the study. It was also provide for an opportunity for the researcher to thank all parent participants for their involvement in the present multiple case study.

Procedure. The second focus group (October 2006) was the final activity of Stage One. The scheduling for this second focus group followed similar steps were to the ones completed for Focus Group 1. Four parents from the four participating families confirmed attendance at a previously agreed date and time (an evening on a weekday) and at the same IDP of BC location as the previous time. Two of the parents who had attended Focus Group 1 participated in this focus group, together with one of the parents from another one of the family who had not taken part of the interview

⁵ Only in Stage One of the data collection process

process. The remaining two participating parents (Family 4) were not able to attend because of an unforeseen conflict with a family religious celebration. Both parents had participated in the interview process, but had also missed Focus Group 1 due to illness.

Content. Focus Group 2 asked parents questions about their impressions and reflections having partaken in the interviews. These questions also provided parents with an opportunity to share express further suggestions and recommendations for future research and early intervention and special need services provision. Appendix H includes a copy of the description and questions posed during the Focus Group 2 discussion. The final question in this discussion was “Do you have any additional comments, any closing thoughts, suggestions, and/or recommendations?” Since Focus Group 2 was conducted after the final set of interviews in Stage One, those participant parents not attending the group did not have the opportunity to respond to this particular question. In Stage Two of the data collection, however, the question was woven into the closing component of the last interview for all three-participant parents/guardian.

Phase 2

Data transcription. Audio-recorded data collected from Focus Group 1 discussion, Interviews #1 through #3 and #4 (depending on the family) and Focus Group 2 discussion between October 2005 and July 2006 (Stage One), and between January and March 2007 were transcribed with the aid of the Sony Digital Editor Program. The data transcription from these primary sources combined textual (verbatim) with summarized transcriptions, following Quinn-Patton’s (1987)

guidelines for transcription. Transcriptions were typed onto Word documents. Time slots with minutes and seconds were entered for each of the participant's comments that was transcribed verbatim, and that were connected or next to summarized comments. Registered time slots ensured the verifiability of the transcribed materials, and assisted in the process of intercoder reliability, to be described in the data analysis section that follows. Finally, summaries of memos that followed some of the interview sessions were also transcribed in April 2007, by a research assistant hired for the data analysis process in this study. A similar process was followed for Stage Two.

Technical difficulties. This researcher experienced recording difficulties during two of the data collection sessions. Focus Group 2 had only 20 out of 30 minutes recorded, and interview 4 (Family 6) was not recorded. For Focus Group 2, content revision of the session during the final member checks with individual families (Stage One) ensured that the key points were captured. For interview 4 (Family 6, in Stage Two), this researcher immediately transcribed and summarized the interview and completed a member check with the participant within the week that followed the interview. The researcher recorded this member check session and re-transcribed the participant's edits, comments, and additions into the interview. Although the transcribed interview had fewer verbatim quotes, both the participant and this researcher determined that the contents of this interview were mostly intact and accurate.

Ensuring anonymity and confidentiality. This researcher maintained anonymity and confidentiality at all times during the transcription of the focus groups, interviews, and memos. All of the personal and agency, organization, and program names

mentioned during the focus groups and interviews were substituted by number id's for participants; pseudonyms were utilized for some agencies and programs in order to minimize the risk of identifying the participants (parents and children).

The Data Analyses section in this chapter includes the description of a fifth and last set of activities involving the re- contacting participants for member-check procedures including the revisions of the reviewed files, the revisions of the transcribed interviews and the revisions of the coded interviews.

Data Analyses

Content Analysis

Content analysis was the selected method of data analysis utilized to interpret participant parents' coded responses mainly derived from transcribed and revised focus groups and interviews (Holsti, 1969; Krippendorff, 2004; Roberts, 1997). Content coding was used to interpret the identified themes (Berg, 2001; Krippendorff, 2004; Roberts, 1997) that would emerge out of the different categories. Thematic content analysis is situated within qualitative content analysis. In contrast to quantitative content analysis, qualitative content analysis includes quotations illustrating the identified categories, as opposed to counting the instances of responses (or frequencies), and presenting them in tabular form according to different categories (Wilkinson, 2004, as cited in Silverman, 2006, p. 163). For example, the theme "Cycle of Disability" referred to parents' cyclical encounters with their children's special or unique needs that had to be addressed. Several categories provided examples for this theme, for example, the category labeled "Awareness of Child's Development."

Categories grouped examples of participants' responses. Categories were labeled with key terms that captured the essence of the examples coded; for example, participants' responses referring to instances where they had felt "empowerment" were included within the category labeled "Empowerment."⁶ Thematic coding was used in combination with "item" analysis (by interview topic). The coding process incorporated both "in-vivo" and "sociological constructs" (Strauss, 1987, pp. 33-34) and sought for explicit --or manifest-- themes (Berg, 2001). In addition, and considering the ethnographic character of the study, a combination of text analysis ran through the interpretation of the reviewed files used for data triangulation. Text analysis used the written comments from consultants or other professionals entered in home visit reports, telephone memos, or evaluation reports. Within the ethnographic tradition of this study the transcribed contents from file reviews would assist in the representation of reality (Silverman, 2006, p. 168). Altheide & Johnson (1998) explain how researchers use a social-anthropological approach when they acknowledge and understand that the context provides meaning during the interpretative process (p. 307). The Results chapter includes examples of the coding process.

Integrity of study

There were safeguards in place to protect the integrity of the study throughout the data analyses, including inter-coder reliability and inter-coder audibility, or "external audit" practices (Glesne, 2006, p. 38). (1) Ensuring inter-coder reliability required for the researcher and a trained research assistant to review the coding

⁶ Note: It is important to note, that in order to obtain a preliminary overview of the most commonly used examples for the across-participant (or Inter-participant) analyses, this researcher initially conducted a frequency count of categories and their association with some of the themes. These frequencies provided an overall "map" of participants' responses that guided the first level of data analyses. (M.P., June 6, 2008)

procedures, using online and written transcripts, and with the help of N'VIVO qualitative software (Scholari, TM) (QSR International, 2002). There was an established 90% baseline of agreement between the two coders. Inter-coding disagreement was reported and alternatives were presented (Stage One). Similar processes were replicated for Stage Two. (2) With the aid of N'VIVO software, he researcher and the research assistant followed inter-coder audibility practices. These practices required the maintenance of transparency of steps throughout the coding process, until the establishing of categories and subcategories and both the researcher and the research assistant reaching an agreement with regards to the emerging themes (personal communication, J. Nicholls, December 6, 2006; S. Reibling, April 28, 2008). This researcher also followed external auditing practices (Glesne, 2006) through ongoing supervision with her supervisor and methodological advisor throughout the data collection and interpretation of the findings (M. Buchanan, personal communication January 2008, May 2006, April 2008).

Training. In order to ensure the technical integrity throughout the coding process, this researcher and the research assistants in Stages One and Two of the data collection process received training and/or refreshment sessions in accessing and utilizing the NVIVO software. This researcher and the research assistant in Stage One attended an introductory and a second training NVIVO 7 session dictated by the Teaching and Academic Growth (TAG) Centre at UBC. This researcher also attended an advanced follow up session offered through the same centre. The research assistant in Stage Two was already trained in this software through her graduate program, and required a one-time refreshment session with this researcher in order to familiarize

herself with the newly upgraded version of this program (N'VIVO 8) and to clarify and agree on the coding techniques and commands.

Dependability and Representation

This researcher evaluated both the dependability and the level of representation through member checks for all the sources of information. A description of how this first stage of member-checks was completed follows.

Member checks through file revision sessions. This researcher met with each one of the parents who had participated in the interviews to conduct an exhaustive file revision session. The purpose for these sessions was twofold; one, to ensure the integrity in the researcher's capturing of the information in the child's file; and two, to verify key background information about the child and family, as well as the sequence of medical, family, and program events with which the family had been involved. These sessions lasted for approximately 30-45 minutes, while the researcher, together with the participant parents read, edited (added, or modified) the information that had been entered about the participating child, checking for accuracy –in terms of the information being complete and correct. The researcher advanced to parents the possibility of crossing out or deleting any segment of information that they would consider unnecessary. Although participant parents completed edits related to accuracy of the data or data omission, they did not request to delete information entered at any point during the file revision process. Quite the contrary, parents often added new and insightful observations or comments during file revision sessions that the researcher entered later on in the form of memos.

Member checks of transcribed interviews. The purpose of these meetings was

to confirm the verisimilitude of the families' different experiences and what was captured in terms of their relationship with IDP of BC, for families who received home visitation services, and from those who attended the "waitlist monitoring" consultations. Moreover, these sessions touched on and captured similarities and/or contrasts of service provision encountered by participants and on their relationships with other program consultants and/or therapists. This researcher re-contacted parents to review the transcribed and printed interviews. The identification of the transcribed interviews included case number, interview number, and date completed. Parents received instructions to read, carefully, each one of the transcribed interviews, and to edit and do corrections and modifications wherever they deemed necessary.

Overall guidelines for parents' member check sessions included inviting parents to reflect on their own recollection and to acknowledge their level of comfort upon re-examining the information they had previously shared during the interviews. Of the 11 parents who signed consent to participate in the study, seven out of the eight parents who participated in the interviews reviewed the transcribed interviews. This process took an average of two to three 30-minute sessions with the researcher. One of the parents completed only one review session with the researcher (Interview #1), and chose to revise Interviews #2, #3, and #4 on her own time (Family 3). This participant parent accepted the offer of this researcher to deliver the remaining interviews to her home address in a sealed envelope. The participant returned the revised interviews for pick-up within a period of two weeks.

All participant parents who reviewed the transcribed interviews included the following edits: (1) clarification comments; (2) addition of missing contextual

information; (3) re-wording some of the researcher's summarized transcriptions; (4) checking accuracy in quotes; (5) typos. None of the parents chose to delete any of the information shared during the interview sessions.

It is important to note that there was an extended invitation to take part in the file and interview revision sessions to the three parents (fathers) in those families who had agreed to participate in the study, but who were not available to take part in the interviews. None of these fathers attended these sessions.

Revision of transcribed Focus Groups. There were no member check sessions conducted with participant parents in Stage One to revise the Focus Groups transcriptions. There were, instead, revisions of the contents of the introductory question in Focus Group 1 and the closing question in Focus Group 2 discussions with participants (in Stages One and Two) through the member check sessions corresponding to Interviews 1 and 4.

Criteria for Evaluating the Worth of Study

Validity

In the post-positivist paradigm, determining the validity of the findings that were interpreted through content analysis is of paramount importance (Krippendorff, 2004). Determining validity, as a construct, implies that the researcher ensure the truthfulness of the study findings through results that "speak to as many as possible" (Riffe, Lacy, & Fico, 1989, as cited in Krippendorff, 2004, p. 313). This researcher followed Riffe et al.'s (1989) "Typology of Validation Efforts in Content Analysis" (p. 319) to examine the validity of the findings of the present study using its three

validity constructs: (1) face, (2) social, and (3) internal validity.

Face validity. Also termed “common truth,” face validity refers to how findings make sense to others. The examination of face validity took place with different representatives, as will be further elaborated in (3) “Internal validity.” The question posed during these presentations and meetings was, “Do the categories presented in these findings make sense to you?” (a) Participant parents, through the revisions of the different file and interview transcriptions and through the member check sessions once the interviews were coded (2006 - 2008); and, (b) representatives from the IDP of BC, including informal presentations to staff and formal presentations to the Program’s Steering Committee and Board (2005 – 2007). For example, following the first set of member checks with participant parents (Stage One), and during Stage Two of data collection and data analyses, this researcher maintained ongoing consultation and sharing of preliminary findings with the IDP of BC representatives (consultants, coordinators, Board members) on a quarterly basis (an average of three yearly presentations).

Social validity. Social validity refers to the way others make findings acceptable. This type of validity examines the ‘practicality’ of findings (e.g., how to translate these findings into actions, and how they are relevant, beyond their academic meaning). An example of the examination of social validity includes the periodic presentations conducted with representatives from other groups. Presentations included (a) academics (personal communication with supervision committee, 2005, 2006, 2007); (b) fellow graduate students (meetings in January 2006; November 2006; November 2007); and, (c) delegates to local and international workshops on early

intervention sharing their findings (May 2007, June 2007, July 2007, November 2007, and January 2008). Presentations ended with the researcher asking for comments and feedback from the audience in terms of the relevance and practicality of the findings. The final structuring of the methodology, as well as the presentation and interpretation of the findings of this study, incorporated the comments, feedback, and ideas that came from discussions with these representatives.

Internal or empirical validity. This study consistently adhered to the principles of internal validity throughout the different research stages already described. The Results chapter of the study presents an exhaustive analysis of the findings, according to the criteria for internal validity, listed as follows: The first criterion refers to the findings of this study representing evidence in response to the study's research questions. In addressing this first criterion, the organization of the findings followed a response to these questions. For example, to address the research topic on parents' perceptions of their experiences with early intervention on (a) early childhood development, (b) parenting, and/or (c) family dynamics in families with a child at-risk for developmental delays, or diagnosed with, developmental disabilities, this researcher ensured that the findings would portray parents' responses. Coding these responses into specific categories; for example, early memories, perceptions, hopes, and values, as well as their first experiences and events within the program ensured that participants' responses would be utilized as evidence to address the research topic in this study. The integrity of this process, reaffirmed through inter-coder reliability procedures and through member checks allowed, in turn, the confirmation of the salient themes emerging from these responses. A similar process was followed through the first, second, third and fourth specific questions. The second criterion refers to the findings

analyzed and interpreted presented resonating with findings from other research, concerned with related topics, for example, the experiences of parents with children at-risk for developmental delays, and parents and children who have received early intervention services. Meeting this second criterion for internal validity requires of the contextualization for the themes that emerged from participants' coded and categorized responses. This, in turn, entails drawing on relevant findings derived from research that is germane to the topics of parents' experiences and early intervention for developmentally at-risk children. The third and final criterion refers to the sampling validity of members and of representatives. This study met with both of the sampling validity criteria through the completion of several member check sessions with participants, and asking participant parents, as members, "Do these findings represent you as a participant parent in the IDP of BC, having children who are at-risk for developmental delays?" The sampling validity of representatives referred to asking participants about their representation through the experiences shared; for example, "Do these findings represent 'your [transitioning] experiences' as a participant parent in this study?" The description of the second and third member check sessions with participants illustrates ways in which the study addressed the sampling validity criterion.

Second member-check session. A second set of member-check procedures with participants followed the initial ones previously described through Stages One and Two of data collection. In addition to adding to the rigor of the study in terms of integrity and verifiability, this procedure supported the representation of participants' voices throughout the data analysis process. Following ethics approval to re-contact participant families, this researcher mailed summaries of the parents' coded responses

to the three to four interviews they had previously completed. The researcher met with participants in individual sessions and asked participants: “Do these categories and themes make sense to you?” Four participant parents in Stage One representing each one of the families reviewed the individual summaries, and verbally expressed the researcher their understanding and agreement with the coded responses.

Third member-check session. A third and last member-check session was attempted when all of the preliminary findings for Stage One were integrated. The procedure included the mailed summary of the study’s findings to all participant families. The cover letter in this last package invited participants to provide feedback to this researcher (in person, via telephone or email communication, or in writing, through mail). Participants were to respond to the question, “Do you see yourself represented through these categories and themes?” Only one participant parent (Family 2) responded and agreed to meet with this researcher, stating that as a parent she understood and saw herself represented. There were no responses from families 1, 3, and 4. A limitation to complete this last set of member checks derived from the fact that the ethics consent did not allow the researcher to re-contact families over the telephone. This researcher interpreted the restriction imposed by the ethics committee in terms of the extensive length of time between the first, second, and third member check sessions (2006 to 2007), and the fact that re-contacting parents could have posed unnecessary pressure on participant families. At the same time, there were no summary packages returned in the mail; consequently, this researcher assumed that all participant parents had received the packages. Moreover, there were no letters, telephone calls, or emails from the former participants following the mailing of the

packages. Therefore, (1) having received previous feedback from participants regarding the first and second set of member checks, and (2) in the absence of further information from participants indicating any concerns about the summarized coded material, this researcher is confident in her meeting the criteria for sampling and semantic validity while addressing issues of internal validity of the study. A slightly different process occurred with Stage Two participants. During the second member check session, Mother and Father 5, and Grandmother 6 enquired about other participants' perspectives, while reviewing the integrity and verifiability of the categorization process. This questioning process led to a discussion where these participants expressed their sense of representation through the categories and themes validated throughout these sessions. Semantic validity is the final criterion listed within the construct of internal validity according to Riffe et al.'s (1989) typology, posing questions such as "Do the categories and emerging themes accurately describe the meanings of the experiences of participant parents in this study?" The formulation of these questions was not limited to member check sessions with participants, but they were also present in the activities described for face and social validity.

Issues of Ethics and Rigor and Issues of Representation

This study evaluated its credibility by finding out how reliable and verifiable the information was following the conceptualization into categories (Lincoln & Guba, 1985, 2000). For example, as researchers, we make statements about relationships and validate these statements with the data (e.g., "*When* certain conditions are present, *then* parents experience... (Or "believe," "feel"). The second and the third member check sessions represent this researcher's ongoing questioning process. Questions

formulated during these sessions included: “Is the information verifiable?, and Are the issues to be explored in this study a ‘true’ reflection/expression of the IDP of BC issues as represented by the participant parents?” Through this process, exemplified within the section describing the validity constructs, participants had also the opportunity to express their power and voice. Once again, maintaining the commitment for privacy and confidentiality of the transcribed and coded information of participants during the data collection stages continued to be a priority through the subsequent member check sessions.

Issues of Representation

Representation using narratives and tables. In order to accurately represent participants in this study, a combination of narrative and summarized information in tables was used. Numbers were chosen over pseudonyms to identify Families, Parents, and Children; for example, Family 1 comprised Child 1, Mother 1, and Father 1 during data collection activities and throughout the data analyses. The exception were Children A and B in Family 3. The choice of a numbering system over pseudonyms responded to a decision to maintain clarity and consistency throughout the data collection, data analyses and interpretation processes, given the wealth of data collected in the present study.

Voices of parents representing their children. In this study, the voices of children are represented through the voices of their parents, and through the text originated in the reviewed IDP children’s files. The lack of participation of children under represents the voices of all family members in this study (Denzin & Lincoln, 2000). This is acknowledged as a limitation in the present study, and further discussed

in the recommendations for future research. In spite of this limitation, the study maintains its purposes of examining the parents' experiences of the impact of early intervention (Tedlock, 2005), and trying to understand the meaning of these experiences (Miller et al., 2005). This is accomplished by reducing the narratives of parents and the information retrieved through text files through categories summarizing and labeling parents' experiences (Krippendorf, 2004). The analysis and interpretation of such categories results in the surfacing of themes. Each theme, in turn, represents meaningful issues for parents in this study and provides the context for the interpretation about their experiences. Representativeness in this study pertains only to the participants of this study.

Issues of Voice

In addition to recognizing the participants' many voices as individuals, parents, and members of a distinct collective community of parents in the IDP with children who are developmentally at risk, the study acknowledges the multiple roles played by the researcher when meeting families. Exploring the role of the researcher came first. In her role as an investigator, the researcher is an outsider. At the same time, this investigator's previous training as a former infant development consultant and as a teacher working with children with suspected or identified special needs allows her to both have the familiarity with the IDP of BC that it is required by the nature of the study within the ethnographic tradition described earlier (Miller et al., 2005). Despite the researcher's perceived role of an "outsider," there is also anticipation for the researcher to be somewhat familiar with issues experienced or expressed by the participating families. Likewise, the researcher of this proposed study is a parent.

Nevertheless, in the present circumstances of the researcher, no shared issues exist around child rearing in parenting a young child who is developmentally at-risk.

Exploring the role(s) of parent participants was next. This relates to the previous statement on the many voices of participants. At all times, this researcher ensured the issue of “verification of the representation” for each one of the participants in their different roles. These included their roles as individuals, acknowledging their gender, and the gender of the researcher conducting the data collection, their roles as “parents” of children who are developmentally at risk, and their roles of “members of specific communities” (Miller et al., 2005). This researcher also checked with the participants about their self-perception within each of these roles; for example, whether they perceived themselves as included, partially included, partially excluded, or definitely excluded from their ‘communities.’ Finally, the study represents the dissertation proposal for this researcher. Therefore, in her role as a graduate student, this researcher can present and explain to her committee and supervisor for all of them to assess whether or not the ‘model’ is appropriate and reasonable (Buchanan, personal communication, May, 2006). Berg (2007) commented on similar issues in his discussion about the attitude of the researcher, and his or her motivation for guiding their ethnographic research (p. 182).

Summary

This chapter described the framework supporting this multiple case study. The study is situated within the ethnography tradition of inquiry and grounded in a post positivist epistemological stance. The study used content analysis as the method to conduct data analyses to identify the themes emerging from participant parents’

voices. The study comprised six family cases. Information obtained through multiple methods of data collection, including file reviews, interviews, focus groups, and memos or theoretical notes secured a data triangulation process. A rigorous process of data verification and inter-coder reliability followed in order to ensure integrity. Member checks with participant members and with other representative determined the truthfulness (validity) of the findings and ensured the representation of participants' voices. The chapter includes a final mention of the different roles played by participants and this researcher throughout the study.

Chapter IV: RESULTS

Introduction

This chapter presents a summary of the findings of the study. The presentation of the findings is based on the interpretation of participants' responses in focus group discussions and semi-structured interviews; the validity of findings was further triangulated with the examination of participant children's file reviews. Thematic analyses of these responses were completed through the identification of common patterns. These analyses addressed the research topic, on parents' perceptions of their experiences with early intervention on early child development, parenting, and/or family dynamics in families with a child at-risk for developmental delays, or diagnosed with developmental disabilities?" And, four specific questions:

- (1) What are the individual experiences of parents of developmentally at-risk children and their families who participated in the IDP in terms of their child current developmental needs?
- (2) What are the individual experiences of parents of developmentally at-risk children who participated in the IDP in terms of access to resources and programs?
- (3) In what ways do the individual experiences described in 1) and 2) relate to the current preschool/school demands on these parents?
- (4) In what ways do the individual experiences described in 1) and 2) relate to the demands from other family members, and to financial/work pressures?

An in-depth process of thematic analyses, using the qualitative content method of data analysis (Silverman, 2006) led to the identification of a first set of main

themes, and then a second set of dominant themes. Thirteen main themes derived from the analyses and interpretation of the across-participant results. The thirteen themes included the following:

- (1) Theme 1: Memory, memories. Remembering facts, events, processes, and issues from birth to school age.
- (2) Theme 2: Access to Programs and Services. Parents' experiences accessing a variety of programs and services throughout the years with the IDP and after their discharge.
- (3) Theme 3: Effectiveness of services (Stage Two). Parents' comments about how services and programs met their individual needs.
- (4) Theme 4: Cycle of (Anticipation/disability). Parents' ongoing over/covert concerns as the child grows a) confronting the needs/demands of a child with a disability/delay; b) anticipation about child ending up with a developmental condition associated with pre-, peri, or post-natal factors.
- (5) Theme 5: Parents' Multiple Roles. Parents' comments on their daily lives, routines and different roles played at home; for example, how responsibilities are shared and juggled among family members.
- (6) Theme 6: Parents hopes and expectations (Stage One). Parents' comments about their hopes on programs' features and services received or anticipated results from these services.
- (7) Theme 7: Roles of Consultant, Therapist. Comments describing the diverse roles played by consultants and therapists in the IDP and other intervention programs when working with families.

- (8) Theme 8: Understanding and dealing with the system. Parents' comments on their efforts to grasp the way the health, educational and/or social services systems function and their experience in confronting the complexities of each one of these systems.
- (9) Theme 9: Stressors. Examples of compounding stress situations, events and factors that have a direct or indirect impact on the family's quality of life - and specifically when a child is considered at-risk and/or with special needs; I.e. financial or job related, as illustrated by related categories.
- (10) Theme 10: Issues with funding (Stage One).Parents' comments of the difficulties and obstacles they have encountered when following steps to obtain funding.
- (11) Theme 11: Parents priorities (Note: Theme and category for Stage Two). Parents' comments on their individual ideology, belief systems and preferences with regards to approaches in service delivery and intervention to foster their child's development..
- (12) Theme 12: School Registration Process.⁷ Parents experiences during the period of time preceding Kindergarten registration.
- (13) Theme 13: Encompassing Theme Interviews and Focus Groups: Time, Timely, Timing⁸

These themes, in turn, guided the analyses and interpretation of within-participant results. The findings drawn from the participant analyses were the result of in-depth and "thick" analyses (Geertz, 1973). In his essay, " *Thick description*:

⁷ Identified after inter-coder reliability process completion

⁸ Confirmed following the completion of inter-coder reliability process and the reporting of intra-participant findings.

Toward an Interpretive Theory of Culture,” Geertz describes thick analyses as “a stratified hierarchy of meaningful structures” (p. 7). Such structures provided a specific context that allowed this researcher to maximize the consistency and precision in the interpretation of these within-participants’ findings; and effectively complemented their counterpart across-participant analyses. Out of these two complementing strategies of data analyses, seven dominant themes surfaced, and four categories. These dominant themes and categories address the research topic and specific research questions in this study, and do a final integration of the outcomes of this study (see Table 3).

Table 3. Seven Revised Themes

Research Questions	Revised Themes and Categories
Research Topic: Parents’ Perceptions of Experiences of Early Intervention	1. Family Centred Approach and Home Visitation Services
Specific Question 2) Access to Programs and Services	2. One to one relationship with Consultant/Therapist 3. Inclusion of all family members
Specific Question 1) Developmental Needs of Children	4. Collaborative consultation <i>Parent consultation, listening to Joint decision making parents, and empowerment</i> 5. Effective knowledge translation in sharing information/resources

Table 3 (continued)

Specific Question 3) Preschool, daycare and/or school Needs	6. Case Managing and Service Coordination <i>Role of consultant(s), and service coordination following discharge</i>	<i>Loss of support following transition to school</i>
Specific Question 4) Needs of Family (logistics, job, financial)	7. Stressors that Become Barriers <i>Complexity of issues and logistics in participant families</i>	<i>Health risks and disability, child care availability, and the impact on participant families' job and financial conditions</i>

Table 3 shows the variations in the labeling of some of the dominant themes when compared to the labeling of the main set of themes. These variations respond to a combination resulting from the assimilation of key elements from existing categories. Such assimilation came forward during the above-mentioned integration of across- and within- participants' outcomes.

Chapter overview. The chapter is organized as follows: (1) a description of the findings examining features and patterns common or shared among participants, or, "Across Participants Findings"; (2) a description of the individual accounts of each on of the six family cases, or "Within Participant Findings" and (3) a summary and interpretation of the findings in response to the research topic and to the four subsequent questions.

Across-Participants Findings

The findings in this section report features and patterns observed across the six family cases. This first set of analyses were undertaken in order to provide the platform to address the research topic on parents' perceptions of their experiences with early intervention on early child development, parenting, and/or family dynamics in families with a child at-risk for developmental delays, or diagnosed with developmental disabilities. The section consists of the following five sub-sections: (a) A summary of the findings from file reviews; (b) a description the organization of the findings of the focus groups and interviews; (c) a description and summary of the findings of the two focus groups; (c) an overview of the patterns and features identified through the semi-structured interviews; and, (d) a concluding summary of the participant findings.

Summary of Findings from File Reviews

Overview

The information retrieved from file reviews of the seven participant children (see Appendix I) provided this researcher with the background and context needed to address the research questions in the present study. Moreover, this researcher used this information as a source for the triangulation of the data obtained through the individual interviews, and validated through member check sessions (Lincoln & Guba, 2000). Four groupings identified with letters a), b), c) and, d) expose the type of information transcribed and summarized from the file reviews. These consist of the following: (a) descriptions of the children's individual profiles between the ages of 0 and 3 years (see Table 1 in chapter 3, for demographic information on participant

children and participant parents). These profiles mainly derive from information collected through three sources; the Referral Form (see Appendix F); the Central Registry Form (see Appendix E); and, tests, screening and assessment reports summarized in the file reviews (see Appendix I); (b) Family Needs Assessment Questionnaires (see Appendix A) and/or Post-Service Program Evaluation Surveys containing information and comments written by the children's parents (see Appendix C); (c) IDP consultant comments written on the home visitation records, telephone contacts, or on-site consultation summaries (see Appendix G). These records and summaries render the consultants' summaries of the activities completed, in addition to their follow-up comments and suggestions; and, (d) this researcher's comments with her reflections on the file material reviewed (see Appendix K).

Ten common aspects were identified across the reviews of participant children's files. These included the following:

- (1) Age of referral: Six out of the seven children were referred to the IDP by the time their children were age 6 months, with wait-times between referral and intake of under four months (the range was one to three months).
- (2) Reason for Referral: Child 1, Child 2 and Child A (Family 3) were referred to the IDP under the category "developmental delays" (see chapter 2, "Definitions of Terms). The IDP statistics report that approximately 35% of yearly referrals are completed under this category (Office of the Provincial Advisor, 2004, 2006). Child 3 B, Child 5 and Child 6 were referred under the "at-risk" categories (see chapter 2,

“Definitions of Terms). This category represents approximately 30% of yearly referrals to the IDP (Office of the Provincial Advisor, 2004, 2006).

- (3) **Referral source:** For Child 1 and Child 4, the pediatrician was the source of referral, whereas for Child 1 and Child 3 B it was the public health nurse. The public or community health nurse is the most frequent source of referral for the IDP (Office of the Provincial Advisor, 2004, 2006).
- (4) **Medical follow-up:** Child 1, Child 2, Child B (Family 3) and Child 4 in Stage One had a medical diagnosis or combination of identified health conditions by the time of their discharge. These conditions ended up impacting on the children’s development at a moderate to severe level of intensity according to the information on their files.
- (5) **Gestational Age:** All participant children but Child B (Family 3) and Child 5 were born at term, between 38 and 40 weeks. Child B and Child 5 were born pre-term (35 and 36 weeks, respectively). All full term children were also born with normal birthweight over 3500 g (see Definition of Terms in chapter 1). Child 1, Child 2 and Child 4 received genetic-related diagnoses and were full-term babies. All but Child A (Family 3) in Stage One ended up requiring neonatal intensive care treatment after birth following additional post-natal medical complications.
- (6) **Referral to pediatrician:** All seven participant children were seen by a pediatrician. Moreover, all children, but Child 6, were followed-up by a pediatrician and continued to be under medical surveillance until they

were discharged from the IDP. (Child 6 was followed up by the family physician).

- (7) Referral to other specialists: All seven participant children were seen by medical and non-medical specialists between birth and age 3 years. Examples of medical specialists –other than paediatricians--included neurologists; cardiologists, and dermatologists. Examples of non-medical specialists included audiologists, vision specialists; speech language therapists, occupational therapists, and physiotherapists, among several others (see Appendix K).
- (8) Age at discharge: All children participants except for Child A and Child B (Family 3) were discharged at age 3 years; Child A and Child B were discharged at ages 42 and 43 months, respectively. Although the mandate of the IDP is to complete the process of discharge by the children's third birthday, the program's mandate states that services may continue throughout the child's third year if there is an identified need and with parents' previous consent and agreement (see the Infant Development Program's website: www.idpofbc.ca).
- (9) Diagnosis at the time of discharge: Child 1, Child 2 and Child 4 had confirmed diagnoses that were linked to a genetic condition identified and/or confirmed soon after birth. One of the children (Child B, family 3) was diagnosed with a neurodevelopmental condition that was also linked to a genetic condition by age 4 years.

- (10) Special Needs designation for children in Stage One: Although not all children in Stage One received a medical diagnosis at the time of discharge, they all qualified for a “special needs” designation by the time of their discharge from the IDP. These children were liaised for services with the BC Centre for Ability in order to obtain additional therapy support during their preschool years, and/or supported child care during their elementary school years, through the Supported Child Development Program. Hebbeler et al’s (2007) report on early identification and early intervention includes comments on how diagnostic confirmation and assignment of special needs categories for children under the age of 5 years are most common when early intervention services have followed these children up under the “developmental delays” referral category.
- Varying information across the participant children files included the following information:

- (1) Age at Referral: Child A in Family 3 was referred at age 3 years old following his younger sibling’s referral to the program;
- (2) Referral sources: Child A (Family 3) was referred by his parents; Child 5 was referred by a pediatric physiotherapist at the Provincial Children’s Hospital; and Child 6 was referred by a social worker from the Government Child and Family Services;
- (3) Diagnosis at discharge: No developmental concerns were reported for children in families 5 or 6 in Stage Two at age three, at the time of discharge. File revision sessions confirmed the following: (a) Child 6 was

liaised with the BC Centre for Ability upon the recommendation from the IDP physiotherapist to receive physiotherapy monitoring. Details on this follow-up are explained in Family 6 individual account in the section reporting the within or participant findings; and, (b) neither of these two children had received a special needs designation by the time of completion of the data collection process, at ages 5 and 4 1/2 years, respectively.

Additionally, files reviews confirmed information about the levels of services provided for the seven participant children, and about the programs they attended. All five children in Stage One of the data collection received home visitation services. Children in Stage Two attended waitlist or monitoring sessions. Child 1, Child A and B (Family 3), and Child 4 attended sessions of the Parent-Child Mother Goose through the IDP. All participant children, but Child A, received physiotherapy consultation through the IDP.

Table 4 represents the families' different transitions experienced at the time of the data collection (Stages One and Two).

Table 4. Participant Families: Services Received and Transitions

	Stage One (Established risk; Home Visitation services)				Stage Two (Suspected risk; Waitlist-Monitoring Consultation services)	
Case #	1	2	3	4	5	6
Age of transition to preschool/daycare			Child A	Child B		
	3	4	4+	3	3	
Initiator	IDP	Family	IDP	IDP	IDP	Family
						Family

* Child development centre, then preschool.

Table 4 (continued)

Case #	Stage One (Established risk; Home Visitation services)				Stage Two (Suspected risk; Waitlist-Monitoring Consultation services)	
	1	2	3	4	5	6
Sources of data	File reviews; Interviews; Focus Group 2	File reviews; Interviews; Focus Groups 1 and 2	File reviews; Interviews; Focus Groups 1 and 2	File reviews; Interviews	File reviews; Interviews	File reviews; Interviews
Support and/or program	Yes	Yes (at age 4)	Child A Yes	Child B Yes	Yes	No
Transition to school (K- 3)	Yes	Yes	Yes	No	No	Yes (completing K Registration)
Special Needs Designation (for school)	Yes	Yes	At age 4y	At age 4y	Yes** (Child age 3)	No

* File closed at age 4 ½; never used services

** Permanent designation for school

Table 4 shows similarities and differences among the seven participant children within the six family cases in the transition process experienced by their

families, and in the support services and designations obtained. Table 4 also displays the sources of these data. Children 1, 2, A, B (Family 3) and 4, in Stage One ended up receiving special needs designation by age 5 years, while children in Stage Two families did not receive any designation or specialized support. Details on each child's profile and findings are presented in the within-participant findings section of this chapter as well as more information on the families' specific interactions and relationship with the IDP program and with their consultants (see Appendix K).

In sum, an overview of the reviewed files provided rich information on the multiple services provided for participant children between the birth and age 3 years and the numerous contacts between parents and consultants/physiotherapists. Examples included referrals to different specialists and included records of the multiple tests and/or progress reports completed. The characteristics of the home visitation or waitlist/monitoring sessions were described, as well as the discharge process. The files indicated whether or not labelling or special needs categorization were completed, and listed follow-up activities recommended for each child. Although common aspects for most participant children were identified, the complexity and variation between each child's file of the data reflects the individual character of each one of the intervention services provided for the six family cases. At the same time, the organization of these files follows similar criteria concerning the organization of their contents. This organization facilitated the transcription and categorization of the extensive anecdotal information entered by consultants and physiotherapists. Therefore, the findings from files provided a unique reconstruction of times and events in the early intervention support process provided for each one of the children and

their families. Such reconstruction of times and events supported and complemented the information relayed by participant parents through the individual interviews. The next section describes the organization of findings from focus groups discussions and interviews.

Organization of Findings from Focus Groups and Interviews

Overview

The presentation of the findings from focus groups discussions and semi-structured interviews was completed through the categorization of the data. In addition, findings derived from secondary sources of data collection; for example, memos and theoretical annotations, were utilized to complement the data, and were used as sources of verification (Denzin & Lincoln, 2000; Lincoln & Guba, 2000). An association between these secondary-source findings with their corresponding primary source assisted in the process of highlighting of the findings derived from primary sources of data collection. This association process was repeated in the case by case presentation of the findings, reported in the within-participant analyses. The elements above enumerated provided further consistency in the presentation of the findings; in turn, this consistency added to the internal validity of the present study.

In contrast to the individually-reported participant responses from interviews, contributions deriving from the focus groups' discussion were reported in group responses. Key terms were identified to sort these responses. Using these key terms assisted this researcher in the coding of group responses into categories (Silverman, 2006). These broad categories were organized within an overarching topic termed as "Participants' Contributions." Responses obtained through the discussion in Focus

Group 1 provided a “group” insight on the specific question, “What are the individual experiences of parents of developmentally at-risk children who participated in the IDP in terms of access to resources and programs?” For example, responses that were initially coded under the categories “Referral Source” and “Referral Process” during Focus Group 1 discussion session were also captured under distinct categories during the interviews (see Table 5). These distinct categories ended up emerging as two themes throughout the analyses of interviews coded responses: “Memory, Memories,” and “Access to Programs and Services.” These analyses revealed that “Memory, Memories,” and “Access to Programs and Services” contained some of the richest of the findings in the present study. For example, coded responses under “Access to Programs and Services” referred to parents’ experiences on their accessing a variety of programs and services throughout the years with the IDP and after their discharge. The theme portrays the wide variety of ways parents accessed diverse programs and services throughout their years with the IDP. The theme also reflects the similarities and differences in parents accessing programs before and after their discharge from the IDP. It also highlights the differences in the program’s structures and models of service delivery. The consultant in the IDP sustained the role of case manager in order for parents to access and attend programs or receive services. However, following their discharge from the IDP, Stage One parents took over a “case manager’s” role in order to reach out for other services and programs. Explicit quotes from Mothers 1, 2, 3 and 4 illustrate these roles further along in this chapter. These quotes show how the differences in service delivery models have impacted on participant parents. Such quotes are distinctly captured during the interviews through the theme “Roles of

Consultant/Therapist.” These preliminary findings substantiated specific research question 1) “What are the individual experiences of parents of developmentally at-risk children and their families who participated in the IDP in terms of their child current developmental needs?” and specific research question 3) “In what ways do the individual experiences described in 1) and 2) relate to the current preschool/school demands on these parents?” The next sub-section describes the processes that were followed to organize the preliminary and subsequent findings, by theme.

Table 5. Focus Groups and Interviews: Categories and Sub-Categories.

Categories	<i>Sub-categories</i>
Referral Source	<i>Referral Process</i>
Parents’ Perceptions/experiences	<i>Examples of Parents’ Perceptions/experiences</i>
Parents’ Priorities	<i>Parents’ values</i>
Program model of services: Description; compare & contrast	<i>Examples of Parents’ Perceptions/experiences</i> <i>Service coordination /service models</i> <i>Perceived misinformation</i>

Table 5 (continued)

Categories	Sub-categories
Awareness of Child's special/unique needs/Child's development	<i>Meeting child's needs</i>
Barriers	<i>Perceived misinformation</i> <i>Communication issues</i>
Role of School Support Worker (Stage One)/ Health Professionals (Stage Two)	
Family Logistics	<i>Childcare issues</i>

Organization of Findings by Theme

The coding of participants' responses involved a thematic grouping that led to their subsequent thematic analysis. The grouping followed four steps listed as follows: (1) Coding responses within general categories (entered through the N'VIVO software program as "free nodes"); (2) analysing in depth the content of participant's responses, within categories, and identifying common threads to them. These threads emerged as "themes," as illustrated in the previous section; (3) organizing these categories within the emerging themes, while refining categorization through the creation of sub-categories; and, (5) additional refining of the categories and sub-categories.

A similar coding process was followed using participants' responses from interviews, and, once again, from participants' responses in Focus Group 2. The coding process for the interviews was guided by the earlier, broad categorization of Focus Group 1 discussion's responses. Themes emerged as a result of the interpretation of the patterns identified through these categories. The grouping and labeling of categories, and the identification of themes deriving from these two data collection activities, in turn, informed the coding process and identification of the main themes listed earlier in this chapter.

The themes emerged in the focus groups discussions were expanded on the individual topic of each one of the discussions. More specifically, comments that were coded and categorized from Focus Group 1 discussion gave rise to themes that emerged later on throughout the interviews, as indicated earlier on. "Stressors" was the only 'topic-centred' theme (throughout Interview #4); whereas "Time, timely, and timing" emerged as a background theme that provided a unifying thread to all of the identified themes. The description of the theme "Stressors" includes "examples of compounding stress situations, events and factors that have a direct or indirect impact on the family's quality of life –and specifically when a child has a child considered at-risk and/or with special needs; e.g. financial or job related. The theme "Stressors" was repeatedly identified during Interview #4. Parents' responses captured under this theme address the specific question, "In what ways do the individual experiences described in 1) and 2) relate to the demands from other family members, and to financial/work pressures?" Participant parents in Stage One and Stage Two alike identified how circumstances associated with their child's birth, their child's medical

complications and/or developmental conditions, and ongoing struggle or anticipation of issues with regards to services provision, ended up impacting on their daily family lives, logistics and family issues.

Two out of the remaining 11 themes did not emerge across all four interview topics; these included “Effectiveness of Services” and “Issues with Funding.”

“Effectiveness of Services,” included comments about how services and programs met their individual needs. It emerged as a theme through Families 5 and 6 participants’ responses, in Stage Two, given the different contexts were associated for these responses. For example, responses from participant parents in Stage One specifically referred to their perceptions on the effectiveness of services when comparing service models between the IDP and the preschool- and school-based intervention programs and services provided for their children. In contrast, parents in Stage Two expanded on their evaluative comments referring to all services received until the time of data collection; for example, medical, early intervention, and social services received between their children’s birth and preschool and/or school entry. “Issues with Funding” included comments about parents’ difficulties and obstacles encountered when following steps to obtain funding. Funding issues were only confronted after children left the IDP. Before discharge from this program, families would not have needed to apply for external funding sources to receive services. Families needed to request or apply for special needs placements in preschools, daycares or out of school care centres. Parents with children already in preschool and school programs provided comments related to this theme, including Mother and Father 1, Mother 2, Mother 3, and Mother and Father 4 in Stage One of the data collection. Not having been

diagnosed or identified with a medical or developmental condition, neither Child 5 nor Child 6 qualified for a special needs category entitling their parents to apply for funding for additional services during their preschool years. These findings provide examples in response to the specific questions, “What are the individual experiences of parents of developmentally at-risk children and their families who participated in the IDP in terms of their child current developmental needs?” and, “In what ways do the individual experiences described in 1) and 2) relate to the current preschool/school demands on these parents?”

Finally, the background theme, “Time, Timely, and Timing” captured an ever present concern for all parents in the present study. During focus groups and interviews, parents’ comments referred to these three words in reference to how hard it was to recall events that had happened a few years ago; and in reference to the notion of “when” early intervention services would happen. Overall, participant respondents mentioned that it was “hard,” or “difficult,” to remember some of the events happening during the first three years of their child’s life. When asked to respond to questions that related to these early memories and the experiences associated with them, participant respondents’ comments included the following terms or expressions: “a long time ago” (e.g.; Mothers 2, and 3); “it’s so emotional” (e.g., Mother 1); “so much happening at the time” (e.g., Grandmother 6); and, not quite remembering “what happened first” (e.g. this mother). These terms refer to “time” in different ways, including, (a) remote; (b) passed, and hard to re-visit; (c) difficulty to discriminate between one event and another happening at a particular moment; and (d) difficulty with the sequence of events, leading to some confusion, at times.

Addressing issues related to ‘time’ as a deciding factor; ‘timely’ events; and, ‘timing’ in receiving or accessing services, was key to meet their children’s needs. Examples from parents’ responses included the consultant arriving at the right time (Mother 4) or not soon enough to their lives (Mother and Father 5); the wait-time needed for certain services required to meet their children developmental and learning needs, and how they experienced this unused time for learning activities as lost time (Mother 1 and Mother 3); and, the many times parents have to check on their children’s health and well-being, and anticipating the next consultation, test, or treatment; for example, “When will it be the next time?” (Mother 3, Mother and Father 5, Grandmother 6).

Summary

This section presented a description of the organization of the findings, and the rationale supporting this organization. This provided a structure that substantiated the findings of the present study. The findings addressed the research topic on parents’ perceptions of their experiences of early intervention services on early child development, parenting, and family dynamics. At the same time, the findings responded to specific questions; for example, how parents dealt with specific issues related to their child’s developmental, and special or unique needs; how parents accessed resources; how they dealt with parenting issues related to their children needs during the preschool/school ages; and how they dealt with family, work and other related issues in their specific roles of parenting a developmentally at-risk child.

Summary of Findings from Focus Groups

Findings from Focus Group 1

Participant parents' responses to the introductory topic question on the "meaning of the study" were first classified into two sub-topics, namely, "Parents' Responses" and "Referral issues." "Parents' responses" contained specific quotes from participant parents expressing their thoughts on why did they decide to participate in this study. "Referral Issues" included participants' spontaneous comments reminiscing about the initial referral process to the IDP, as well as comparing and contrasting their own families' experiences. The two sub-topics provided an umbrella for the categorization of participants' coded responses. The theme "Rationale for Participation" emerged as a result of the coding and categorization process containing responses with explanations on parents' reasons for wanting to participate in the study, how did they think it would be useful, and why is it important for them. Prompted by the topic question, Mothers 2 and 3 reminisced about their early years with the IDP during the Focus Group 1 discussion. They compared their early experiences soon after their children were born; recalled who had referred them to the IDP, and briefly talked about the referral process to the IDP. In spite of the discussion being limited to two participant mothers, the discussion was lively and flowing, and both participants followed each other's train of thoughts.

Mothers' comments from this specific extract were grouped and coded into different categories labelled "Continuity of Services," and "Parents' Hopes and Expectations" (the second category emerged as its own theme during the data analyses of the interviews). At the same time, Mothers 2 and 3's comments included the first

examples of coded responses that were grouped into the categories, and gave rise to themes such as “Understanding and Dealing with the System,” and “Stressors,” also identified throughout the interviews. Additional examples of the coding process and its link with the interpretation of the findings are presented next.

Focus Group 1 was a rich discussion that provided a first glance into the experiences of Mother 2 and Mother 3 before the interview sessions. Moreover, the thoughts and ideas these mothers brought to the discussion laid the grounds for the introductory questions that were later posed for Mother and Father 1 and 4, in Stage One, who could not attend the Focus Group; and, for Mother and Father 5 and Grandmother 6 in Stage Two since no focus group was held during this stage of the data collection.

Examples of categories resulting from the grouping and coding the repeated comments from Mother 2 and Mother 3 during Focus Group 1 included the following: “referral sources”, “referral process,” “access to programs and services,” “continuity of services,” “feelings,” “guidance and support received,” “information and knowledge translation,” and issues with funding”. For instance, expressions about the “referral process” included the following quote:

Mother 3: I was pretty impressed that it kind of went faster than I thought...you know the nurse...getting you an appointment.

Mothers 2 and 3 reminisced on their personal stories, and how they first were involved with the IDP. This researcher utilized the information derived from Mother 2 and 3’s responses dealing with their experiences about the referral process, and their first contact with the IDP, as a point of reference for further, in-depth discussion

during Interview #1 on the topic questions about their “Early Experiences” with the IDP of BC. Therefore, the focus group discussion was utilized as a platform, as indicated by Berg (2001) in his guidelines on the purpose and rationale for focus groups. More specifically, the responses collected through both focus groups discussions served as a basis to bring back questions during semi-structured interviews. This process prompted more elaborated responses from participants.

Categories from Focus Group 1 discussion were essential to provide an initial coding framework for parents’ responses. This coding framework was further elaborated during the individual interviews, as participants proceeded to unfold their experiences during the different stages and transitions. In addition to the themes “Rationale for Participation,” “Memory, Memories,” and “Access to Programs and Services,” other themes emerged from a few of such categories, and they were salient during the interviews in Stages One and Two of the data collection.

Inter-coder reliability check-in sessions. Further review of the coded responses for Focus Group 1 or Interview1 introductory questions for coder reliability revealed 100% agreement for Stage One data collection (December 2006) and over 95% of coded responses for Stage Two data collection (May 2008). Recommendations for recoding responses in Stage Two under the theme “Rationale for Participation” included the creation of a new category “Explicit and Implicit Values.” This new category contains parents’ comments revealing value judgments and/or statements in their comments grouped under the overarching topic of “Participants’ Contributions.” Re-entering these comments under the new category, as a subordinate of the theme “Rationale for Participation,” revealed an important aspect of participants’

introductory comments. This process helped refined the coding of Stage One participants' responses.

Findings from Focus Group 2 and Interview #4 Concluding Question

Participant parents' responses to the concluding question on the topic "Participants' Contributions" emerged under the theme of "Closing comments." These responses added another layer of depth and further context to participants' previous responses in Focus Group 1 and through the introductory question to Interview #1 addressing the research topic on parents' perceptions of their experiences with early intervention on (a) early child development, (b) parenting, and (c) family dynamics in families with a child at-risk for/diagnosed with developmental disabilities.

Participants' insightful responses gathered through Focus Group 2, or in the concluding question of Interview #4 (for those participants not taking part in Focus Group 2) contributed to the understanding the findings of this study in their reflecting participant parents' preoccupation with the processes they underwent through from their child's birth until their transition into school; in reiterating parents' concerns with regards to the ways systems operate in providing the required health/medical, social and/or educational services; and in highlighting parents' recommendations for effective service provision, service continuity and coordination among service providers for other parents confronting similar needs with their children.

Responses from these participant contributions underwent a process of coding that was similar to the steps followed for responses coded in Focus Group 1 and Interview 1-4 in order to ensure a similar level of organization that would lead to a deeper understanding of the findings. The findings deriving from Focus Group 2

discussion substantiated previous findings in this study addressing the specific question: “In what ways do the individual experiences described in a) and b) relate to the current preschool/school demands on these parents?” Indeed, participant parents in Focus Group 2 insisted on the need to address the current uncertainty with regards to service provision during the children’s school years –once the umbrella of the early intervention case management had ceased to operate for families. Father 1, Mother 2, and Mother 3 reiterated the need to maintain programs and services, with easy access to them and with ongoing funding. Parents’ final interventions stressed how the mismatch between the written information and the reality of access to direct health, social and/or educational support services was disconcerting and frustrating for them, and denied their children the support they were entitled to:

Father 1: think there are programs between 3-5 years old, like the Supported Child Development Program, but what I don’t understand is what **do** they have to be in a separate form? Why can’t there be programs on top of another program?

Mother 2: Yes, and it is confusing sometimes like I don’t know who is in charge of who, of what... (Brings up an example re looking for childcare and being told that that was not the right place to apply.)

[Father 1: (“So you have to go to the [Government Agency] ” !)

Interviewer: Summarizing, (checking) "Many agencies managing many services instead of one agency - like a centralized entity orienting everyone..."

Mother 3: Brings up an example of IDP of BC and [BC Centre for Ability] (OT from both agencies) and working together while they were still with IDP of BC.

Father 1 adds, instead, that part of his frustration, [and being a bureaucrat, he adds, he knows how it is]... "One gets tired of being told, you have to work with less...this means writing letters, accessing people... tiring... frustrating."

Mother 2: Comments on this frustration and shares an experience with the (current) government about not only not receiving services but services being cut and receiving a letter saying that *'even if her child is a priority there is no funding for that' ...*

Father 1 comments on the problems that Child 1 may develop over time, and, considering that in her case her disability is not overtly visible, but will relate more to mental health issues and with lack of social and emotional skills... "[My] child has the potential for 180 problems... physical to psychiatric' ...It's more difficult when you try to make your case and you get patronized..."

Father 1 sees how it is going to be more and more difficult for parents to advocate for support for these children, because of her invisible

disabilities... "Like [my] child 1 could walk away with anyone right now." He refers to first his earlier comment re accessing the school board...

Mother 3: That's when the label comes in; it helps things when you have a label.

Parents' voices echo those of early intervention administrators and service providers that have also been captured through two separate documents, Hebbeler's report in the U.S. (Hebbeler et al., 2007) and, more recently, a BC report presented by participants of the BC Child Healthy Alliance for Special Needs (Pivik, 2008), as mentioned in the Discussion chapter of this study.

As a final point, the summing theme "The Desire to Share and Contribute" condenses the findings derived from the introductory and closing questions posed in both Focus Group discussions. (As previously mentioned throughout this study, these questions were also posed during the introductory and, respectively, final interviews, for those participants who were not involved in these group discussions). All participant respondents openly expressed their hopes that their voices would be listened, and that the information reported would be shared for other parents of developmentally at-risk children to obtain support services similar to the ones they had received through the IDP since very early on; be empowered to confront complex systems that are alien to their common knowledge (e.g., the medical and hospital systems; the educational, and the social services system); gain knowledge and information about services and programs, so that they avoid experiencing gaps in services during the children's preschool and school years; for example, the three

participant mothers who identified themselves as second English languages speakers made particular reference to all of these issues being particularly relevant for immigrant parents who do not speak English and/or who are not familiar with “the system;” extend the services provided through IDP until school entry, and implement a centralized case managing system that continues working with the families all along, or, as Mother 2 expressed, (quote) “Until they graduate from High-School.”

Overview of Findings from Interviews

Interviews revolved around four broad topics deriving from the four specific research questions. As previously described in this chapter, responses were coded utilizing the categories generated in the Focus Group 1 discussion. New categories emerged out of patterns identified in participants’ responses from interviews. For example, as participants discussed their access to programs and services, they specifically elaborated on the ways that these services were delivered to them. Their responses were then coded within the category “Program Model of Service: Description, Compare and Contrast.” A total of 28 categories emerged throughout the 21 semi-structured individual interviews completed. The coding and recoding process followed the steps outlined earlier in this chapter.

Participant responses were consistent in both stages of data collection, and across themes 1, 2, 4, 5, 7, 8, 9, 12, and including the background theme “Time, timing and timely.” This consistency confirms the positioning of the present study within the ethnographic tradition of inquiry, in that it captures the meanings of the experiences shared by parents of developmentally at-risk children (Miller et al., 2005;

Tedlock, 2000). Given that the interviews conducted in the present study were face-to-face, individual interviews (Berg, 2001), the findings from them are presented separately, in the section presenting the within-participant findings. A brief, concluding summary of this section precedes the description and reporting of the individual accounts of the participants in the present study.

Summary of Across-Participant Findings

The coding of participants' responses resulted in 13 main themes, highlighting commonalities across the participant families. This framework revealed three levels of impact of the models of early intervention service, according to participant parents' experiences. These included, their ways of understanding and following up their child's development and special and/or unique needs; the ways that these models affected either supported or hindered their priorities, hopes and expectations, and values in their parenting of their children; and how the family dynamics, including coping mechanisms, operated throughout the years, in terms of daily logistics, dealing with internal and external stressors; for example, job and financial situations, childcare issues, and confronting obstacles such as lack of funding for resources for their children. The following section includes the individual stories of the six participant families, and examines the themes that emerged through the analysis of each participant's responses. The information condensed from their individual files provides essential background to participants' responses, thus complementing each one of their unique stories.

Within-Participant Families Findings

Overview

This section focuses on the findings derived from the individual, face-to-face interviews with participant parents in families 1 through 6. The individual findings include the reports from the participant children's file reviews, and the participants' responses from the interviews. The presentation of the findings have been organized as follows: First, an in-depth description of two model cases, Family 3, in Stage One, and Family 5, in Stage Two; and second, the interview summaries for Families 1, 2, and 4, in Stage One; and Family 6, in Stage Two. These are preceded by the participant children's individual profiles from the reviewed files. Family 3 and Family 5 were selected out of the six cases that exemplify the rich and complex process of data collection and data analyses in this ethnographic multiple case study. All six cases presented a wealth of unique data that would be impossible to include in the body of this manuscript. The rationale behind the selection of Family 3 in Stage One was the following: Mother 3 was one of the two participant mothers participating in Focus Groups 1 and 2 discussions; and, Family 3 case provided information on both children, Child A and Child B. While information from Child A illustrated his path between birth and school entry, Child B's information covered from birth to preschool. Children and parents' paths comprised a seven-year period. The rationale behind the selection of Family 5, in Stage Two, is that it included the voices of both Mother and Father 5 through all the data collection activities, in contrast to Mothers 2 and 3; and to Grandmother 6's interview accounts. Child 5's profile included detailed information that covered the birth and post-natal period, with the complications that

originated at the time and the impact on Mother and Father 5's perceptions and experiences since then and until the present time, when they are completing Child 5's Kindergarten registration process.

The accounts and descriptions presented in this section highlight unique features for every family case. In addition to the themes that had previously emerged as common or shared features across the different families, individual themes within each family's unique contexts provided the structure for the interpretation of the outcomes of the present study. Nonetheless, it is important to point out the effort invested in reflecting the uniqueness of each family as a "case" in the presentation of the findings. Rather than aiming for homogeneity, every sub-section varies in the selection of the content presented from one family to the next. This variation was important to preserve the integrity of each participant's account. For example, variations are noticeable for the file review summaries containing information from each participant child (see Appendix I). This is not only attributable to the uniqueness of each child's profile, but also to the individual characteristics of the consultant's summaries and comments or suggestions to individual families.

Exemplary Case from Stage One of Data Collection

Family 3

Background. Family 3's members include a mother, a father and two children. This mother took part in the focus groups and interviews. As mentioned in Chapter 3 of this study, it was Child B who was first drawn as part of the original sample in the study. Out of the two siblings, only Child B fully met the criteria for recruitment in terms of his obtaining a final diagnosis and special needs designation by the time of

discharge from the IDP. Child A met all but one of the recruitment criteria of the study --the one referring to obtaining a final diagnosis by the time of discharge from the IDP --in spite of developmental delays being identified at the time of referral to the program. Child A's file was only reviewed during Stage Two of data collection to complement and triangulate the data obtained about his developmental history through the interviews. Child A was age 6 years old during Stage One of data collection when the mother participated in the focus groups and interview sessions. At this time, she contributed with dual information for Child A and Child B. Child A was 8 years old at the time his file was reviewed; this corresponded to Stage Two of data collection.⁹ This section presents the accounts for Child A and Child B under the same script and commentary headings; however, the file reviews for Child A and Child B are presented under separate headings.

File Reviews. Child A

Background. Child A's referral to the IDP came at age 2 under the "developmental delays" category, following his younger brother's referral to the program by a public health nurse (CHN). According to Child A's file, these parents identified speech/language and behaviour (overactive and perseverative play) as concerns. Details about Child A's referral and intake at 25 months were largely obtained during the file revision session with this mother, where it was learned that the public nurse (community health nurse) had originally referred Child B, Child A's younger sibling to the IDP consultant under the "at-risk" category. Both parents had

⁹ The decision to include Child A within the final sample supported by the Researcher's Thesis Committee, in the months following the proposal's defense, and having obtained Ethics Consent to re-establish contact with Mother 3.

already voiced their concerns for Child A, so they brought Child A along to the first visit originally scheduled exclusively for Child B.

Medical History. Child B's ante-natal history was uneventful with Mother 3 reporting good prenatal health status. Child A was born at 39 weeks, gestational age, two days after his due date, with normal weight (over 3500 g). During the file revision session Mother 3 reported that Child A had suffered fetal distress during labour. Child A was monitored due to his low heart rate during his mother's contractions during labour. Child A was born by c-section, and did not require additional post-natal attention, while she had to stay in a recovery room during that time. Child A's file reveals that he received physiotherapy at age 1 year for torticollis at the Provincial Children's hospital, and was hospitalized with a respiratory infection at age one and a half years. During the file revision session this mother described Child A as "a child susceptible to colds."¹⁰

Additional health and other professional involvement. Other professionals involved with Child A included the following: (a) Audiologist, for a hearing test at age 2 years old. The results reported "grossly normal hearing." A follow-up test at age three reported "hearing within normal limits" and "fair accuracy of test," with sound localization only on one side; (b) Speech and Language (SLP) at age 2, confirming language delays and recommending speech therapy and a follow-up assessment at age

¹⁰ Child A's file revision session (April 2008) started with Mother 3 sharing a very recent, quite dramatic experience about the family's holiday trip back to this mother's country of origin to both visit her relatives and vacation with friends from Canada. A close relative of Mother 3 died quite suddenly and under tragic circumstances while they were vacationing away from the mother's family's town. Interviewer: asked Mother 3 whether she would like to postpone the member check file revision session, but this mother wanted to continue with the session, after she finished describing these very sad events. (M.P)

3. The file indicates that Child A received therapy sessions during this year, with progress observed at the follow-up assessment for the expressive language, but not for the receptive language where the expressive-receptive language gap increased from a mild to a moderate delay. The reports show that the SLP therapy work was conducted in partnership and collaboration with the consultant's work with both parents. Child A's difficulties included not maintaining a conversation because he had not acquired enough words he would understand and difficulties with the development of social and functional language. Child A demonstrated appropriate intonation and facial gestures. The SLP recommendations included continued therapy and attendance to a specialized language preschool.

IDP involvement and follow-up. Home visitations occurred once every 3 weeks between year 2, and until the end of year 3 when Child A was discharged. Date for visits indicate that they were independent from Child B's visits (Child A's sibling) – with some of the visits coinciding.¹¹ Child A attended Parent-Child Mother Goose program with sibling (at least two sets of sessions), and both parents and maternal Grandmother (during a visit to Canada); the sessions' summaries report progress in imitating songs and actions, as well as Child B demonstrating high levels of enjoyment through his participation in the songs and rhymes. No diagnosis was obtained at the time of discharge. However, the consultant completed two referrals, one to a specialized preschool, and one to a Provincial Children's Hospital for Children in preparation for school entry the following year (Community/School

¹¹ In personal communication with the IDP Coordinator it was established that due to child's developmental delay (language) and concerns around behaviour, he would have been a home visiting case, even if sibling would not have been seen by IDP (B. Barnes, Program Coordinator, personal communication, April 2, 2008)

Services Form). During the file revision session, Mother 3 wondered whether or not the agency for children would have been involved here during this referral, and explained that almost two years had passed since Child A's discharge from the IDP before they obtained an appointment; this appointment was granted only when Child B, Child A's brother was referred to this same Centre. The mother describes this situation by saying that "Child B, the younger brother, brought Child A, the older brother!" Child A's files indicate that he attended a specialized preschool at age 3 for language stimulation and intervention. During the file revision session this mother pointed out that Child A attended this preschool for one school year. During the summer, parents only found placement available in an inclusive preschool. His progress was significant at this centre, as Child A had more opportunities for learning to "copy" from other children's language than in the specialized language preschool. Child A remained in the inclusive preschool until his transition to school at age 5. Through the file revision session it was also learned that Child A obtained a Special Needs designation by the time he started Child Kindergarten (Autism Spectrum Disorder); this designation granted Child A with a special education assistant (school support worker) at school. This mother reports that Child A's "is doing great at school," [now in Grade 1] that "his spelling is at par with classmates," and that she is "hoping that Child B will be the same."

Consultant's notes and comments. Child A's file includes comprehensive notes and comments from his consultant, including (1) suggestions for parents at home; (2) telephone numbers and professionals' names (as requested by parents); (3) summary of visits with comments on what was accomplished during the visits; and, (4)

connections with other agencies, services or programs, following parents' requests.

Parents' comments. Parent's comments included in the IDPs' Post Service Evaluation Form included exceptionally high ratings regarding the services received from this program during the past two years. High ratings included items about (a) their learning about their child's development; (b) their being in control of the learning experiences, (c) the type of service received ("a great deal:"); and (d) learning about resources, programs, and services in the community ("improved"). Parents expressed their openness to learn more about the IDPs the "LAC" (unknown term, also by parent) in the years to come.

Researcher's comments about consultant's notes and progress reports. Both the consultant's and the speech therapist's notes reveal a great deal of care and in-depth follow up with Child A in trying to meet his and his family's needs. Both the SLP assessments and the consultant's progress reports acknowledge the parents' dedication and commitment to Child A in terms of his development and unique needs. No reference is made to Child B in these notes --except for summary comments from the Parent- Infant Program sessions. In contrast, the file includes notes referring to Child A, with comment on his involvement with the IDP in Child 6's file. The Post Service Evaluation feedback reflects these parents' total satisfaction with the program model of services and the consultants' work with Child A and all members of the family. Discrepant ratings were noted between two ratings. Whereas both parents adjudicated the highest rating for the "program's model of services," they gave a second high rating to the item referring to "family's learning about other services in the community/program." During the file revision session, this mother clarified that

this discrepancy referred to the fact they would have wanted "more information" [during the transition period following the discharge], (quote),

Mother 3: From here to there, I cannot jump like that...
I need to be hand held during the transition.

Mother 3's comments resonate with other participants in Stage One who also mention their desire to be helped during transitions, and that transitioning would include support throughout the school years, as opposed to being limited to the preschool years (Mother and Father 1, Mother 2 and Mother 4. Their comments are captured under the "Access to Programs and Services," and "Understanding and Dealing with the System" themes, and within the "Information," "Service Coordination and Service Models," and "Continuity of Services" categories.

File Reviews. Child B

Background. Child B's referral to the IDP came at age 2 months, through a public health nurse (CHN), and under the program's "at-risk" category. Child B was four years old at the time of data collection, and he attended preschool. Both Child B and his brother Child A received home visits from the same IDP consultant. Child B's home visits started at age 4 months, and continued up to age 3 years. Parental concerns at the time of referral included developmental delays, especially for the motor skills domain.

Medical history. Child B was born pre-term at 37 weeks, with a low birthweight of 1 650 gr, and with intra-uterine growth retardation. Child B remained in an intensive care unit or "NICU" during the first three weeks following birth. Child

B's notes on his medical history make reference to in-depth exams conducted while at the hospital. These included head ultrasound due to suspected [cranial] bleeding. During the file revision session this mother reported that, to her knowledge, Child A did not suffer from bleeding; other tests included a couple of echo-cardiograms; and tests examining [suspected] cysts. No reports were included on the results of these tests, and the mother could not add information to these queries during the file revision session. Child B's medical records include comments on his being colicky for first 6-8 weeks, and that he had pneumonia at age 13 months. During the file revision session, this mother added that he also had pneumonia at age 2 years, and then one more time at age 3 years. Medical information included reports of Child B suffering from one seizure due to high fever, and that he had ear tubes place to control fluid at age 2 ½ years.

Health and other professional involvement. Tests and consultations for Child B included the following: (a) Metabolic tests and a Magnetic Resonance Imaging (MRI) test following an abnormal electro encephalogram (EEG) at age 2 years. During the file revision session, this mother commented on a follow up appointment that had been recently scheduled. (b) Consultation with physiotherapist for torticollis at the Provincial Hospital, similarly to his brother Child A (c) Referral for Orthopedics at BC Children and Women's Health Centre to rule out scoliosis, length of leg discrepancies, and head and skull abnormalities noticed by the IDP physiotherapist (scoliosis was confirmed; minor abnormalities reported for other concerns with follow-up stretching and sitting exercises). Follow-up tests revealed a connection between a metabolic condition and the physical scoliosis. Other medical involvement

included testing and follow-up from the Neurology, Cardiology, and Genetics Departments at the Provincial Children's Hospital. Child B received additional consultation and treatment for a skin condition with a dermatologist at this hospital.

Additional professionals involved. During the file revision session it was confirmed that Child B and his family received consultation services from a physiotherapist from the BC Centre for Ability after age 3 years, and from a private Occupational Therapist. Furthermore, he was assessed at age 3 through the Provincial Children's Hospital to rule out autism spectrum disorder –this diagnosis was eventually confirmed, and a special needs designation obtained entitling Child B to special needs preschool placement. Child B was assigned a special needs label that entitled him to support at school at the time of Kindergarten entry. Child B was assessed by a private Psychologist. The assessment results confirmed the diagnosis “autism spectrum disorder.” Child B and family received support through a specialized agency, through the Applied Behavioural Analysis program, following up Child B's diagnosis of autism. This mother's accounts throughout the focus group discussions and interviews make reference to this assessment and to the diagnosis confirmation.

IDP involvement and follow-up. Home visitations occurred twice each month between the age of 2 months, and until Child B turned 3 years old --at the time of discharge. These visits combined both physiotherapy consultation and the consultant's developmental guidance sessions. As previously mentioned in Child A's file review, Child B also attended the Parent-Child Mother Goose with Child A and other family members for at least two sets of sessions. Summary notes indicate Child B's active

participation and enjoyment. Child B frequently sang with the other participants, and maintained eye contact during the sessions.

Consultant's notes and comments. Consultant's records for the home visits included the following: (a) the completion of motor skills and related activities with physiotherapy consultation and support; (b) playing with toys including exploration and manipulation; (c) working on Child B's eating and drinking skills; (d) social and communication skills; for example, modeling non-verbal & verbal interactions between parents, consultant and child; (e) language stimulation; (f) sharing resources and information regarding programs, agencies, and services available through their community (similarly to Child A) as well as videos and literature for parents; (g) guidance during the transition to daycare/preschool, BC Centre for Ability and Supported Child Development Program (among others, including liaising with the Provincial Children's Hospital for developmental assessment); (h) discussion about possibilities about assessments and screenings; and, (i) ongoing communication with doctors/health professionals. Consultants' summaries included (1) language summary notes mentioning Child B's acquisition of spontaneous words, but a decline in communication skills after age 1 year; and lack of pretend play, mannerisms, and difficulties maintaining eye gaze were observed. These skills and concerns were also noted also through the ASQ (Ages and Stages Questionnaires) quarterly reports; (2) the physiotherapist's progress reports on gross motor development, with performance being within range until age 2 years, but with deterioration after age 2 years associated with scoliosis (genetic) condition; fine motor delays were also observed at 18 months. Recommendations were in place for follow up with sensory integration therapy (with a

Private Occupational Therapist, as confirmed through the file revision session).

Parents' comments. During the file revision session, this mother commented that she had sent pictures and cards in the file sharing family moments with the consultant and Program staff. No additional comments from either parents were included in the file. (Note that the Post Evaluation Form is included only in Child A's file).

Researcher's comments about consultant's notes and progress reports. The consultant, physiotherapist, and speech therapist's notes reveal an overwhelming number of medical-related information for this case including at least five medical specialists involved in addition to at least three therapists working with Child B and his family. The notes and summaries include reference to in-depth and consistent assessment processes. These include a combination of observations, screening, and formal assessments. The file reveals the complex process of referral, and the gathering of documents for different programs and agencies that are now all in place for the family. This documentation confirms the successful referrals and intakes for Child B. The consultant and therapists' notes confirm how the mother is "behind and on top of everything." This statement is highlighted on the consultant's notes; this mother confirmed it during the file revision session, and then reiterated it during Interview #4.

Focus Group 1

Mother 3 participated in the first focus group discussion together with Mother 2. This mother's intervention complemented that of Mother 2's in her providing

detailed information on the family's early contact and work with the IDP. This mother brought up her very specific issue of having two children with developmental delays, and how without Child B, Child A would not have had any services assigned to him had it not been for the consultant's support:

I guess all start on by talking what's the IDP all about, when my son was four, I was so worried something was not right with my son, he was not, you know, talking... I didn't know who to go to, I know something is not right, well, the doctor would say "oh, he's fine", he would say that, you know?, and it didn't happen until when my other son was born... well, I already had a concern [concerns] with my older son, and then my younger son, he was born really, really, really, small, like almost 3 lbs., and I guess because it was with the community nurse, and part of what the community nurse was doing was to ask about the sibling; and then we told her we had concern with the older sibling, and then, and they said why don't the two of you, you have got the two kids, why don't you bring them to the IDP...Because my son was low birth weight he was asthmatic then [M.P. *"it's part of the criteria..."*] yes, he met the criteria, and my older son, he is healthy, over 8 lbs, and nobody referred him to the IDP...

Mother 3 comments on her rationale for participating in this study:

Mother 3: ...I think, I don't know, it would help other families; had it not been for that nurse, then I wouldn't have known...then my older son could have a consultant lined up early on; you look at him, and he looks fine all other than he's **not talking**; Child B, we go to the doctor; the doctor would say "Child B, he *IS* a boy, just wait"...Child B, [we] wait, but how long we are going to wait?, I don't know: Is this fortunate or unfortunate that we have a son with light birth weight, like small, and finally...

The mother vehemently expresses her wish for other parents to know about her story so that they can access services early enough – as opposed to being asked to “wait and see.” This mother shares her frustration reiterating how having a second child with obvious risk criteria for developmental disabilities is what brought attention to Child A's needs, who had no obvious “risk” criteria.

This mother continues her description of her experience with accessing programs and services for both her children. Throughout the discussion in Focus Group 1 she highlighted the role of her consultants as a crucial one in providing her and her husband with invaluable information and support to obtain the referrals needed to complete an assessment on Child A, her older child.

Mother 3: My husband and I went to the IDP, and told them that my baby, he is the younger one, [Child B] we don't know if this is there is anything wrong with him by now, he is only 6 months, but we have a concerns about our older child [Child A]. Everything got

rolling and then IDP did the referrals and to we got assigned for therapy, and we got play therapy (this information is only mentioned in this discussion and is not included in Child A's files). After that the ball got started and IDP helped us a lot and [consultant's name] was so good with our son, [Child A]...She told us what to do, where to go, and then we found out about to the Parent-Child Mother Goose and then you found that you were not ...in a...situation where you were not alone all by yourself. Then [we] would get together and kids would do their thing. Later on we found out that our younger son has also problems and, IDP took over again, and we got help ...

Similar to contributions provided during interviews by Mother 1, Mother 4 and Mother 5, Mother 3's elaborate account reflects the complexity of these experiences. In her account she mentions the steps involved in contacting and being referred to or from one program or agency to the next, and from one specialist, to the next, and concluding, once again, referring to the importance of sharing this information with other parents, especially when they don't speak English (and English is this mother's second language).

Mother 3: It's like with my son... My older son and we went to the doctor and he didn't smile, you know he is still in the [autism] spectrum; we wouldn't have known anything about that, without IDP, because [name of consultant] she helped us a lot; she asked us to see

the doctor, and the doctor would say "Wait" and an in what [name of consultant] said *"Why don't you go and see to **this** doctor"* as she recommended us a different doctor, this doctor she knows that would help. I go to my doctor and say: "Can you recommend me to this doctor?" and she says: "How do you **know** that doctor?" ...In fact I didn't know whether, Child B, how we know that my son is in the **spectrum**. So she told us *"Child B, do this, tell your doctor to make referral to [Provincial Health Centre for Children]."* I didn't even know about [this centre] at this time, and then we got there for the [Provincial Health Centre] **and** **[our consultant]** came to the meeting. If not for [name of consultant], my son would not be diagnosed, and then nothing would have happened, we've not have any help, because they say "oh, no" in [the] [Provincial Children's Hospital they had] just said, *"I think it's just language delay"* but [consultant's name] said *"Wait a minute, you forgot this, this and that,"* cuz you know, [you would] go to [the] Provincial Children's Hospital, [for Child B] and they would look at your son, and it's only for him, and a few hours; but [consultant] worked with my son for two years, forever, so she is more an **expert**, so the doctor said then, at the Provincial Health Centre, because [consultant] is more a professional, the

doctor said, "Child B maybe we give him a [provisional] diagnosis" and that got me the funding, and [consultant] said to me "It's just a label, if they say 'your child is autistic', even better, here because you can get help." You know, you have child who has delay, you don't get help... **unfortunately** help depends on the label... So there we go, we got the label; and now if you see my son, is night and day if you compare him...[consultant] helped him to do that, and of course with my other son [consultant] helped too... and because of the experience for other families especially for some families who can hardly speak English, maybe they have children, maybe like **my** children, and don't know what to do; they go and get a diagnosis, but then they would know what to do after that, because [the] Provincial Children's Hospital just said "[name of Child B], your son, has autistic disorder," but, **Who** to you go to next? Perhaps they could talk to the parents and tell them what to do next... [Mother 3 refers to the fact that Child A's diagnosis and label came after Child A had been discharged from the IDP]

Having the time to elaborate on these experiences and transitions throughout the interviews and subsequent member check sessions proved invaluable for this researcher to gain a better and fuller understanding each one of the participants' stories, and their struggles in making their voices heard. Mother 3's comments

substantiate the findings addressing the specific research question, “What are the individual experiences of developmentally at-risk children and their families who participated in the IDP in terms of access to resources and programs?”

Interview Accounts

From early experiences to coping with transitions, change and demands. This mother was the only participant during Interviews #1 through #4. It was this mother’s choice not to include her husband in these sessions, as she indicated during Interview #3. In Mother 3’s words (quote) “I am more in the talking/doing...” Her statement echoes Mother 1’s statement (quote) “I do all of the footwork.” These statements speak to Mother 1 and Mother 3’s being more directly involved with activities related to their children’s services and programs.

Interviews were conducted during the morning, while Child A was at school, and Child B was at preschool, at a community centre café area near the mother’s home. All interviews were completed between March and August, 2005. This mother was willing to extend each one of the sessions for an additional 15- 20 minutes each, so that the four topics were covered in three, rather than four, sessions.

Selected comments from Interviews #1 - #4. This mother began her account retrieving following up on her comments during Focus Group 1 about Child B’s referral process to the program. She stressed how expedient the process had been, and how surprised she was at the time. Neither the mother nor her husband understood the reason for this referral for Child B –and especially with her experience in the past year with her family doctor’s lack of receptivity with regards to the mother’s expressing concerns for Child A’s delay in language development and play skills:

Mother3: I was pretty impressed that it kind of went **faster** than I thought...you know the nurse...getting you an appointment to go with [the] consultant. At first I had **no** clue about what 'it's' happening, you know...What it is for?

In Interview #1, this mother recalls the referral was completed through the phone with the public nurse's assistance. Then the family received a letter from the IDP coordinator with whom they arranged a visit. At the time of the consultant's first visit, the purpose was to follow-up Child B:

Mother 3: But we were not sure there was anything wrong with him yet, he was so small, but we did have a concern about older son. The [consultant, who was the program coordinator] got pretty excited..And she referred them to audiology, and speech therapy for Child A...Without that [refers to referral and help from IDP], I don't know where to go, where to start...Before that I am waving the flag, but I don't know to **who**...The doctors may know that...the health department...but... **Where** to start?

At that time, this mother ensured that both the consultant and the doctors received copies of the audiologist's and Speech and Language Pathologist's (SLP) reports (the hearing test came normal for both children, whereas Child A required speech therapy). The mother recalls that the consultant helped her to interpret the reports. This mother reiterates Child B's "involuntary" role in facilitating services for his older brother:

Mother 3: Without having a younger son.....Maybe, I'd fall through the cracks...I did not know where to go.

This mother's recollection of the home visits echo comments from Mothers 1, 2 and 4 about the wealth of information learned about her children's needs and development, and how easy it was to have the consultant there in terms of guidance, but also for support, both of them working with the children within a collaborative partnership; and finally, her level of comfort with the consultant being at her home. These comments are captured under the themes "Role of Consultant/Therapist" and coded within the categories "Guidance Received," "Information," "Empowerment," and "Program Model of Services: Description, Compare and Contrast."

Mother 3: Well, the sessions were actually good because it helped me tell the consultant the things I observed or the changes I observed...in fact, [the] Consultant and I were kind of sharing the kids... I established like a friendship with consultant and trust...

In reference to having home visits, as opposed to taking the children elsewhere for therapy, the mother explained that meeting at home was more comfortable for her children:

Mother 3: I liked it...Sometimes [consultant's name] would come and the house would be quite messy...and [she'd say] "it's ok."

At the same time and for certain type of therapies this Mother indicated she would [like to] take Child B to see a therapist because it could be less

distracting.

The guidance received through the consultant's home visits is evidenced throughout this mother's account.

Mother 3: I wish we could have seen the consultant more (than twice each month)...I wish it could have been every week...I guess that does not happen...with her busy schedule (The mother also commented that sometimes the family logistics got in the way for scheduling visits).

Among the many benefits of the work conducted with the IDP, this mother stressed three aspects that were relevant for her, and that were coded within categories labelled accordingly to key terms that summarized these responses. These included: (1) the wealth of information received, and additional services accessed through the consultant; (2) the way the consultant supported her and her husband in being networking agents, with other parents who had children with special needs, and to also benefit from the support that networking with families living in situations that were similar to their own; and (3) the sense of empowerment gained through the collaborative process with the consultant. The next set of quotes illustrates these aspects and the connection among them. The themes "Role of Consultant/Therapist" and "Parents' Priorities" captured this mother's viewpoints:

Mother 3: I didn't know that IDP had physiotherapy services! When I mentioned this to consultant she said ok, next time I come I will bring [name of physiotherapist]. You know, so physiotherapist showed up, and checked up Child B...and she did a very, very

thorough assessment of Child B...I really liked it...So because of the 'torticollis' they both had... Child A's [had] got corrected, but Child B didn't.

The mother was informed about the characteristics of this condition:

Mother 3: This happens because of the position they were both born [in]; now Child B is followed up by a specialist at Provincial Children's Hospital.

The mother also explained that she was concerned about the impact of the condition on the children's spine.

Mother 3: [name of consultant] listened.. and understood my concern and contacted [the family] doctor, who had not previously paid too much attention to her [the consultant's] concern.

The mother adds that the next time she saw her doctor, his attitude had changed:

Mother 3: Now she showed more sorrow, now she [the doctor] even said: "Now we need to get a *professional*"...Who said [this other professional] "*something may not be right*", and then she [doctor] started to get an X ray and stuff...

The mother elaborates how this situation had been ongoing in her dealing with her doctor, and in general with the doctors following up on her children –but mostly for Child A. This mother illustrates with her account the empowering role of the consultant that led her to continue being an advocate for her children's needs. At the

same time, the examples reflect the role played by health professionals within their positions of authority where they have the last word in deciding who is referred —and who is not—to specialists according to the established “at risk” criteria for developmental assessment. Had it not been because of the consultant’s professional support with the doctors, this mother’s request would have continued to be left unattended.

Mother 3: Both with their diagnoses I got the doctors saying oh wait and see...and then someone said: *"Well no, ask the doctor to get a referral to Sunny Hill"*...If I say that...the doctor is going to say...*"Maybe"* because they think...*"I am a doctor, I can tell."* Maybe if I think I need another pediatrician to take a look at . him, they say, *"Why? I am a pediatrician too!"*...And that’s how I got my assessment...Because if I went on my own and if consultant was not there I would not have got that done! (Excerpt from Interview #1)

During Interview #2, this mother expanded on this issue. When developmental concerns arose about Child B, and their family doctor did not seem to be worried, this mother let their consultant know. The consultant offered to make contact with physiotherapy services and followed up with a referral for the family physician. The struggle to obtain referrals for assessment for both Child B and Child A was a continuing one for this mother. She reiterates two points: One, that the doctor should have initiated these referrals, and not the consultant. Two, that had it not been by the presence and support of the consultant in following up with the referrals, their children

(and especially Child A) would not have obtained special needs funding they required -through their being assigned with a special needs label. Her voice as a knowledgeable and articulate parent was never 'good enough' to have her children's needs addressed.

Mother 3 said that at the time that the IDP consultant had not worked with Child B yet, but that she had worked extensively with Child A. This mother ended up getting a private assessment for Child B. (Excerpts from Interview #1)

Mother 3: Right...but again...we needed to have a speech therapist that can say... Yeah...go ahead you know...but you know it **should** be really coming from the doctor...

This mother explained how, upon the consultant's recommendation the family ended up seeing another doctor who had also supported another family in a similar situation and that second doctor gave the consent to see a psychologist...

Mother 3: ...So she agreed with that, and then I got my diagnosis.

Interviewer: clarified with this mother about her understanding of obtaining the diagnosis for Child A to qualify for a Ministry designation, and that Child B had the rights to preschool with Special Needs placement, to which this mother responded:

Mother 3: AH - HA! And the funny thing was that when Child A was seen all he said was that Child A had...You know, [a] language delay...But[the] consultant is there, and she knows that we get help when we get the label.....A child with language delay and a child in the spectrum...[They] do not need the same kind of

therapy...The guide was the **label**...And actually because of consultant, we got that ...label...And even if it was 'provisionary'...Then we were re- assessed.. and now the doctor said, "*You're right; we're glad you've got the label.*" (During the first Focus Group this mother had brought up the issue about obtaining a diagnosis that is associated with a label; this is how she learned that "label" equals "qualifying for funding.")

During Interview # 3, this mother reveals what she would have liked to tell her their doctor, after Child A obtained the "autism spectrum" diagnosis:

Mother 3: "I wanted to tell you...and you would not, you would not give the diagnosis" ... [and adds] If [IDP consultant] had [not] been there...

Going back to their involvement with the IDP, this mother added that their consultant had also connected her to the Parent-Child Mother Goose; at the time, Child B was just born and the mother did not have help with a nanny so her mom came from abroad to help the family. Mother 3's mom would also attend the Parent-Child Mother Goose with them (this information coincides with what is described in both Child A and Child B's files). Mother 3 attended at least two sets of sessions, as Child B grew older, and her mom attended more than once, during her trips to visit the family in Canada, (quote) "...And my mom enjoys it! ...She enjoyed it a lot."

This mother's comments on her mom enjoying the sessions corroborate the contents of summary reports from the Parent-Infant session in Child A and Child B files of having the children's grandmother, and, later on, their auntie, come to the sessions and expressing their enjoyment.

The mother reminisced about how the information exchange went both ways in sharing resources. Both parents had found useful for Child A's language development with the consultant. She, in turn, encouraged them to connect with other families receiving services through the IDP, and who would also be interested in learning about this resource. The connection with other parents who also had children with special needs resulted in both parents developing a network of friends as well.

During this time, Child A was not receiving speech therapy services—and he was not talking yet. His parents retrieved a wonderful resource from the internet.

Mother 3: It's called Bumble Bee... from the US]... At the time we would do whatever we needed Child A had some words, some words...so we ordered that...when consultant came back [from Spring Break}, Child B was like a different boy...It [he] had so many words! So ... consultant was amazed and ...shared this [video interactive program] with... other parents [clients] ...It was like [the] consultant would phone me and said "*I have a client can she phone you?*", and I would say yes, and then they would call and then we would go out [reiterates: at night, socially]

This mother reiterates how their consultant was great in not only bringing and sharing resources, but also explaining, writing down what they could do at home with them...

Mother 3: And she [was] always good to come up with ideas...like ok, if Child A wants a video, get a **picture** of the video...and then, Child A...would point!!!

This mother expands on the specific and pertinent information the consultant would share with them, and on the impact it had on her learning and understanding more about her son's development. Her comments are captured under the Themes "Role of Consultant" and "Cycle of Disability," and coded within the categories "Information, Importance of," "Awareness of Child's Development" and "Awareness of Child's Special/Unique Needs."

During Interview # 1, this mother refers to Child A as "high functioning," and had not been identified [as a child with autism]. She recalls that they followed up on his language delays and on "the whole issue of autism" (referring to their suspicions at the time. Child A had started recognizing letters when he was pretty young; and consultant mentioned the possibility for S being "Hyperlexic:"

Mother 3: 'Hyper-lexic'..."What 'does' 'hyperlexic' mean?"...Then consultant would give us this materials...to see if Child A was 'hyperlexic' or not...And she is pretty nice...because it was like someone coming to your house and actually showing you how to play with your son...And teach me how to play, how to relate with my son...And all the toys she would bring...and it was so exciting when Child A said his first words...which was...'bubble'...

During Interview # 2, in addition to learning about resources and obtaining a

better understanding of her child's development, this mother recalls the specific example of finding out about additional benefits, such as tax reimbursement to cover Child B's expenses thanks to the ongoing contact with the Early Intervention 0-3 consultant.

Mother 3: I found about that... I wish I wish...People [would] know, and if consultant did not tell me I would not know...And it is a lot of money, it does go back.

The mother also comments on other expenses covered:

Mother 3: Obtaining refunds for diapers, since it was difficult at night (toilet training)...

Having Child A go through the discharge period with the IDP was hard for this mother and her family—even if through Child B they continued to see their consultant for one more year. This mother's comments are captured under the theme "Roles of Consultant/Therapist" and within the categories "Information: Importance Of," "Guidance Received" and "Empowerment."

This mother praised how their consultant (quote) "...was so nice" and she left it all in place for them in terms of the preschool for Child B. The mother mentions how their consultant did not want to leave her family until she made sure that Child B had got his placement [for daycare], the same way she had helped to select preschools for Child A:

Mother 3: I had no idea about the kind of schools that are out there...She helped me *picked* the ones that are

good...and she was the one who showed me about [specialized preschool] and then about [inclusive preschool], and Child A at the time was accepted **both** at [Language Preschool] and [inclusive preschool]

This mother commented on an excellent teacher (quote) “the best teacher ever at [Language Preschool].” Because of time allotment with special needs, they family decided to find a placement for Child A at an [inclusive preschool], since this placement better met Child A’s learning needs. This mother appreciated the consultant’s more personal contact with the teacher, (quote) “That’s nice.”

The mother elaborated on the transition to daycare for Child B, and how once again, the consultant helped her find a good daycare, an ‘inclusive’ daycare where Child B’s needs would be met. Both parents would have also liked that Child B went to Child A’s [inclusive preschool], but no spots were available at that time. The mother recalls that what concerned her most was to have after school care when Child A entered Child Kindergarten. At the time, the family was not involved with the Supported Child Development Program yet, and this mother was not aware of the possibility of obtaining support for placement through this program.

Mother 3’s memories about this double registration process for preschool with special needs support hint to their complex family logistics. Both parents had to deal with multiple scheduling, transportation and simultaneous contact with two different programs. This mother’s comments echo those of Mother and Father 4’s description of their family logistics, and the stressors associated with these. In Mother 3’s case, they have had to deal with almost simultaneous transitions of one child to preschool and the

other one to Kindergarten. Her comments are captured under the theme “Stressors” and within the categories “Family Logistics” and “Parents Multiple Roles.”

Mother 3 reminisces about the family’s experiences after they were discharged from the IDP, first for Child A and then for Child B, in dealing with different service models. As she compares and contrasts the different programs; e.g. IDP, with the BC Centre for Ability and the Supported Child Development Programs, her comments illustrate her perceptions on the levels of coordination and continuity of services, and express her preferences in terms of the effectiveness of services received. The mother’s comments echo those of Mother and Father 1, Mother 2 and Mother and Father 4 and are captured under the theme “Access to Programs and Services.” In Interview #2, this mother’s account begins with memories about the intake process with the Supported Child Development Program consultant:

Mother 3: [consultant] would pop at my place to ask me things, “*how things are going*”...but [she was] not really involved.

This lack of involvement referred to the fact that once this mother took Child A and Child B to [the inclusive preschool], a preschool that was not in the programs’ catchment area at the time (the family had finally found part-time placement for Child B in the same inclusive preschool by the time Child A was leaving preschool).

Mother 3: They [Supported Child Development Program staff] don’t have like a teacher for that... [Whereas] staff [at inclusive preschool] is trained...They only had a part time spot for Child B. He had one month of

full time...And he did very well!!! And then when they cut back...and my spot was only part time!

This mother states her beliefs about how funding should be implemented for children with special needs. Her comments resonate with Mother and Father 1, and with Mother 2, in reference to the unique needs of these children requiring their being addressed fully and consistently. Children's special learning and/or developmental needs should not depend on bureaucratic or administrative issues with funding. The themes "Issues with Funding" and "Understanding and Dealing with the System" capture these issues, within the categories "Parents' Values," "Wait times and Wait Lists," and "Parents' Perceptions and Experiences," among others.

Mother 3: I really believe that children with special needs...They really need it...Like five times? [per week]...and I really saw it, for Child B...(In reference to the progress observed when he received the help he needed at the preschool)

The mother adds that only when the family finally obtained special needs funding through the Supported Child Development Program, Child B could go back to full-time. The mother also explains the differences in services needed and provided to Child B and Child A according to their identified needs:

"Child A...He did not require special help...a lot of help...all the time? ... While Child B needs one on one..."

This mother also elaborates on the additional therapy services going on at the time for both children.

Mother 3 makes reference to her understanding of how the different programs and agencies work, for example in the way they provide therapies to children of different ages. These agencies include the Health Department and the BC Centre for Ability. Services were in place for both Child A and Child B; however, this mother took on the role of 'case manager' as she organized the integration and provision of services for her two children. The following excerpt provides an example of the mother's perceptions on how the different services were offered and provided, and the transitions that happened in between services and agencies:

Mother 3: I don't think the program had this service available; Child A's SLP [speech therapist] was from the [Health Agency]... I think... [it was accessed] through IDP...IDP finishes at 3, but [Health Agency], speech, continues...) so physiotherapy with IDP, goes to physiotherapy with BC Centre for Ability.

This mother recalls physiotherapy services from IDP for Child B and comments on how physiotherapy from IDP worked better for Child B as she had Child B's file since he was a baby. There was no transition time that she recalls in terms of physiotherapy services between the two agencies:

Mother 3: When BC Centre for Ability took over, she only knew Child B the way...when she took over

In Interview # 3, this mother complemented this information on the different

transitions. When Child A entered school, the SLP services through the Health Agency stopped, and they had a private speech therapist provide services for him; at the same time the family became involved with another program providing Applied Behavioural Analyses therapy to work with both children.

These examples resonate with the examples provided by Mother 2 and Mother 4, in Stage One, and are captured under the themes “Parents’ Multiple Roles,” “Access to Programs and Services” within the category “Parents Perceptions and Experiences.” At the same time, the mother’s effort in trying to make sense of the different programs and services echoes comments from participants in Stage Two of the data collection: (a) Grandmother 6’s confusion with the Supported Child Development Program and BC Centre for Ability’s after Child 6’s discharge from the IDP at age 3 years old, and (b) Mother and Father 5 confusion with the many professionals and agencies that were involved in providing them with information about the health progress of their child, and her mentioning that she would have liked someone doing the case managing at the time.

Mother 3: Too many transitions!!!

This mother reminisced about the services received during the children’s preschool years with the Supported Child Development Program and BC Centre for Ability, and how they were provided. In her account, this mother reported continuity between the occupational services provided for Child A, and then for Child B. This information corroborated the information retrieved from Child A and Child B’s files. The mother’s account is similar in her description of the service models and the roles played by the therapists to Mother 1, Mother 2 and Mother 4. These comments are

captured under the theme “Roles of Consultant/Therapist,” and within the categories labelled “Service Coordination and Service Models,” “Continuity of Services,” and “Parents Perceptions and Experiences.”

During Interview # 2, the mother described how they [therapists in BC Centre for Ability] would go to school after they do therapy at home, when they worked with Child A. With Child B, they would observe and work with Child B while in class with other children, in a small group of children. The mother commented on the difference in the way services were provided, even if it was the same agency. She was appreciative that she did not have to “tell the story” to a different person when Child B’s turn came for services, as it was the same therapist providing help to Child A and Child B:

Mother 3: They [BC Centre for Ability] were involved very little...added that they have an OT (occupational therapist) from and they ...they go to the preschool...[BC Centre for Ability] OT used to work with Child A, and then when Child A was discharged follow up with Child B ...[the therapist] was the same person.

During Interview #3, the mother expresses her concerns that Child A continues to wait for therapy support from school, and that she has had to pay for private therapists (refers to the Speech and Language Pathologist and to the Occupational Therapist). She reveals her frustration about having to go and check-in with the school about this issue. Her sense is that it should be the school’s obligation to ensure that services are provided, and not the parents’ responsibility. This mother’s comments resonate with Mother 1 when she states that (quote) “There should be enough

resources in the schools” to implement the therapy and individualized programs and/or strategies recommended for her child (Child A). Both parents have also indicated that they have had to rely on private services at times –and this is not their first choice. Their observations are captured under the theme “Issues with Funding” and within the categories labeled “Barriers,” “Parents’ Values,” and “Dualism and Contradictions.”

During Interview # 3, this mother also described her experiences in trying to be involved and knowledgeable about Child A’s progress at school, about the work the teacher does with Child A (this mother wonders whether is it lessons or is it therapy, like speech therapy too?) The mother has been under the understanding that Child A’s Resource teacher provides both levels of services...or at least:

Mother 3: I wish that they would do that, I don’t know exactly what they’re doing.....I wish that the Resource teacher would come in with a report and tell me in her own view where is Child A at.....and I don’t receive that... I know that every week the Resource teacher follows Child A up with a kind of test or exercise, but there is never a report back except from the report card... (Interviewer: Is there an insert?

Mother 3: There is not an insert).

This mother’s response about her perceptions on the ways services work echoes the same ambivalence expressed by Father 1 during Focus Group 2 discussion about how much pressure should parents exert to obtain what they need for their children. Father 2 shared with

the group how he and Mother 1 had exposed their needs and eventually obtaining the feedback and response they needed. At the same time, Father 2 expressed his being concerned with “placing too much pressure on the system as this could jeopardize services for children with special needs.” Mother 3 wonders, instead about ‘silence’:

Mother 3: Maybe because I am not saying anything...If I said something...that I am not getting that? Maybe next year I will do more...It was new, it was a new school... Like a new system for me and I don’t know, ok...what should I be advocating for...?

This mother compares the cases for both children. Child A’s needs are not as evident in terms of support needed, as Child B’s:

Mother 3: I don’t know...because maybe Child B [and his low incidence special needs designation] is political with the school?

When asked to compare the two transitions, the one to preschool and preschool support services and the one to school, this mother replies:

Mother 3: No, totally different. Like you have more control when you are in preschool... I just wish there was more communication, more report[ing].

The mother described what the follow-up recommendations were in Child A’s IEP from Child Kindergarten to Grade 1.

Mother 3: There was a follow up, but mostly in the objectives... The mother comments how she would have liked more detail that she is not getting even from the report card:

Mother 3: I get it [more detailed information] when I talk to the teacher...verbally...so what I do...when I pick him up...I stay longer, until everyone is gone.....I talk to the teacher.

And with regards to her role in being part of the year-end IEP:

Mother 3: Oh yes, I looked at it, pretty much the same what it was before...

Interviewer: asks this mother whether or not she has observed changes on the way Child A is learning:

Mother 3: Oh yes! It has changed ... Child A has improved in so many areas...and there are things he continues to work on...now for example he can write things better and other things like that...

The mother expands on the services Child A has received at school. The mother describes the collaborative efforts between the Resource teacher and the special needs assistant support worker to follow-up with the goals for Child A in his social and communication development.

In terms of support staff assigned to work with Child A, Mother 3 expresses her concerns, and her hopes:

Mother 3: There is an aide...but up to February?
Sept...Oct...Nov...Jan...Feb... Child A has had I don't know how
many aides...'because they keep on changing...but only
since February Child A has got someone that is really
good...it won't change...I know that her position is
permanent...she...she is very wonderful!

Once again, this mother's description of the services received at school, her priorities and her hopes and expectations echo Mother 1's comments. These are captured under the themes "Understanding and Dealing with the System" and "Parents' Priorities," and within the categories 'Staff Changes,' and "Parents' Hopes and Expectations," among others.

This mother has obtained funding for Child A for the Applied Behaviour Analysis therapy (ABA) with the intervention therapist. This therapist goes to Child A's school and works in conjunction with the teacher and special needs assistant. Mother 3 is satisfied with this work, and confirms that it is her role now to maintain it on an ongoing basis.

Mother 3: Somebody to coach him to work with other
children, cuz that's his problem.....and I can't do it!

The mother elaborates on her relations with the classroom teacher and support worker:

Mother 3: ...In fact I talk to the support worker and
she talks to the classroom teacher ...Because I am more
confident talking to the aide because she is with
Child A all the time, everyday.

The researcher confirms with the mother that, although the school Principal is involved in her case, it is the mother who is doing the 'managing' of all these support staff working with Child A first and soon to be working with Child B. The mother agrees.

This mother's response and her reflection echo Mother 1, Mother 2 and Mother 4's statements about their self-perceptions as advocates and case managers for their children. These comments are captured under the theme "Parent's Multiple Roles" and within the categories "Parents as Advocates" and "Empowerment."

This mother describes how it is her role to bring the team together during the IEP meetings, with the teacher, Resource teacher, support worker, Applied Behaviour Analysis therapist (private) and the Principal:

Mother 3: It's been good...I mean you really have to be on top of things...You really have to know...your goals?

This mother also expressed how she would have really liked to introduce her language to her children, but the speech therapist recommended, "Sticking to English..." This recommendation followed the identification of Child A's difficulties with language acquisition and communication, and the fact that he had already acquired some English.

Mother 3: So it would have been even harder...so talk to him in English...

This mother found comfort in the speech therapist's words that "there was always time to introduce a second language" once he started to talk.

Mother 3: I'd like for Child A to speak my language;
it's so hard... (Excerpts from Interview # 4)

This mother's quotes reflecting her emotions on her not being able to communicate with her son in her own language are captured under the theme "Cycle of Disability." Her reflections share similarities with those of Mother 2, when she confronted over, and over again, that Child 2 would not walk independently. They also echo Mother 1's thoughts when she acknowledged the fact that her daughter would leave the protected world of preschool to attend the less "cocooned" school world where she would be teased. Some of the categories where these comments are coded include "Awareness of Child's Special/Unique Needs," (and the sub-category "Meeting the Child's Needs), "Parents Hopes and Expectations," "Parents' Fears and Concerns" and "Parents Perceptions and Experiences."

During Interview # 4, this mother acknowledged that she has had support from her husband and from extended family all the way through. In addition, she is grateful that they have financial means that have allowed them to incur in additional expenses for Child A and Child B. This mother comments on their daily life and on how both she and her husband support each other. Her comments reflect her perceptions of support in different ways. Quotes from this mother's examples include,

Mother 3: He (Father 3) understands when I am stressed... I have family support, I mean, less from my family 'cuz family don't live here but...I have family support, my husband family, my in-laws... Is not that they tell me *"Don't worry everything is going to be ok' and then do nothing, but they really help"* [with

my kids, they treat them normal...] Same with friends and my kids, they...they don't pity me.

This mother firmly believes in her family trying to be and act as anyone else. However, her examples reveal how she has experienced exclusion. This mother's comments convey her belief of that communication with families whose children have special needs can happen in two different ways, so that they do not feel excluded (e.g. "I try not to hide the fact that I have 'special needs' children", quote). At times, she likes to say (to others) instead: "They are kids just like the other kids" and "so and so is doing this, but Child B is not doing this yet"

This mother realizes that these mixed feelings are even more pronounced when both parents are in contact with other families. The following quote expresses these mixed feelings – how lucky they are, and at the same time, the yearning for some things to be different than what they are.

Mother 3: Sometimes I go to [Provincial Health Centre] and then I see other moms with other children and then I say "You know what? I am lucky...We are lucky!"...and it's hard because you look at the other world, at the normal world and think "Look at that, look at him play"

Closing Comments: Focus Group 2

This mother's comments in Focus Group 2 support Father 1's comment with the difficulties trying to obtain funding (quote) "so 'many' red tape," so that the children continue receiving the necessary therapies at school –without the need to

bring in additional, private staff. She definitely sides with Mother 2 in advocating for the IDP Services to coordinate services continuing during preschool, and also during school. She adds to Father 1's ideas to have ongoing workshops for parents on how to guide them using the existing services:

Mother 3: Like a mentorship...Especially for ESL parents...Get this through the IDP...help them learn, for the different agencies, what they do, how things work...¹²

Family 3 Summary

“What are the parents’ perceptions of their experiences of early intervention on (a) early childhood development; (b) parenting; and/or, (c) family dynamics in families with a child at-risk for developmental delays, or diagnosed with developmental disabilities?” Mother 3’s account represents a unique case of a family group where parents experience the “cycle of disability” with both their children. Through radically different experiences with Child A and Child B’s health and developmental situations, both parents confronted twice a number of similar issues involving referrals, diagnoses, intake and discharge processes from programs within a period of three years. This mother presents a forceful and detailed description of the family’s attempts to be listened by their family physician and by their pediatrician. Her examples provide a unique testimony of parents despair when they realize that the only way to obtain the help their children’s needs is to have the children fit within certain criteria. At the same time, this mother’s comments illustrate the importance of

¹²Note: Mother and Father 4 brought up this issue during their interviews; e.g., how helpful would it be for families to have a chart/understanding how agencies and programs work.

the role of the IDP consultant, and the impact her presence and commitment had in her family's life. Several examples illustrate this impact throughout the mother's quotes. In essence, it was the consultant's listening to this mother's concerns and following up with the family's requests that made a difference for Family 3. Rather than focusing the consultation and therapy to Child B, –with established medical risks –the consultant's approach and service delivery model made it possible for both of them to address Child A's needs –with developmental delays that were not obvious enough to raise medical concerns at the time. This mother's wish to tell her doctor (quote) "I told you so" exemplifies some of her feelings of frustration in having had to rely on the support of another professional (the consultant) in order to ensure that her oldest son would be assessed; that he would receive the diagnosis; and, that he would qualify for services in preschool and school, even if she had been aware of Child A's special needs since very early on. Moreover, this mother's account is one that reflects the empowerment instilled on her through the work with the IDP consultant for approximately three years. Mother 3's account echoes Mother and Father 1's separate accounts on their understanding the strengths they both brought to their daughter's first IEP meeting. The consultant also played an important role in appreciating this mother's talents in exchanging developmental information and learning resources, as well as in her establishing an effective social network with parents experiencing similar situations with their children. This appreciation and support further motivated this mother to reach out, and to share invaluable knowledge and tools with other parents with children with special needs with whom she and her husband developed friendships. This mother continued to develop these "case managing" skills that were

invaluable for her and her husband to cope with the multiple logistics of their family during the years that followed. Not only did both parents have to follow-up on their children's health with medical consultations and treatments, but they also needed to adapt every moment of their daily lives to meet Child A and Child B unique developmental and learning needs. Examples of these adaptations included preparing special meals for their children every day and helping them eat; an ongoing re-arrangement of their household furniture for Child B to be safe, although this mother expressed, (quote), "But ...one needs chairs in their house!"; taking each child to a different centre or school where they receive special support; dealing with transportation and scheduling issues for each centre, and maintaining contact and follow-up with at least two therapists, teaching and support staff at each location; and, carefully planning their social outings, as each different situation or schedule would throw off the routine of one of their children, (quote, "Here comes another birthday party!")

Had both parents not worked in collaboration with the IDP consultant and therapists during those very early stages, this mother declares, (quote), "I would not have known where to go...I would not have done what to do." This mother found it invaluable to have the consultant's presence through out the first series of transitions, and would have liked to extend this supporting bridge for the years to come. In this mother's words "From here to there, I need a hand." In the end, and with the assistance provided during the preschool years by the IDP, Supported Child Development Program, and BC Centre for Ability's, essential services for both children were ensured through the labelling system of funding. Even without the

“hand,” but thankfully with financial means, and also with a very supportive extended family, both parents made it “there.”

Exemplary Case from Stage Two of Data Collection

Family 5 File Reviews

Background. Family 5’s file reviews reveal that Child 5 is the first and only child to Mother and Father 5. Child 5 received services from the IDP between the ages of 3 months and 3 years old. Child 5 had just turned 5 years old at the time of data collection.

Medical history. Child 5 was born pre-term, at age 36 weeks gestational age and with normal birth-weight, close to 3000 gr. this mother’s pregnancy was uneventful, according to her report during Interview session #1. Child 5’s files indicate that he received medical attention and follow-up by several specialists soon after birth due to severe jaundice (high billirubin levels) associated with blood group incompatibility, and required of a transfusion. He soon had to be re-admitted to the hospital with a respiratory infection, and additional medical complications. When discharged, he was referred to the IDP by the pediatric physiotherapist at the hospital. The reason for referral indicated muscle tone abnormalities at the time, for example, hyper-tonicity and hyper-reflexivity associated with the post-natal medical complications. Bothe parents provided an extensive description and explanation about their experiences during Child 5’s first couple of months, regarding his post-natal complications, hospitalizations and the different follow-up activities.

Health and other professional involvement. Child 5’s records indicate he has

required follow up from a pediatrician since birth. During his first year of life, Child 5's medical progress was closely monitored with CT scan and a Magnetic Resonance Imagery tests due to concerns related to neurologically-based risks, following the birth complications previously listed. Child 5's medical attention soon after his birth was an important topic for discussion with both parents during the interviews. Their responses reveal the intensity and anxiety experienced in trying to understand their son's medical condition, and to cope with the different medical professionals who, according to both parents experience, not always provided clear, understandable or accurate information see to theme "Understanding and Dealing with the System;" to categories "Parents Perceptions and Experiences" and "Role of Health Professional;" and to sub-categories "Miscommunication," "Perceived Miscommunication"). Child 5's file includes notes about additional follow-up between birth and age three years old with other professionals. These have included the following: (a) the audiologist, for hearing tests checking the integrity of Child 4's hearing, both for sensorineural (or the integrity of the auditory nerve) and mechanic (or the conduction of sound) hearing (Harrison, 2008, pp. 377-378). Reports from these tests stated that Child 5' hearing was within normal limits, with no sensorineural, or damage to the auditory nerve, identified; (b) the IDP pediatric physiotherapist consultant, to follow-up on Child 5's muscle tone, reflexes and motor skills acquisition. Pediatric physiotherapy assessment report and consultations recommended specific exercises to be followed-up and reported that muscle tone and motor skills development were progressing within the typical range; and (c) the speech language pathologist (SLP) from the Health Unit, to assess Child 5's language acquisition and development. The language assessments

were suggested by the IDP consultant following indicators of mild to moderate expressive language delay in developmental screening reports at age two years old. Child 5's file included the language assessment reports. Following the first assessment, speech therapy was recommended and implemented. Subsequent reports throughout years two and three indicated progress in Child 5's expressive language acquisition, and noted that Child 5 was raised bilingually (English and German), although parents indicated to the SLP that they avoid "mixing" the two languages at home. Consultations with these professionals continued until soon after his discharge from the IDP, as parents confirmed during interviews see to theme "Cycle of Anticipation;" to categories "Awareness of Child's Development" and "Awareness of Child's Special/Unique Needs" and to sub-category "Meeting Child's Needs").

IDP involvement and follow-up. Child 5's file lists and describes the periodical developmental screenings conducted through the IDP using the Ages and Stages Questionnaire (ASQ), a non-standardized measure of development administered by early intervention consultants in conjunction with parents. Progress was consistently noted throughout the different developmental skills in the assessment reports. By the time of discharge at age 3, Child 5's overall development fell within the typical range of skills acquisition, including Child 5's physical (muscle) development and overall motor skills, and with social and play skills rated as Child 5's strengths. Although no major concerns were raised with regards to Child 5's language acquisition, recommendations for continuing language development follow-up were in place in the final language report. During Interviews #2, and Interviews #3, and #4 (combined for this family), the mother, commented on their heightened --and some

times hyper-sensitive-- levels of awareness of Child 5's motor, language and cognitive skills acquisition following their work with the IDP consultant and with the program's physiotherapist, as well as with the speech and language therapist see to the theme "Cycle of Anticipation" and to categories " Roles of Consultant/Therapist," "Information, Importance of" and "Awareness of Child's Development"). The interview sub-section presented next illustrates examples of these comments.

Consultant's notes and comments. Child 5's file shows the family's regular visits to the IDP on a monthly to bi-monthly basis during Child 5's first year and up to quarterly visits after his second year. The records indicate that consultations combined visits with both the physiotherapist and the program's consultant. The records do not indicate the family's involvement with other programs, nor do they mention the program's involvement with Child 5's transitioning to preschool, receiving childcare services and/or proceeding to any of the child development and special needs support programs after Child 5's discharge at age 3 years old. The progression of visits through the year includes the family's involvement with up to seven consultants, and two physiotherapists (one of them being the key professional following Child 5's case, and the other one consulting while the first professional was away temporarily). Summary notes from the consultants and physiotherapists in the waitlist and monitoring groups confirm the participant's comments referring to the consultative and collaborative nature of these visits, where parents had the opportunity to voice their concerns and express their needs, following the principles of family-centred model of services. The following examples highlight some of the terms used in these notes from visits and telephone calls. These terms illustrate the flow of communication between

both parents and the program consultant, and the respectful, non-hierarchical, consultative tone utilized throughout (see Appendix I, Families in Stage Two):

"...September: ASQ 18 months corrected age [for prematurity]. Summary re motor skills: fine; doing better tone wise... mom **concerned** re speech...

January: Parent telephone call: Booked visit with consultant for Feb 5 Waitlist group...parents **would like** to see physiotherapist...

February: consultant telephone call re message **inviting** family to Waitlist group Oct.

September: Parent telephone call: **booked** visit with physiotherapy ...**to follow-up** re high tone...

October: Waitlist group attendance - Parents express **no need** to see physiotherapy at this point

March: Child in preschool; SLP sessions through the community (Health); mom **and** consultant to **close** Child 5's file (mom in **agreement**)"

These summary notes portray the progression of consultations and activities for Family 5 during the second and third year of their child, including information on Child 5 attending "preschool" since age two see to the category "Program Model of Services: Description, Compare and Contrast). During interview # 3 the mother clarified, however, that Child 5 had attended a child development centre since age 2, and that this centre has a preschool program where Child 5 has been enrolled since age

three. Child 5 has also attended a small program with bilingual activities for preschool children since age three.

Parents' comments. No parents' comments or evaluation form were included in Child 5's files. The consultants noted some of parents' comments within their progress or summary notes during the family visits to the waitlist/monitoring sessions.

Researcher's comments about consultant's notes and progress reports.

Through the reviewing process of Child 5's file, this researcher noted the following:

(1) the consultants' entering of parents' comments expressing their perceptions re child's progress, therefore allowing parents' voices to be on record; and (2) the level of detail for the written information. This information is, overall, highly consistent in terms of notes and summaries about Child 5's progress and updates. Some of the more specific information; for example, information about hearing tests and information about the referral for an MRI test do not necessarily include the dates and place where these tests were conducted. Hence, this researcher clarified this information during the file revision session with parents. Additional comments include the following: (a) the number of consultants that have filed information, --as opposed to one or two consultants entering information—in comparison to children's files in the home visitation component. Overall, notes and summary reports are consistent, revealing the sequence and coordination between the assigned consultants in following up the scheduled visits to the waitlist/monitoring group sessions. At the same time, an example of a reminder phone call while family was vacationing, even if previously noted that Child 5 and Mother 5 would be away for two months, may indicate that through the rotation of consultants an overlap of information recorded could have

happened –unless this phone call was entered as a confirmation call; and (b) the number of medical tests and referrals indicate a large amount of medical information for parents to listen, receive, and process, in addition to following up on Child 5's development. This observation was confirmed with both parents during both the file revision and the interview sessions.

The next section expands on these findings of Family 5, through the summaries and examples of both parents' responses and contributions during the three interview sessions conducted at their home.

Interviews

Background. Upon receiving the contact letter of invitation to participate in this study, This mother telephoned this researcher to clarify some information about the study, and specifically referring to how and where the interviews would be conducted. Having received clarification to her questions, This mother expressed her wish for herself and Father 5 (Child 5's) to partake in the study, and indicated she would be mailing the consent form immediately. Before ending this telephone conversation (January 28, 2008) This mother indicated how receiving this letter had coincided with her son's recent fifth birthday and her visit to the family for this occasion. These connected events had brought memories to both parents about Child 5's birth and his referral to the IDP, and they had both talked about their desire to partake in the study. At the time of the data collection, Child 5 was attending preschool, and both parents were starting the school registration process for Kindergarten. Both parents were through interviews #1, 2 and 4, and follow-up member check sessions. (Interviews #3 and #4 were not completed since the transition

to school had only just begun). All interviews were conducted at the family's home between February and March 2008, and completed during the day, while Child 5 attended preschool.

Introductory comments (Stage One, Focus Group 1 introductory question).

Both parents' responses to the introductory question, "In what ways would it be meaningful, empowering and/or challenging to participate in this study?" echoed responses from Stage One participants. As both parents reminisced about receiving the introductory contact letter from the IDP inviting them to participate in this study, they associated this memory to their previous involvement with a previous study, a telephone survey, conducted by federal agency. Both parents responses reflect how having been connected to the program made it meaningful for them to participate in this study –in contrast to their attitudes toward the telephone survey. At the same time, they both feel differently about their rationales for participating:

Mother 5: Well, let see... I got the letter ... thought about it had helped a lot...then talked to Father 1 and [they both] thought it would be a way to, **not 'give back'**, but to **contribute**.

Father 5: Agrees ... because they had been through the IDP, they accepted to participate:

Father 5: [We had] obviously [been] concerned with Child 5 and had gotten something out of it, [and also] **could give back** and could help others going through similar things.

As with previous participants who began their participation in Interview #1 with these introductory comments, both parents' responses provided a frame of reference for the first interview topic, "Early Experiences." After this researcher read question # 1, this mother re-read out loud all the questions on the sheet provided with interview #1 questions. Both parents then began their interview journey, and reminisced back to the days when Child 5 was born.

From early experiences to coping with transitions, change and demands. Both parents reminisced about Child 5s' early days in the hospital. They associated the events happening during Child 5's post-natal medical complications and how these led to Child 5's referral to the IDP. All interviews moved back and forth in time, so that a strict timeline on the sequence of events was not followed, considering that the different topics seemed to "cross-over." Responses to Interview #1's questions alternated between Child 5's two hospitalizations, the impact of all of these events on both parents, and their finding a 'safe haven' in the IDP, where they both felt their concerns were validated. At the same time, they found some of the answers to their many questions. The descriptions of their experiences surrounding Child 5's past medical complications, and their concerns on how these may have impacted on Child 5's behaviour and language skills are evident through throughout the interviews.

Selected comments from Interviews #1, 2 and 4. Questions for Interview #1 referred to both parents recollection of their referral to the IDP

During Interview #1, this mother recalled how at the hospital (where Child 5 was hospitalized soon after he was born). Both parents try to retrieve the

exact sequence of events (they were referred to IDP through the Neurological Department).

Mother 5 They did not know very much what was going on with Child 5 ... I think at that point I did not really care...anymore...

Father 5: They could not make anything out of it.

This mother recalls that the hospital was not communicating anymore what to do regarding Child 5's follow- up. Mother 5 was not 100% sure (about the referral process):

I think they called us and they made contact with us...they left their number to contact us...I must say I was reluctant to do it, after all the nightmare we had gone through the hospital... I said "*I am not going to go through that again*"... and then we had to call and then somebody called back...yeah, and then, in the end, we went!

Further along in the interview, both parents remember that it was the physiotherapist at the hospital where Child 5 had been admitted who referred them to the IDP. These comments are coded within the categories "Referral Source" and "Referral Process," under the themes "Rationale for Participation" and "Memory, Memories":

Mother 5: There was no kind of [This mother makes hands gesture indicating "integration and/or communication"] among...all the

people at the hospital...He [the physiotherapist] was the one that gave us the paper, I think...

Father 5: I think he was the one who made the referral and then they called and then we called back

Mother 5 added that she thinks that otherwise they might have not followed up at that time...

"I am not going anywhere where they tell me that my kid *'is this and that'*" (The father agrees...).

This comment refers to both parents previous consultation experiences with the neuro-pediatrician at the hospital, and to a breast-feeding specialist.

This mother acknowledges her attitude shifted once she and her husband took Child 5 to the IDP monitoring group visits. This shift appears to be related to several factors, including: (a) the family feeling comfortable with the physical setting and organizations of these consultation visits, and (b) the family appreciating the invitation from consultants to actively be part of Child 5's follow-up evaluation and monitoring process. (See to the categories "Program Model of Services: Description, Compare and Contrast," "Guidance Received" and "Information: Importance of" under the themes (a) "Memory, Memories," and (b) "Roles of Consultant, Therapist" for additional examples).

Father 5: It was very different once we were there...it was pretty comfortable and pretty casual...He recalls that pretty quickly they found out what were the "benchmarks" for child development. We found out what was really going on with Child 5(in

contrast to what had previously happened with doctors, including comments such as) “...*It could be this, it could be that*”... Now we could do evaluations ourselves.

This father repeats this statement further ahead in the interview, and indicates the relevance of this collaborative process of intervention for both of them; the mother agrees with her husband, and expressed her liking the welcoming environment at the IDP

Mother 5: Mmm... cookies, and there was coffee, and there were other parents (also with their children) .

Later on during Interview #1, the father summarized the activities carried out during the waitlist group consultation. His statement also included a comment about having “cookies and coffee” (echoed once again by this mother!) In addition to the sequence of steps parents followed upon their arrival to the program, including signing in and taking their badges, before proceeding to the one to one consultation with the consultant and/or the physiotherapist. The welcoming environment with other parents and children, and the predictability of activities during the consultation visits appeared to be enticing features of these sessions for both parents:

Father 5: Yes, there was one to one, and she would check in with us...

Mother 5: I think they were very organized...And then there was a big room with a climbing structure for Child 5 to play... Cookies and coffee... Always a great

thing; then... they would call you inside (refers to a separate room).

Examples like these are captured within the categories of “Program Model of Services: Description, Compare and Contrast”. The description of the visits also included the followings statements, captured within the categories of “Information: Importance of” and “Guidance Received.” These categories were part of the themes “Memory, Memories” and “Roles of Consultant/Therapist.”

This mother recalled that both of them had questions too; this time, however, they were given information with regards to what to expect as well, what to watch for (in contrast to their previous experiences at the hospital)... What's going to happen and how often do we have to come back with the consultant... I think for me what I remember the most important thing for me for a long time was to go to the physiotherapist [name]) ...She was really good because even going back like the second time she was like *'Good! Now Child 5 is making contact with his eyes... laughing'*...She knew pretty much... she knew all those things...she was 'really' there. I found really reassuring...from the first time...

So you were like maybe 15 minutes with the consultants...So they were very organized for time as well...And then you went to [name of physiotherapist]...I felt for sure it was always the same thing.

This mother mentioned it was her taking Child 5 to many of the monitoring

group sessions. She recalls how much she appreciated the physiotherapist saying hi to her child using his name, and recognizing him, and starting the session... Then she describes the sequence of sessions (consultant –physiotherapist at first, and then shifting to physiotherapist-consultant in following sessions). This mother adds how important it was for her and her husband to be asked about their concerns and about their opinions by both consultants and physiotherapy; then refers to Child 5's referral to the SLP (after concerns had been raised at about age two years with language, and followed up for 9 to 10 months:

Mother 5: And they also asked you what the most important thing is for you about your child.

Father 5: They asked "*how we would feel*" (this is regarding both parents' feelings and concerns about Child 5)

Mother 5: Yeah, that was good they asked.

In Interview #1, this mother reflects on her own preferences during the monthly visits with the consultants:

Mother 5: From the first time... What I would have liked to see, I think... it's much more nicer if... because there was always a different one... That's what I really liked about the physiotherapist, because she was always the same one... Although then she went on vacation... and then [when she came back] Child 5 would have been three years (indicating this would have been the time for discharge)... I think it would have

probably been better if they did not change so much...
Yes...I did not like that so much...if they had had maybe
one or two of the same ones, but you always had
different ones...

Both parents re-state these preferences regarding service delivery model
during Interview #2:

Mother 5: And also because the change in consultants...I
don't know if it had been the same consultant...if we
would have asked... (Referring to their concern re
possibility of ADD).

Both parents shared their perceptions about the rationale used by a consultant's
referral for Child 5 to speech therapy. This mother commented that by the time Child
5 was about two years old they had seen several consultants; he would then be
introduced to a new consultant who said that "Child 5 only had a few words" so that
he would have to be referred to see a speech therapist. Notwithstanding the fact that
they appreciated this referral and the therapy sessions that Child 5 received, both
parents think that the rotation among consultants prevented them to appreciate Child
5's language acquisition process as a child who was being raised in a bilingual family.
This mother also ponders whether or not she would have called the Program when
concerns arose about Child 5's attention levels, had consultants not rotated during
their periodical visits. The mother's responses about her preferences for service
delivery models were captured and coded within the categories "Continuity of
services," and "Service Coordination and Service Models" under several themes,
including "Effectiveness of Services."

In Interview #1, both parents summarized the steps followed during the one to one consultation regarding the use of the “Ages and Stages”

Questionnaire:

Mother 5: And the ages and stages...that I must say I found valuable with the consultants...That... and the reporting...[Father 5: They used a “sheet”...]...Yes, what kids could do and what they could not (This seemed especially important because both parents were so concerned about Child 5’s development) ...Whatever thing he did, we noticed...In the end, it was good that there was always there to see Child 5 to see if something could be wrong, but in the end, it would have been nice to only have one or two [consultants, and]...having to [only] adjust to a new person ...or a new name...That, I think it was lacking...

These examples speak to the relevance this mother assigns to continuity and her desire to avoid frequent change among service providers. The rotation among consultants appears to represent a barrier in establishing a more personalized or individualized relationship. This mother’s hopes and expectations resonates with Stage One participant parents’ positive comments on their long-lasting, one to one relationship with their assigned consultant, and their longing for maintenance of this model of one-to-one services after age three, by the time of discharge from the program.

Both parents went on to elaborate on Child 5’s very challenging early

experiences soon after birth, following a number of medical interventions. Their responses throughout Interview #1 –with additional mentions in Interviews #2, #3, and #4-- conveyed mixed emotions related to their sense of concern, followed by a sense of relief- in recalling how their first and only son outlived severe medical risks. At the same time, both parents continued their reminiscing of the myriad of health and developmental professionals who represented several agencies and provided them with conflicting messages. During Interview #1, both parents reported that the way doctors conveyed the information only made things worse for them:

Father 5: The one thing that was pretty difficult for us was...Well...We had interns coming in and out to check Child 5 all the time...while at the hospital¹³... We kind of thought it was a bit of an experiment...We had a constant derange, just with people coming in and out...a bit like an experiment (A previous reference in the interview mentions Child 5 becoming a “Guinea Pig”). At some point we had an intern neurologist...

Mother 5: Why!...She was...she was...She did an assessment...she pretty much told us that Child 5 had brain damage...So we were in quite a bit of a shock...And the way it was said, just like a “by-the way” thing...

Father 5: At that point we asked for some clarification

This mother asked for the head of neurology department for clarification, (to

¹³ All the subsequent blood and hearing tests were conducted at the Provincial Hospital.

obtain) another opinion (C could not recall exact title) following up the comment made by the young pediatric intern...

Mother 5: That was a real nightmare.

This mother explains Child 5's blood group incompatibility (described earlier in this chapter), but then doctors thought everything was all right for that night with Child 5, and he was discharged from hospital, to only be brought back almost immediately. Both parents discovered later on that Child 5 had caught the flu from his father; however, they did not know this at the time of the second hospitalization:

Father 5: He was doing some really weird things...he was arching...anything that was really connecting with...you know...So they were all concerned...

(They were, in fact, thankful for their paediatrician being there at the time, and he was reassuring presence, for a while; however a 'wave' of complications followed, with multiple examinations and diagnoses.)

Mother 5: And then the doctor (refers to the neuro-pediatrician) came...she told us that... (This mother refers to the brain damage diagnosis) ...And the way it was done! I thought...I could not believe it...! She told us "Can I take a look"? ...And then she said "*He has brain damage for sure!*" The (neuro-pediatrician) doctor explained about brain damage being related to the Child 5's previous complications and finally asked, "*Do you have any more questions..?*"

Both parents account of their experiences at the hospital preceding Child 5's

referral to the IDP portrays a complex situation that combined the urgency of Child 5's care with the doctors having difficulty in communicating their findings and impressions to Child 5's parents. The examples presented next were captured through the categories "Perceived Misinformation" and "Communication Issues" under the theme "Understanding and Dealing with the System."

Mother 5: I was so out of my mind that I was ready to leave the hospital...I told the nurses.

During Interview #1, this mother further reflected on how upsetting it was, including the constant exchange of information between nurses and doctors, and on her (needing to) check-in with the nurses; she added:

Mother 5: Sometimes the nurses knew more than the doctors.

(The father brings back this comment once again throughout the closing question of the final interview. Both parents brought back another example, this time about an unnecessary referral and the complications it brought for them. Overall the inconsistency and difference of opinion between doctors and nurses, in their presence, was something difficult to bear for them:

Father 5: Actually you know...we were much happier to speak to the nurses than to the doctors...they seemed...detached from the whole thing...And also often times we could even feel that there were...battles between the two of them, which was... probably not that healthy...

Both parents elaborated in detail about (a) the miscommunication between

health professionals in the different hospitals, agencies and doctors' offices, and (b) how they perceived they had been constantly misinformed during the first couple of weeks after Child 5 was born and was twice hospitalized. At the end of Interview #2, this mother mentioned to this interviewer about her wish to talk about an important event that impacted them during those days. Both parents shared this account at the beginning of the last interview, dealing with the topic "Coping with Transitions, Change and Demands." Reporting these events during the final interview helped both parents to wrap up their last thoughts and recommendations that were captured in the theme "Closing Comments," and coded as "Parents' Suggestions and Ideas." In Interview #4, both parents' comments speak to their imperative need for clear communication that it is also mindful of parents' needs; integrated and coordinated services with more time for listening –and counseling or coaching--- and less time for medical testing, unless it would have been absolutely necessary:

Mother 5: May be we talk about...like one piece was missing ...like remember when we went back to that specialized breastfeeding doctor... (referring to the time when Child 5 was not gaining weight?)...Like how many people where involved in our case?

(Father 5: Why did we get sent there?)

Mother 5: I thought about it...I thought I'd forget about it, but at this time I thought it was a huge thing because we came out of the hospital, we were seeing this doctor, that doctor, everybody...(refers to Child 5 hospitalized and receiving blood transfusion) [He was there] for

about a week, maybe 10 days, I don't remember any more, and then, yeah, because he was not gaining enough weight we had to bottle feed him -I was pumping because I was hoping *[to breastfeed]*...

(This mother makes reference to how their pediatrician had told them that Child 5 needed to be fed and gain weight so that he had to be bottle-fed)...

Mother and Father 5 were referred to a family physician specialized with breastfeeding. During the doctor's visit, Mother and Father 5 were surprised with the doctor's response to their concerns about Child 5 not breastfeeding well:

Mother 5:... So, OK, appointment in the afternoon, we go there, she asks (GP) *"What's the problem"*... Mother 5 says: *"Not breastfeeding"*, and well, we tell her the entire story and (GP) *"This child looks dehydrated."* This mother pauses, and then adds, recalling that ... [We] Just came out of the hospital -(GP continued: *"He is dehydrated, and there is a problem with like [Mother 5: pointing to her lips] ...This is, this was too short...* [Mother 5 & Father 5: giggling] *this is all too short..."* [This mother points again at her lips and jaws, dramatizing, in jest] *"It's all too short"* [refers to Child 5's lips and jaw configuration] *"so that's the problem and there are really signs of dehydration..."* The mother proceeds to tell how this G.P. [who was a]

specialized doctor [in breastfeeding] arranged for Child 5 to be immediately seen at Hospital for a blood test to be done.

Interviewer asked whether their doctor had gone over previous charts:

Mother 5: This is the problem; there were like ten people involved in this case -in addition to the breastfeeding doctor.

Father 5: Then she sent us back to the hospital

Mother 5: ...And then we went back to the pediatrician..."*And what the heck are you here.*" (Mother 5 summarized the dehydration diagnosis to the paediatrician) ...At that point the doctor...he almost lost his marbles...because...it was just ridiculous...and then...there was nothing...we were sitting for another six hours in the hospital for this dehydration...And nothing was done about breastfeeding!

... I didn't want to go back to her because I thought it was absolutely ridiculous, and I had received no help, and they thought at the hospital that everything was fine, so we went back home.

This mother then recalls how at the time when Child 5 was at intensive care the hospital did not have a place to for parents; hence, they had to come back home every night...

So Child 5 was just there...there was no-one to help you with the breastfeeding...

She remembers being asked if the pumping was working and that was it.

Mother 5: So I think that this whole thing...like the lack of everybody communicating...like they should have...like just one person in charge...like everybody...even the GP should be like involved in this...If you have a kid like this, right? You should not 'be having' to send him to the GP at the beginning, right? Because they don't know...they were not there, not that they take the time to be involved - some GP's do, others may not...With the breastfeeding, it was the nurses who came in the room in the end to help out...There is no efficiency, in my experience...

In Interview #1, going back to their account of Child 5's first and second hospitalizations, both parents reported how in the end they obtained an apology from the doctors about the way the information had been relayed, and an acknowledgment that they had not been sure about Child 5's condition and diagnosis for a while. The received a final reassurance from doctors that this condition and the complications deriving from it would not leave any severe 'sequelae.' Although it was important for both parents to receive these reports, their apprehension around the possibility of Child 5's development being impacted in the long run continued:

(Mother 5 adds that the doctors mentioned about 'things to follow up in a few years, not right then...) We were so happy to leave the hospital that I said "whatever"

(Father 5: [in agreement with his spouse] yeah, I was going to say...)

The possibility of mild sequelae for Child 5 brings up the theme “Cycle of Anticipation” with this mother’s examples referring to concerns about Child 5’s development and developmental and learning unique needs emerging through all three interviews. These examples have been included in the categories “Awareness of Child’s Development” and “Awareness of Child’s Special and/or Unique Needs.” During Interview #1, both parents made references to some of these concerns:

Mother 5: And of course, in the beginning we were very concerned, if Child 5 was doing “uh, uh, uh” and they would report “*he is doing eh, eh, eh...*” We were looking out for everything... Until consultants or others –like their pediatrician or other parents-- would tell them “*Kids do that, you know?*” (Both parents laugh; this researcher clarifies whether or not it was useful for them to be validated in that these were typical things for children to do.)

Father 5: All the questions we had...We still do it... today.

In several instances throughout their accounts, both parents identified the pediatrician as their primary contact at the hospital; someone whose presence was – and continues to be-- reassuring and who provided sound information about Child 5’s progress, when “too many” specialists were not clear about Child 5’s condition. During Interview #1, both parents shared several examples of how and when they contacted the pediatrician over time. Examples capturing these comments were coded within the category “Role of Health Professional” within the themes “Memory, Memories,” “Understanding and Dealing with the System” and “Effectiveness of

Services” as well as in the “Closing Comments.”

Mother 5: And then 20 people come in and out...So many people! The only person at the end of the day was our pediatrician... (who explained Child 5’s condition)

...“Pathological jaundice, high levels of billirrubin.”

This mother recalled the conflict of information with regards to the treatment of Child 5’s condition. Discussions took place between the pediatrician at the hospital (who is now Child 5’s pediatrician) and the neurologists around Child 5’s needing a blood transfusion –which he required in the end. The family continued to see the pediatrician while they also received the guidance of the consultants and physiotherapist at the IDP:

Mother 5: ...and then there was the hearing test, the first one from the hospital ...where they put down electrodes.

This mother adds that that test came back fine; this test was also a follow up test from the IDP. The hearing test and the speech language therapy followed each other:

Mother 5: [They were] connecting hearing test with hearing loss and speech ...The hearing was a major thing...connected somehow to the brain. So that was good and we went to the hearing and the speech therapy...And I think this is why we never moved up from the

waitlist group¹⁴ ...Was there once a month at the beginning?...And then (it was more spaced).

Both parents bring back the topic of transitioning out from the IDP at the beginning of Interview #2. Father 5 commented that toward the end they had an evaluation where they had been told that Child 5 was no longer in need for this type of follow-up:

Father 5: It wasn't as it we felt that we should continue to go...It was a very comfortable transition, it wasn't abrupt at all; I guess that if we've felt that we've wanted to do more there, then we could have just mentioned it, but... (Mother 5 adds to the father's response referring to the number of visits they had during years two and three, and confirming the information retrieved through the file reviews.)

During Interview #2, both parents recalled their experiences after Child 5's discharge from the IDP, and examined Child 5's preschool experiences. At the same time, these memories brought back comments about both parents ongoing concern related to the possibility of Child 5's post-natal complications affecting Child 5's development. Both parents reported that Child 5 attended a child development centre since he was about two years old; this centre included a preschool program where Child 5 was registered at age three. This researcher inquired whether their choice for Child 5 was related to a referral or information coming from the IDP at the time, but this was not the situation for the family. Neither parent recalled having asked for or

¹⁴ As opposed to receiving ongoing home visitation, as in the case of children with established risks.

received specific information about preschool or daycare programs at the time of discharge. The programs they attended with Child 5 (bilingual preschool activity program, family drop-in centre through the community centre in their area) were all family initiatives.

Mother 5: We were engaged in all kinds of programs...they were all on our own.

Child 5's preschool program has been uneventful until this point; nevertheless, both parents' comments reflect some apprehension regarding Child 5's learning style and behaviour, as these examples from Interview #2 illustrate. In addition, both parents describe at length some little games or activities that Child 5 has engaged with in the past that only add to their ongoing concerns about his developmental well-being. As in the previous quotes during Interview #1, these are captured under the theme "Cycle of Anticipation," and coded as "Awareness of Child's Development," "Awareness of Child's Special or Unique Needs" and "Parents' Fears and Concerns."

This mother recalls no special meetings with preschool teachers at the time, but some comments from Child 5's teacher:

Mother 5: He would not engage in group things but he could still like...sing the songs...

This mother reflects on what both her and her husband observed in reference to Child 5's ways of engaging at school and wondered if the fact that he had been a 'premie' had to do with a different way –or pace--- for Child 5 at the preschool:

Mother 5: From their side everything is normal, you know, they would give us his report cards (This mother

describes how the report cards did not bring up any concerns)...The motor (skills) aspect which had been "the biggest concerns at the beginning (for both parents, recalling Child 5's medical history) ...he was the most advanced in his class...

This mother adds that from early on (at age 3 years) Child 5 taught himself how to cut and do other small muscle activities; his large motor skills were fine as well. The contrast was, for both parents, what they perceived as Child 5's social skills in class with group activities:

Mother 5: Like he would not sit and listen to the story, but then he would still know the story...and I don't know why he...why he...

Father 5: He's a very social child, so it would be a little bit odd for us...

This mother's comments echo their memories of Child 5's speech therapy sessions where he would also have difficulty concentrating while listening to a story. This mother reflects about their concern with a possibility of attention deficit disorder. At this point she went online --to then deciding not focus on this concern afterwards. Father 5 echoed this joined decision process:

Father 5: Not over analyze all of this; otherwise you could drive yourself crazy... (Father 5 adds that they did not think of anything else in particular that had to be identified, but, the way they experienced Child 5)... he was an overactive child..We had to look at our personalities too! [laughing]

This mother continued to ponder whether or not she would have referred back to the IDP (this example is also cited earlier on, in reference to the mother's preference of service delivery model:

Mother 5: And also because the change in consultants...I don't know, if it had been the same consultant...if we would have asked (referring to their concern with Child 5's over-activity and him having attention deficit disorder).

Father 5: That's why we went back to our pediatrician because we feel he knows Child 5...from the beginning; he is not comparing Child 5 to 'the benchmark'...but rather to 'the benchmark' and who Child 5 is..."

During Interview # 2, both parents proceed to talk about a situation that has brought some concern in the past, where Child 5 has been engaged in an activity where he appears to be looking intensely at something. This description complements other examples shared during the interviews, and that illustrate both parents' ongoing fear and/or concern about the onset of a developmental condition for Child 5

Father 5: There's something with his eyes...like if there was refraction...It would happen mostly at night, he was mostly half-conscious...; as if "he were doing something optical...but very rarely. (This mother confirms this information) ...And this really freaked us out...it looked as if he were following something with his eyes like this (shows with hands gestures).

This mother confirms and demonstrates Child 5's action and adds that Child 5 did this first when he was two to three years old; at that point they told the Program consultant and she tried for him to do it, but he did not demonstrate it. They asked Child 5 to tell them more about these actions:

Mother 5: Child 5 laughed..."ha, ha, ha," as if this were a normal thing, and I thought "Autism" or "Asperger's."

This mother recalls a training experience during her professional training where she had visited a Kindergarten program with children with Autism and Asperger's disorder, and how they would be observing and playing with their hands. Then this mother realized that these children were doing these actions most of the time, whereas in Child 5's case was infrequent...

Mother 5: He still does it, sometimes...

Father 5: Very rarely though... Now he does it with his eyes.

Mother 5: ...I can also see sort of a geometrical shape in front of my eyes...I see it every time...So I'm wondering if it is the same kind of thing...

(Both parents confirm that their child's vision has been tested)

Father 5 adds that at one point Child 5 was saying that he could not see something...

Father 5: It was a little bit of a game... (In Interview #2, both parents describe Child 5 as being playful. This researcher validates

their sentiment around Child 5 being playful, and in good health and following typical developmental patterns. At the same time, this researcher reflects with the parents about the presence of a lingering shadow, like a concern that ‘things might change.’)

Father 5: There was always something out there...

Mother 5: It’s not like if would go away. (This mother provides the example of Child 5 being “on the go” constantly, between the ages of three and four; even if they knew that children at this stage are quite active)... We thought that there might be something, like, you know, Attention Deficit Disorder...Especially at that time he couldn’t focus well...

This mother adds information regarding their visits to the SLP for speech therapy:

Mother 5: Child 5 would be 2 years and 3 months, and she was sitting there with this beautiful book and Child 5 would look, and then onto the next thing, and “*bang, bang, bang...*”

This mother recalls going online and checking information about premature children –and what could go wrong—and “attention deficit disorder” would come up... And then I would go back to the (IDP), but he was already 3 by then, now that you mention, so we were out of the program...And I would go

back to our pediatrician and he would say "Ah...not to worry.

This mother laughs-- and adds that the pediatrician would recommend her and Father 5 "to wait and to see" what would happen at school, and that providing the ADHD label would be "over-diagnosing" at this point.

Mother 5: We went there quite often...for about half a year...and then that SLP changed, so there was another SLP...but, they were quite confident that there was nothing wrong.

Mother 5 commented on the language follow-up by the SLP and pointed at Child 5's performance:

Mother 5: I think I went there for 9 months, 5 times; I think they did fill in some... test...There were like 3 months gap...vocabulary and comprehension... I think when they read him a story, if he could respond to questions when the SLP would ask "What's happening here" type of questions; they were looking for action words, like "jump."

Both parents referred to English being their second language and Child 5 inserting words in both languages within a conversation:

Father 5: Just that he mixes them up ... Mother 5:
...Getting the expressions mixed, you know, half English... (This is the mother's first language that the father does not 'speak much', but can understand some.)

Both parents conclude Interview #2's transitioning topic into the preschool years with their own reflections on 'who' their child is. Their comments reflect two important considerations, (1) the way they have integrated Child 5's early experiences into the child who he is today at age five, and (2) their deep awareness of their child's developmental characteristics and of his unique needs.

Mother 5: Now he is very active - which is good—which I was telling Father 5: the other day that it's better that he is this way... Otherwise, he would be a vegetable and would not have gone over all of these things the way he did at the beginning, right...? So he is fine now...

Other comments about Child 5's development and unique needs are re-stated during interviews # 3 and #4 (held within the same session)¹⁵. At this point, this researcher inquired of both parents whether or not they had additional comments with regards to the situation with Child 5, and especially having been through these medical complications; moreover considering they had observed different or unusual aspects that had led them to wonder about their child's developmental needs. Even with their pediatrician's reassuring comments, and with the decision to avoid "over-analyzing," both parents continued to have concerns. At the same time, and further along in interview # 4, both parents reflected about what makes Child 5 special, and how his unique personality is related to his high level of resilience. Both parents' comments indicate their trying to understand, and to manage, adapting to their son's unique

¹⁵ Since Interview #3 deals with the topic "Transition to school," and Child 5 has just been registered to start Kindergarten in September, Interviews #3 and #4 were combined into one session.

characteristics and needs:

Father 5 acknowledges that they tried to go the doctor's way, and that did not go anywhere. One of the doctors suggested video recording Child 5 when he would engage in the specific activity Child 5 where he would engage with the lights and his hands. They were not successful in recording this activity.

Father 5: Then we decided that there might be some damage...And we had to deal with it [refers to Child 5 engaging with lights]...And it could have been much (more) worse. [At times]... Child 5 would engage in this activity while at the table, but he would quickly come out of it...And not as when he was a baby where he seemed more like that to get stuck on it. Now there is more communication... (because of Child 5's age), and that it became more like a game...

Mother 5: [Now] I think that this is something that belongs to Child 5 and that he needs...Comments that he has his own 'time' right now to get out of it, like 30 seconds.

Father 5 comments on how Child 5 has been always on target with physical/motor skills; he observes other level of skills in other areas, however:

Father 5: ...the reading, the verbal or the words, he has always been later than [the] average child, I

would say...so there's always been this list of things
were he should have been up to date and not been
'right there.'

Interview # 4 questions moved how they managed to cope during the early
days, after Child 5's birth, and through the rest of experiences and
transitions they have commented so far throughout the previous
interviews. In the end, both parents acknowledged --and longed for-- the
help coming from their immediate family; however, both parents agreed
that they mostly relied on each other for support under very stressful
times.

Father 5: I don't know if there was something in
particular that helped us cope; I mean... it wasn't
easy...

This mother talks about how helpful it was for her mom coming from abroad
when Child 5 was about 3-4 weeks; her in-laws were also around at that time, but
could not provide as much support.

Father 5: There wasn't anything they could do...at the
end of the day...I think we should have ...backed out
earlier from all of these other people who had
different ideas of what was going on...They made it
worse...like the breastfeeding, I think we should have
backed out...And I had reservations even then...I think it
took us back to a part ...to an avenue of other
problems that we did not even care about...At the end of

the day it was our pediatrician the person to whom we could go back to, because he would say "Don't worry about that now...I think that that is ridiculous..."

Mother 5: ...We had to fight our way at the hospital for a lot of things...You have lots of energy...and you want to survive...like you have so much energy going throughout all of these things that you don't break down at this point...you just go...I think afterwards...or like three weeks after, four weeks when my mom is not here...I feel I cannot do it...My mom was a big help for me!...[in terms of] coming to some appointments and managing and things like that...

Some of the examples also speak to the way the family has dealt, and continues to deal with the daily family life logistics, including the demands and pressures from work. Both parents have been self-employed, with the father having been a company owner; but the job situation took a drastic turn for Father 5; the family has lived on savings since the Fall:

Father 5: It has been pretty difficult... Mother 5 owns a small business, part time; I am unemployed right now after working with a company for 13 years, I was one of the owners of the company and that ended at the end of November on not-so-good terms... But I think at the end of the day it has worked for the better; I can spend more time at home, and I can take care of Child 5 two to three days a week.

This father adds they have saved enough that they can be comfortable for a while. The father comments how it was stressful, for the first two years, with a combination of stress related to being unemployed. At the same time, they are more at ease now, thinking about different options; e.g., to travel and perhaps live abroad for a while and stay in both parents' countries of origin, taking advantage of Child 5's young age that makes it less difficult with school attendance.

The mother talks about how the major stresses happened during the Fall, and towards the end of the year since they had to deal with major decisions regarding the company including the selling of equipment ...

Mother 5: I think that since the beginning of this year we have found our routine and [husband] transitioning into something else where he is self-employed, and sharing Child 5 between the two of us, and I think it's working much better...right?...

Father 5: I think that Child 5 can get a little bit too much of one of us at one time.

Mother 5: I think that [husband's] job was also very...I think also what's stressful for a family is, you know 6:30 or 6:00 p.m. job everyday, 'troddening' schedules, I mean, we lived very good financially and now we have to cut back, which is good too, so you know, we live the life of...type of students... but we can do it...there not too much house keeping anymore...

Father 5: I think it's better...I think there is a point there with Child 5...I was working more...I remember the time when Mother 5 gave birth a month earlier...I mean we have partners where they don't have children and even consider maternity/paternity leave from the company you know it's not an option!

The mother recalls how the father went back to work and she had all the nurses helping out. At the same time, they explained to the work partners and friends what the situation was and they all supported her husband in taking the time he needed (a whole week) to be with The mother and Child 5.

The issue of Kindergarten registration came up during this interview. Once again, both parents revealed an underlying concern about Child 5's development. This concern appears to go beyond parents' expected anticipation of their child entering school. Both parents' responses reflect their priority for Child 5 to be in the "right" school, one where he adapts easily and, in a way, matches his learning style and unique needs. The mother commented on her being in charge of completing the school registration for Child 5, and how this process has elicited discussion among both parents about their own experiences at school. This mother stayed basically in her same school until high school; the father, instead, changed schools several times with the family moving to different places. The following examples illustrate both parents' experiencing with this new transition, and the stresses related in the decision of the school where Child 5 will be registered, and especially dealing with cross-boundary school applications (they have completed several of these):

Mother 5: Sure, there is some stress transitioning into the Elementary school. At preschool where you feel more in control...He has been with the same teacher for two years now...Especially where is he going to go...

The mother talks about the specific examples of schools chosen in the district and her understanding of the reasons why they have long waitlists and only a few spots available, how they have joined registrations for two schools and now allowing anyone in -- and why are people not registering in their own catchment's area. The mother explains why she finds this a difficult process: It's not just registering into a school, but the process of choosing schools, and especially not in their catchments area --they are not happy with the school within their area. Stresses their concerns about how Child 5 will fit in.

Mother 5: (wondering): Is he a little bit hyper active?

Father 5: I think we do have some concerns... He talks about getting to know what Child 5 needs, for example: "Some more calm activities? ...I think there might be some issues about...some attention kind of span..."

Father 5: I think that we keep hearing recommendations from other families regarding which school should we get him in...I think that we need to decide in which school do we want him...It's going to be tough to get him in the school that we want to because it is out of our area...I think we might have to spend one year in another school...I think also that it might be that the

school we want him in is not the school he wants... and...
that he might be happy in that first school
[corresponding to their catchment's area]

In closing Interview # 4, both parents go back in time, to the early days soon after Child 5 had experienced medical complications and they were referred to the IDP. Both parents reiterate their initial rationale for participating in the study, and articulate strong and clear recommendations:

Mother 5: For myself, I think to know that we are contributing to something and that we are contributing to change, as well, you know. I hope it will reach the people -who were involved- I think there were good parts in the whole thing, but there were also bad parts, and I think...at the end of the day, I don't know what I think with missing communication...I don't know, I don't know, if you could take the Infant Development Program into the hospital to move us back into there...

Father 5: [there was] Too much information! (Referring to the medical experience).

Mother 5: I think that [in the Provincial Hospital] there is the connecting point [for parents with children who went through similar experiences at birth], there is...Intensive Care and [IDP] like connecting like a Lego or something and bring everything together; I think that will be like a good thing and then you wouldn't have to go through

"breastfeeding doctors"...because I tell, our pediatrician...Yeah, like a social worker, I never had a social worker coming at the hospital [as a case manager]...Half of them (children in the Intensive Care Units) will have problems)...For instance there were a set of twins...when we were there...(The mother recalls having seen the couple later with only one of the twins, maybe the other one died, the baby was born too early!) ...So that's really important ...like a connection right from day one, because...I have a lot of respect every time I go back there [to the hospital] for Child 5's [follow-up]...and I'm sitting and there are children who have something, and they're like 12 years old...I feel really sorry for those parents (The mother expresses lots of emotion in this statement) because I just imagine through what kind of trap-hole they are STILL going...So I think it would be really good; and it would save the government a lot of money too, and I think that the IDP [staff] knew a lot...knew sometimes more than "breastfeeding doctors" (smiles)...So they knew a lot, I felt. I think they (Program) should get an office right in [Provincial Hospital - Intensive Care--] or in Neurology...

Summary of Family 5

"What are the parents' perceptions of their experiences of early intervention on (a) early childhood development; (b) parenting; and/or, (c) family dynamics in

families with a child at-risk for developmental delays, or diagnosed with developmental disabilities?” For both parents, early intervention during the first three years of Child 5’s life symbolized a process that provided gradual closure to the traumatic early experiences following Child 5’s birth. Both parents’ account is unique in that these two participants were the only ones in the multiple case study who took part together during the entire sequence of Interviews 1, 2, and 4 – with excerpts of #3 and #4, on the topic “transition to school,” included during Interview #2 and # 4. (Mother and Father 4, in Stage One, took part together in two out of the three interviews, and in one out of the three member check sessions.) During the waitlist and monitoring group sessions from the IDP, both parents found answers to their many questions. They also obtained reassurance for many --though not all- of their concerns about their son’s development. Both parents identified the motor and language developmental domains as their two priorities throughout their involvement with the IDP. They reported that their needs were met at that time. However, some of their comments revealed how the service delivery model utilized during the sessions had somewhat impacted on the effectiveness of parent-consultant information exchange over time. The mother, in particular, highlighted how important it was for her to have, and maintain, a key contact figure during the sessions. This figure was represented in the physiotherapist conducting assessments and consultations during their visits. Thus, the physiotherapist provided the continuity that she and this father needed and preferred for follow-up therapy and consultation services. It meant, in the mother’s words, to have someone who “knew” her child, who recognized him, and “greeted him hello” every time they attended the sessions. There was a difference for

these parents between (a) having someone following up on Child 5 on an ongoing basis, where they could track his progress based on previous observations; and, (b) having someone different interacting with them and Child 5 every visit, and imparting suggestions and recommendations without having spent time with Child 5 beforehand on a continuous basis. Nonetheless, the experiences of both parents during these three years attending the group sessions were crucial in their attaining knowledge and understanding of their son's development. In particular, both parents gained a deeper understanding of: (a) what were the milestones they could anticipate; (b) how to be cognizant of the individual differences they observed in their son's development; and (c) where to find some of the answers, and other services for Child 5 (for example, speech therapy) in order to address his language acquisition needs, especially being a bilingual family. Both parents give credit of their positive and successful experience with the IDP to two main aspects: First, the program worked using a family-centred approach that made of every session a collaborative and empowering experience. Both parents identify the following aspects about the way the consultant led the sessions: (1) The consultant(s) asked them about their needs for their child; (2) the consultant(s) listened to the concerns they expressed about their child; (3) the consultant(s) respectfully asked about their ideas and opinions about any issues on their child's development and behaviour; and (4) the consultant(s) followed-up and addressed these needs and concerns with suggestions, recommendations for specific activities, and additional services/therapy for Child 5. Second, all consultants demonstrated a high caliber of professional knowledge and effective knowledge translation skills. This provided both parents with invaluable information and

resources that guided them in following-up on their child throughout the different developmental stages. Both parents' early experiences with Child 5 had not only been traumatic because of the risks outlived by their son, but also because of the poor service coordination and case managing of the many medical specialists who handled the situation. Their account resonates with Dr Susan Albersheim's recent research on critically ill infants receiving intensive care in the Neonatal Intensive Care Units, and the impact on parents. The results in her research support Dr Albersheim's call for an evaluation of service delivery practices in the NICU's currently being focused on the babies. Her call is for practitioners to balance their focus, and include the parents in medical decision processes—acknowledging mothers' and fathers' distinct needs. They were thankful for the presence of the pediatrician, who has remained, until the present time, their point of contact with regards to any health or developmental concerns of their child. Both parents continue to anticipate the possible consequences of the dramatic post-natal medical complications may have had on their son nowadays. The information provided at the early stages through the consultants has been invaluable for them. Nevertheless, as her child turns 5 and they anticipate Kindergarten entry, additional concerns have arisen. The mother would have liked to know of the possibility of accessing the consultants (at least via telephone) for additional information and reassurance after their son's discharge. At the time of data collection, both parents continued to wonder about their son getting often distracted when his class group is engaged in story telling or singing activities; they also question how typical their child's tendency for 'over- activity' is. For both parents, having (quote) "...An office...of the IDP... right at the Provincial Children's Hospital" would make a

difference for the many parents going through similar experiences to theirs, and whose children, (quote) "...For sure...will need this type of follow-up."

File Reviews and Interview Summaries

Family One (Stage One)

File Reviews

Background. Family 1 is composed by Child 1, Mother 1, Father 1, and Sibling 1, (Child 1's older brother, age 9 years old). Child 1 was age 7 years old at the time of data collection. Child 1 was referred to the IDP at age 7 months by the family's pediatrician.

Medical history. Child 1's file reviews reveal that Child 1's has a congenital medical condition that was detected prenatally through ultrasound. Child 1 was born full-term, and received medical attention and follow-up by a number of specialists since birth. Her condition involved a heart anomaly, and was linked to a low-incidence syndrome affecting multiple areas of development, including motor, language, adaptive and cognitive skills.

Health and other professional involvement. Regular follow-ups continued with (a) medical specialists; for example, cardiologist, immunologist and geneticist, and with (b) other professionals; for example, audiologist, physiotherapist, and speech language pathologist) until her discharge from the IDP. Medical attention throughout this period included several treatments (e.g., antibiotics) and corrective heart surgery. During the interviews, and later on during Focus Group 2 discussions, Child 1's parents, Mother 1 and Father 1, confirmed that the involvement with medical and

developmental professionals was ongoing. For example, in addition to the previous specialists following Child 1, their medical team now included an urologist, Child 1 required of an occupational therapist, and the family was under a counselor's guidance. These additional services were not covered by the medical plan. Mother 1 mentioned that the family was able to cover these services through "extended medical" coverage, or else they would not have been able to meet Child 1's changing health and developmental special needs. Mother 1 added that the family had required professional support to learn coping strategies to deal with their complex family life situation. Child 1 required additional professional consultations and assessments between the ages of birth and three years old, including a hearing test, and speech-language assessments.

IDP involvement and follow-up. Child 1's file lists and describes the periodical developmental assessments conducted through the IDP using the Gessell Developmental Schedules, a standardized measure of development administered by early intervention consultants (see chapter 2). Progress was consistently noted throughout the different developmental skills in the assessment reports. By the time of discharge at age 3, Child 1's acquired skills ranged between 24 and 36 months indicating moderate to severe delays for especially for receptive and expressive language, with fine motor and adaptive skills ranging between 30 and 36 months. During interview 4 Mother 1, commented how Child 1's difficulties in language acquisition were now impacting on the development of her social and emotional skills. Child 1's file includes records of the family's involvement with the Parent-Child Mother Goose between Child 1's birth and age three, where the family attended series

of group sessions involving singing and dramatizing rhymes and songs. These sessions were offered by the IDP and included all members of Child 1's families. Child 1's file confirms the family's transition and intake process to receive services from early child development support programs after their discharge from the IDP, between the ages of 3 and 6, e.g., the "BC Centre for Ability" and the "3 to 12 Program."

Consultants' comments and progress reports. Home visit records filed showed monthly visits, on a regular basis between age 7 months (intake) and age 3 (discharge). The Early Intervention (IDP) consultant's comments illustrate examples of joint visits with the pediatric physiotherapist, with recommendations for follow-up in reinforcing motor skills. The language of the consultant's home visit record corroborates the participant's comments referring to the close and trustworthy relationship established with the IDP consultant, and to the consultative and collaborative process established between service provider and the recipient family, following the principles of family-centred model of services. Some examples include, "a delight to work with..." and "delightful family." Examples of follow-up phrases used include "A few suggestions to strengthen Child 1's thighs..." "to encourage Child 1 to..." "Consultant will contact [Mother 1 & Father 1] to consult..." and "we will consider whether to have a consultation with..." (See Appendix J)

Parents' comments. The participant's own testimony confirms this collaborative process, as shown in her letter to the IDP upon the family's discharge. Her comments describe the journey lived by the participant since the early days of intake and until being discharged. The following quotes are excerpts from this letter.

"...I [first] wanted to accommodate this expert...[refers to tidying up the house] That was a long time ago...recent visits were in more 'lived-in' surroundings..."[refers to her house not necessarily looking tidy]

Mother 1 refers to being worried, at first, about needing to have her home perfectly clean and orderly for the consultant's visits, and then realizing that this level of order and cleanliness was not needed. This aspect is further examined throughout the interviews with comments captured within the theme "Role of the Consultant/Therapist," and it is coded under the category "Program Model of Services, Description, Compare and Contrast" included within six themes. An example from Interview #2 follows:

Mother 1: Child 1 was delighted to spend time with consultant)...I am sure because of the unfailing respect...shown to this little person... referring to Sibling 1, Child 1's sibling), he too likes to spend time with IDP consultant.

Mother 1's appreciation for consultant goes far beyond the guidance provided. It extends to the recognition of the level of respect shown to both of her children, and the inclusion of Child 1's older sibling in the home visits, reinforcing once again the family-centredness service approach of the program.

Mother 1: I have discovered...that the consultant does not get uncomfortable with me when I'm scared, mad, sad, worried...(consultant) has also changed the view I had regarding raising a challenged child...I commend the

[program location] of the IDP for the excellence of its staff.

Mother 1 clearly expresses her appreciation for the role played by the consultant in raising a child with special needs. These comments are captured under the theme “Roles of Consultant/Therapist,” and are coded within the categories “Parents’ Perceptions and Experiences,” “Information,” and “Effectiveness of Services,” among others.

Researchers’ comments and reflections following file reviews. This last section in the file reviews quotes the researcher’s memo at the concluding stages of the file reviews. This memo was revised with Mother 1 during the member check session revising the information from transcribed the files. Please note edited text contained within brackets. The relationship between [Child 1’s] family and the [Early Intervention] Program consultant appears to have been very close and attuned to the family needs and wishes, on the consultants' end. [Parents appeared to be open] to -- and feel comfortable with—the consultant and [the] program, as they discovered their child's needs. [It appears as if this resulted in] an equal partnership relationship where more than resources and skills where shared --in terms of personal growth for the family and the consultant through these years.” The next section elaborates on the findings that have become apparent through the file reviews. These findings are the outcomes of the transcribed and coded comments from the narration and description of the interview sessions with Mother 1, the participant respondent in Family 1.

Summary of Family 1 Interview Responses

“What are the parents’ perceptions of their experiences of early intervention on

(a) early childhood development; (b) parenting; and/or, (c) family dynamics in families with a child at-risk for developmental delays, or diagnosed with developmental disabilities?” Mother 1’s account of Family 1’s experiences in receiving early intervention services portrays a tightly knit family unit whose members rely on one another, and with deep family and community values. Mother and Father 1 outwardly voice their readiness and commitment to support the (Canadian) public systems that (ought to) respond to the needs of children and families. At the same time, they confront the reality of cuts and service gaps after age 3 years, and they painfully accept the fact that their daughter, now in elementary school, may not be able to receive the services she is entitled to “as a planetary citizen” (quote). Moreover, and at the risk of betraying some of their societal values, they are forced to contract some of the services needed privately. Mother 1’s account reveals a deep sense of gratitude towards the IDP consultant. Her responses indicate how her guidance and information provided her and Father 1 with skills to understand her daughter’s rare medical condition, to address her unique developmental needs, and to provide them with the tools they needed to maintain and enhance this support for the years to come, after Child 1’s discharge from the Program. Although the consultation services were targeted for Child 1, all four members of the family gained from receiving the consultant’s guidance and support. The way services were implemented, using a family centred-model, addressed the family’s unique and complex needs, while maintaining a deep respect of Mother 1 and Father 1’s individual family culture. This model of respect, collaboration, and inclusion provided Mother 1 with the structure she needed at the time, and with a basis she used to take the necessary steps

in accessing programs and resources for her daughter, and for her family. It also enhanced her skills as a “case manager,” and helped her further develop a sense of empowerment. These skills instilled her with strength to continue acting, together with Father 1, as strong advocates for Child 1, and their family, needs.

Family 2

File Reviews

Background. Family 2’s members include Father 2, Mother 2, and Child 2, the couple’s only daughter. Child 2 was age 7 years at the time of data collection. Only Mother 2 participated in the focus groups, interviews and file revision session.

Medical History. Child 2’s files indicate that she was born full-term and after an uneventful pregnancy. Soon after birth, Child 2 was diagnosed with a complex medical condition linked to a specific disease that would affect her physical health and well-being and her overall development. At the time of the data collection, Mother 2 and Father 2 had not received confirmation about her daughter’s condition being linked to a rare genetic disorder. Referral to the IDP came through the public health nurse when Child 2 was 5 months.

Health and other professional involvement. Child 2 has been followed up by a number of medical specialists since birth. Her condition involves anomalies related to organ formation, including a heart valve, and gastro-intestinal complications that had Child 2 requiring of tube feeding since very early on. Child 2’s condition has also affected a spinal disc, and involves some facial dysmorphic features that affected her feeding. Child 2 has undergone facial and organ surgeries that have addressed her

feeding and digestive difficulties, among other treatments. Child 2's pediatrician has been involved since her very early days; Child 2 has received occupational therapist's support for her feeding soon after birth when she was diagnosed with gastro-intestinal complications. She was also followed up by the pediatric physiotherapist between ages seven months, at the time of her first visit with the IDP, and three years, at the time of her discharge from this program. Through the interview process it was learned that Child 2's parents had decided not to follow-up with genetics testing in order to rule out a rare genetic syndrome. During the interviews, Mother 2 confirmed that both she and her husband monitored Child 2's health very closely, and especially after she had started to have seizures at around age two years, quote:

Mother 2: Child 2 is quite healthy, although she goes through occasional seizures, but she is healthy otherwise.

Child 2's hearing was tested by age one year; no results from this test were found in the reviewed files; however, Mother 2 did not report Child 2 having hearing difficulties.

IDP involvement and follow-up. Child 2's file lists the periodical informal developmental assessments conducted through the IDP using the Ages and Stages Questionnaires. Child 2's progress is described as having a "wide range of skills, scattered through different stages." Home visit records files showed monthly visits, on a regular basis between age 7 months (intake) and age 3 (discharge). Child 2's file includes the same number of home visitation reports from both the IDP physiotherapist and the consultant. Through the series of interviews, Mother 2

mentioned that their main developmental concern for Child 2 had been regarding her motor development, in contrast to other areas of development. Child 2's files indicate that when she reached age three years, the family was referred to the BC Centre for Ability, for ongoing physiotherapy consultation. Neither parent follow-up with arrangements for specialized childcare nor for preschool program at that time, as Child 2's Grandparents took care of her until she turned 4 years old. During the interviews, Mother 2 reported that Child 2 had started to attend a preschool at age four.

Consultant's notes and comments. Consultant's comments illustrate examples of joint visits with the pediatric physiotherapist, with specific recommendations for follow-up in reinforcing motor skills and notes regarding Child 2's motor learning progress and the equipment used to support Child 2 with sitting, standing and mobility.

Parents' comments. No comments from Father 2 and/or Mother 2 were retrieved in Child 2's file.

Researcher's comments about consultant's notes and progress reports. The researcher's reactions to these files relate to perceptions of family being involved with the IDP through their physiotherapy services. A sense of ongoing uncertainty is perceived in Family 2 regarding Child 2's undiagnosed medical condition. Although the file has a referral for Child 2's parents to attend a specialized language instruction program for parents known as "The Hanen Language Program," no confirmation exists of the family's involvement in this or any other IDP --or community program-- based preschool activities or services.

Researcher's reaction to comments and information in reviewed files. This researcher acknowledges Family 3's connection and special relationship with the staff at the IDP through yearly pictures of Child 2 and greeting cards (e.g. for Christmas) sent to the Program's staff after years after Child 2's discharge from this Program.

Summary of Family 2 Interview Responses

“What are the parents’ perceptions of their experiences of early intervention on (a) early childhood development; (b) parenting; and/or, (c) family dynamics in families with a child at-risk for developmental delays, or diagnosed with developmental disabilities?” Mother 2’s account of Family 2’s experiences in receiving early intervention services illustrates the clear and distinct roles played by her and Father 2 with their daily life and work precisely revolving around Child 2’s caregiving. Throughout her interview responses, and her interventions in both Focus Groups, Mother 2’s comments illustrate how she specifically linked the information received from the IDP consultant to the very specific needs she needed to attend to at the time Child 2 was an infant. Mother 2’s account illustrates how she implemented a “theory to practice” approach throughout every transition stage lived with Child 2. From the information exchanged with --and modeling provided by--- the Early Intervention 0-3 consultant, she understood the importance of learning and being aware of her daughter’s development. Mother 2 identified working with Child 2’s motor development as a priority. Mother 2 aimed to support Child 2 in developing these skills in the hope that she would attain as much mobility as possible. In terms of practical needs, the information and leads received was priceless in leading Mother 2 to find out where to go, and how to apply for physical equipment to support Child 2.

In addition, learning about where to apply for funding and reimbursement for other items, such as diapers, was priceless for Mother 2. In retrospect, Mother 2 realizes how important it was for her to have had the consultant and physiotherapist's visits for the first three years, at a time where she and Father 2: had not fully understood the impact of their daughter's condition on her overall development. Mother 2 acknowledges that she, in particular, needed time to understand, to comprehend, and to evaluate the situation for her and her spouse with Child 2 being totally dependent on her parents. The ongoing contact with the consultant and physiotherapist resulted in a safe and trusting relationship that helped her to rely on their guidance, thus grounding her and allowing her to face Child 2's unique needs during her early years.

As Child 2 grew older and was registered first in preschool/daycare, and then at school, Mother 2 gradually implemented the knowledge about tools and resources she had attained during the first three years, either through the consultant, physiotherapist and/or from another. Mother 2 stood up to advocate for her daughter's rights for quality, safe and dependable childcare. She also learned to anticipate Child 2's needs as she grew up, and was no longer an infant, but a school-age girl. As the moment approached to have Child 2 registered in grade 1, Mother 2 embarked one more time on a search for the school that would provide the support Child 2 needed – including after school care. During the Focus Group 2 discussion, Mother 2's motion to have an integrated case managing system that continues through all of Child 2's school years was echoed by Father 2 and Mother 3. Mother 2 expressed her appreciation and described how she benefited from the follow-up therapy and support services received through the Therapy and Supported Child Development Programs.

However, she did not provide examples illustrating a follow-up relationship with these consultants as Child 2 grew older and was discharged from the BC Centre for Ability. Mother 2 has continued to be in contact with her former consultant four years later after Child 2's discharge (e.g., through her sending pictures and greetings to the Program staff, and through occasional telephone calls when she has been in need to check-in). Her contact initiatives clearly support her preferences, hopes and expectations to maintain the relationship with the same program staff who first guided her, soon after Child 2's birth, (quote), "And until the child is in high-school."

Family 4 (Stage One)

File Reviews

Background. Family 4's file corresponds to Child 4 --just turned three years old at the time of the data collection, and the youngest child within the Stage One participants. Child 4's file shows that Child 4 lives with Father 4, Mother 4, and his older sister, Sibling 4. Child 4 was referred to the IDP at age one month, with a diagnosis of Down's syndrome that would impact on all areas of development, and was complicated with an ear-nose-throat condition that ended up requiring medical treatment.

Medical history. Child 4 was born at 37 weeks of gestational weight and with normal weight at 3500 g. Mother 4 was assisted at home for her birth. Following the recommendation of Mother 4's midwife, Child 4 was examined a couple of days after his birth at the Provincial Children's Hospital. The diagnosis was confirmed through a genetics consultation and examination.

Health and other professional involvement. Child 4's file indicates that Child 4 suffered from frequent colds that were complicated twice with pneumonia, requiring hospitalization both times. Child 4 required ongoing medical consultation and testing since very soon after birth. Testing including (a) echocardiogram, with normal results; (b) routine vision testing (resulting in glasses at age 2 years), and (c) routine hearing testing, with normal results; (d) ENT follow up until ear-nose-condition ameliorated. In addition, Mother 4 consulted a lactation specialist after Child 4 developed lactose intolerance and required specific medical treatment for this condition. (During the interviews, Mother 4 and Father 4 shared how Child 4's fragile health conditions had been overwhelming for all members of the family, as he had been extremely ill several times.)

IDP involvement and follow-up. Child 4's home visit records show that the monthly consultations started at age 2 months, after one month in the waitlist. Home-visits revolved around motor skills language development, social-communication and self-help skills (e.g., eating and dressing), and cognitive stimulation through play activities, as requested by Child 4's parents, Mother 4 and Father 4. The file includes an extensive list of resources and information for the family regarding Down's syndrome.

Child 4's files do not include formal or informal assessments conducted through the IDP consultant or physiotherapist. Instead, assessments were conducted by other professionals through the BC Centre for Ability and included an Occupational Therapy (OT) assessment report at age 17 months; the Bayley Developmental scales (with results for the Motor and Mental scales indicating a range in skills between 8

and 11 months) and a Speech assessment (BC Centre for Ability) at 21 months, with communication skills situated at a pre-linguistic stage (< age 12 months). Follow-up activities included a focus on sign language, developing lip movements and sounds; and feeding skills, for example, using utensils. Child 4's file includes extensive reference to the language assessment and follow-up activities, on a monthly basis -- this time through the Health Unit and not through the BC Centre for Ability, as it was confirmed in the file revision session. Child 4 attended other activities, including art. Child 4's progress was observed anecdotically, in terms of his gaining sign skills and meaningful sounds, e.g., animal sounds. Child 4's progress is noted in the IDP physiotherapist and consultant's monthly record months (intake) and age 3 (discharge). The focus for Child 4's physiotherapy consultation during the first year was his large muscle skills, and after year two, combination of small and large muscle skills. The family kept the physiotherapist services after year 3 through extended medical insurance (in order to maintain the same physiotherapy consultant).

The family participated in the Mother Goose Program, through the Parent-Child Mother Goose for four out of 13 weekly meetings. During the file revision session, Mother 4 clarified that they attended other Parent-Child Mother Goose programs that were closer to their home later on. Sibling 4, Child 4's sister, was included in these sessions. In addition to participating at the Mother Goose sessions, the family participated in another program "Learn to Play" through the Down Syndrome Research Foundation. Additional speech-therapy services were sought but did not work and were cancelled.

Consultant's notes and comments. Child 4's file indicates that two consultants

worked with the family within a three-year period. Differences observed in the home visit records written by the two consultants were subtle. They included different labeling styles; for example, consultant 1 labelled follow-up parent activities as “homework,” whereas consultant 2 would term them “suggested follow-up activities.” Child 4’s file includes notes about the transition towards discharge from the IDP, and about the consultation process taking place for intake so that Child 4 can receive services from early child development support programs after their discharge from the IDP, between the ages of 3 and 6 (the “BC Centre for Ability” and the “3 to 12 Program.”) Home visit records filed showed monthly visits, on a regular basis between age 2 months (intake) and age 3 years, 4 months (discharge). Child 4 received a special needs designation obtained placement in an inclusive preschool (full-time) for the coming school year starting in September.

Mother and Father 4’s records included reminders for visits, and notes regarding follow-up appointments for Child 4 with other professionals involved (e.g., vision and hearing). Resources included using the Sign language videotapes, and they were registered and attended a Sign language course. During the file revision session both Child 4 and Mother 4 described how the consultant and the physiotherapist conducted home visits together, and described these visits as “excellent” All home notes included greetings to Child 4’s family. Consultant 2’s home visits also include positive individualized and personalized comments, for example, “the consultant’s joy to share Child 4’s skills and progress.” These comments are intertwined with thorough descriptions of Child 4’s developmental skills, suggestions for follow up to further support Child 4 in developing these skills. In addition, consultant #2’s notes include

her reflection of the parent(s) explicit goals; for example, Mother and Father 4 appear to be focusing on language development at this time." Ongoing telephone message and notes complement the home visit records.

Parents' comments. No parents' comments were included in Child 4's file.

Researcher's reactions to consultants' comments. Although some contrasting aspects are noted between consultants 1 and 2 in their individual styles of service delivery, their notes are very similar in content. For example, both consultants reflect how they work within the context of family-centred care in the ways they describe the activities related to skills being focused at the time, and the follow-up comments; for example, offering information and suggesting resources. Consultant 2's notes indicate a closer and more personalized relationship with the family and their needs. Mother 4 and Father 4 indicated during the file revision session that this could have been related to the time and stages of their relationship. Consultant 1 attended to the family's medical needs at the time when Child 4 was a newborn baby, and she provided a great service. Consultant 2's notes and other documentation on the file reveals that, overall, the main focus of consultation is on the child's month by month progress rather than on more formal developmental assessments (except for motor and language development, concurring with parents' main concerns).

Summary of Family 4 Interview Responses

"What are the parents' perceptions of their experiences of early intervention on (a) early childhood development; (b) parenting; and/or, (c) family dynamics in families with a child at-risk for developmental delays, or diagnosed with

developmental disabilities?” Within the context of the sample in this multiple case study Child 4 (Child 4) is the youngest of all participant children. Child 4 was 2 years and 10 months at the time of the data collection. Therefore, Mother 4’s memories of their involvement with the IDP are the most recent ones, in comparison to the rest of the participant parents in the sample whose children had all been discharged for a minimum of one year at the time of data collection. The examples provided throughout the interview illustrate the family’s experiences during the process of discharge from the IDP, and liaison with the Therapy and Supported Child Development Programs. Overall, Mother 4 and Father 4’s account describes their family unit as one where all four members rely on each other and hold a very strong sense of community –with the family dog holding a very special place too! Both Child 4 and Sibling 4 (age 6) are very present in the family’s daily activities. Their presence and importance has always been acknowledged. Mother 4 and Father 4’s quotes and comments reveal how the family’s daily functioning largely depends on the way they share their loads and their responsibilities. They have no support from extended family member, from whom they are basically estranged. Mother 4’s reflections on the family’s experiences with the IDP convey how crucial the program’s services were for her, Father 4, Sibling 4 and Child 4. Mother 4 and Father 4 described different stages, and ways, in which the family was impacted by the services of the IDP. The examples shared throughout the interviews illustrate the different layers of services provided. These services adjusted to the different needs uncovered –and discovered—with the gentle, prompt and reliable guidance of their two consultants. The family first went through a period of almost “survival” mode, with Child 4 being very sick and the

family barely coping with the demands from both Mother 4 and Father 4's work. At that time, Mother 4 perceived the role of the consultant as "protector," in Mother 4's words, checking on her and on the family members' well-being during her visits. The consultant would almost "guess" the information and resources they needed to address Child 4's motor, self-help, play and language needs. In addition, she would always ensure that Sibling 4 was an integral part of the support system for Child 4 and invited Sibling 4 to be involved with his physiotherapy exercises. At a certain point, consultants changed –and so did the needs identified by the family. The program's model of services did not change, however, in that the second consultant promptly attended to the family's call for information, resources and programs for Child 4's motor and language development. Mother 4 describes the second consultant being accommodating to the family's needs for Child 4's sessions as their previous consultant, (quote) "everything would be in its right place." This sense of flowing services and of information provided Mother 4 and Father 4 with a level of comfort in that the services offered to the family required the minimum effort on their part. This was crucial for Mother 4 and Father 4 who were already strained, and in constant need to attend to a myriad of tasks and deal with daily financial and work logistics. As Child 4 turned 3 years old and his needs as a preschooler varied, Mother 4 and Father 4 became aware of their needs to adapt to the new situation where their child would be out at a preschool or daycare of part of the day. Mother 4 recognized that, at that point in the family's life, the home visitation level of services would not have been the most effective from them. Nonetheless, they longed for service that were provided following an inclusive, family-centred model, as opposed to the therapeutically-led

and child-centred services offered to them through speech and physiotherapy. In addition, they would have liked to maintain the level of organization and coordination among services and service providers that had been previously available through the IDP. As the time approached for Child 4 to start preschool, the number of therapists and special needs staff and services for Mother 4 and Father 4 to be in contact with seemed to increase, with not all the therapists providing services that would meet Mother 4, Father 4 (and Sibling 4's) expectations. Although services were "in place," they were not "in the place" were Mother 4 would have hoped for them to be for Child 4.

Family 6 (Stage Two)

File Reviews

Background. Family 6's file reviews indicate that Child 6 was referred to the IDP [program location 1] at age 1 month by a social worker from the Agency for Children and Families; he was transferred to [program location 2] at age 4 months. Child 6 was 4 years old at the time of the data collection and living with Grandmother 6's his paternal Grandmother since age 4 months.

Medical history. Child 6 was born at a normal weight of 3,950 Kg, after a full-term pregnancy with no complications during labour. File review sessions with Child 6's Grandmother provided additional information with regards to Child 6's biological mother's pregnancy going over-term and labour was induced after the 40th week of gestation. In addition, file revision sessions with Grandmother 6 provided details on Child 6's referral to the IDP, in reference to Child 6's medical history. Grandmother 6 indicated that Child 6 was exposed to crystal methadone in-utero during the first two

trimesters of pregnancy and that his biological was a minor at the time of conception and birth; therefore, Child 6's referral to the program came through a social worker (of the government's agency responsible for children) soon after birth. Child 6 received in-home services at the program located within his biological mother's area of residence, until Child 6 was three months when Child 6 came to live with Grandmother 6, his paternal Grandmother, Grandmother 6 in his present residence location. At this time, Child 6's file was transferred to the IDP corresponding to this area. One of the concerns upon Child 6's referral referred to "jerkiness," in reference to his muscle tone. During the file revision Grandmother 6 indicated that the doctor and other professionals following Child 6 up thought of this condition being associated to his drug exposure while in utero.

Health and other professional's involvement. Child 6's records indicate that he has been followed up by the family's GP (family physician). Child 6's file includes notes about additional follow-up between birth and age three years old with other professionals and testing service departments. These have included the following tests and consultations: (a) hearing tests, to check the integrity of B's hearing at age three years, following concerns from Grandmother 6 that Child 6 talked using a very loud tone of voice. Reports from these tests stated that Child 6' hearing was within normal limits; (b) Electroencephalogram tests to rule out –and follow up—for seizures/epilepsy. (Grandmother 6 explained during the file review session that epilepsy was a family illness, including for Child 6's biological father; (c) a referral for vision screening test at age 36 months to rule out difficulties with depth perception. During the file revision session Grandmother 6 explained that difficulties with depth

perceptions would have been related to difficulties with balance and coordination. Although Child 6's skills were at par with children his age by age three, he seemed to fall frequently when running. During the interviews, Grandmother 6 elaborated on this aspect and mentioned a follow-up referral being now in place with the neurologist, with regards to Child 6's difficulties when running; (d) once to twice yearly consultations with the physiotherapy consultant with the IDP to follow-up on Child 6's muscle tone, reflexes and motor skills acquisition and motor coordination skills. The pediatric physiotherapy assessment report and consultations recommended specific exercises to be followed-up for large muscle skills coordination and balance; for example, jumping skills at age two. physiotherapy reports at age 26 months describe Child 6's skills being at par with his chronological age; except for Child 6's jumping skills still being in transition, the physiotherapist did not make mention of any other concerns in this area.

IDP involvement and follow-up. Child 6's records of attendance to the waitlist and monitoring groups indicate he was followed up by at least four consultants, with frequent follow-up conducted by the program's coordinator. In addition to physiotherapy consultations and the final assessment previously summarized, Child 6's file includes quarterly developmental informal screening reports using the Ages and Stages Questionnaire (ASQ). After completing the 4 months ASQ with the consultant, Grandmother 6 completed most of the remaining questionnaires between ages 10 and 36 months at home, and mailed them to the IDP. However, review notes on Child 6's skills progression were completed with the assigned consultant during Child 6's visits. Although the first ASQ noted mild motor developmental delays, by

the time of discharge at age 3, Child 6's overall development fell within the typical range of skills acquisition. The pediatric physiotherapist consultant's notes do recommend paying attention to specific motor skills over time, and specifically to muscle tone, balance, and gross motor coordination. The program consultant's suggestions included following up in (a) language development in terms of speech fluency; and (b) attention, in terms of eye contact, and indicates the possibility for Child 6 to have difficulties with visual perception. Child 6's records include a referral for Child 6 to the BC Centre for Ability. During the file revision session, and later on during the first and second interviews, Grandmother 6 explained her confusion in accessing this program; in addition, she had not perceived a need for Child 6 to be followed up by their therapists. Grandmother 6 was given information about preschool and daycares for Child 6, and mentioned during the interviews her going back to the IDP 0-3 Office to pick up a package with this information. Child 6's files have no indication of transition meetings being scheduled between the Early Intervention 0-3 and the Centre for Ability (Therapy program) or Supported Child Development Program. Child 6's file does not include mentioning to Child 6' attending other programs before his discharge at age 3 years. During the file revision session Grandmother 6 reported that she had been given information of programs. Grandmother 6 commented she had had no time to attend these programs because of work scheduling and transportation difficulties. Grandmother 6 elaborated on these difficulties throughout the interviews. Grandmother 6 clarified during the file revision session how the transition happened for Child 6 and his involvement with preschool activities.

Consultant' comments and notes. Few summary notes from consultants are included in Child 6's file, except for the dates of completions and skills acquired. Consultants note Grandmother 6's involvement with Child 6's development, and acknowledge her thorough completion of the questionnaires. Two references of Child 6's possible difficulties with attention skills are included in the follow-up notes of the waitlist/monitoring groups visits; for example, one of the consultants stresses on Child 6's high activity level and short attention span at the time, and the fact that he had been exposed to drugs in utero. During the interviews, Grandmother 6 mentioned once her that she thought her grandson was high spirited and active. She also reflected on the fact he was a young child at the time, so that this high level of activity would not be of a concern for her. This divergence between Grandmother 6's perceptions of her grandson, and what the consultant wrote in the summary serves as an example to support quotes captured under the theme "Role of Consultant/Therapy," and coded within the categories "Service Coordination and Service Models" throughout the interviews. It also echoes this mother's comment on her preference with having one or two consultants who know her child. Grandmother's comment reiterates how well she knows her grandson, in contrast with other people who have infrequent contact with him.

Parents' comments. No comments from Grandmother 6 are included in Child 6's file.

Researcher's comments about consultant's notes and progress report. The follow-up indications on the summary notes reveal a sense of preoccupation from consultants about the impact of Child 6's prenatal antecedents on his development.

These concerns are echoed by Grandmother 6 by way of comments including “one does not know what to expect at the turn of the bend,” during Interview #1. These comments are captured under the theme “Cycle of Anticipation” and under the category “Awareness of Child Development” and “Awareness of Child’s Special/Unique Needs.” The next section expands on these findings of Family 6, through the summaries and examples of Grandmother 6’s responses and her contributions during the three interview sessions.

Summary of Family 6

“What are the parents’ perceptions of their experiences of early intervention on (a) early childhood development; (b) parenting; and/or, (c) family dynamics in families with a child at-risk for developmental delays, or diagnosed with developmental disabilities?” Grandmother 6’s account provides responses to this question through the intertwined stories of two families. One is Child 6’s biological parents, with additional references to Child 6’s younger biological brother. The other one is Grandmother’s three young adult children. Child 6 is son to Grandmother’s middle child. Child 6’s intake from the IDP at age 1 month is the earliest of all referrals in this multiple case study. At the same time, Child 6 is the only one of the seven participant children who did not have medical or health post-natal complications. His identification within the “at risk” category fell within both the criteria followed by the health authorities and by the Government Child and Family Services agency. Child 6 is not the only one of the seven participant children who is presently not living with his biological parents --nor is he living with his sibling. He was also the only participant child who was transferred from the first IDP conducting

the intake to a program within the catchment's area of Grandmother 6's area of residence. Although Child 6 lives with his Grandmother and with his younger uncle, he has frequent contact with his father and with his older uncle. The family dynamics component is clearly present throughout Grandmother 6's account. It includes several examples of her experiences in dealing with multiple crisis and obstacles with her three adult children (referred here as Uncle 1, Father 6, and Uncle 3). Grandmother 6's three children have one or more special needs, including developmental (such as learning disabilities), physical (including epilepsy and eating disorders), and mental health (e.g., addiction) needs. There is no mention of a father figure for Grandmother's adult children, or of any extended family or friends' network providing support for Grandmother's family throughout any of the examples provided. Throughout the interviews, Grandmother 6 made several references to tension between her and Child 6's father over custody and child minding issues. She also referred to tensions between her and her youngest son currently living at home over his little involvement with their household. Grandmother also expresses how much support and encouragement she has received through the social worker who has managed Child 6's case so far. She portrays a strong and unconditional sense of commitment to Child 6 since he was a young infant. This commitment has crystallized in her obtaining his permanent custody. Grandmother 6 diligently followed the consultant and physiotherapist's suggestions and recommendations regarding ongoing screening and follow-up with exercises for Child 6's legs. Having the IDP available for consultation and check-in represented for Grandmother a source of reassurance that her grandson was developing typically. She also described these services from a preventative

perspective; for example, she agrees with the consultants in maintaining a connection with the follow-up preschool support programs for Child 6 (quote) “in case something shows up at the turn of the bend.” Grandmother 6’s examples illustrate her determination and confidence in her relationship with the consultants and physiotherapist’s high professionalism and respect; (quote) “I knew I could ask.” She refers to the familiarity she has with the kind of therapy and professional services provided by the IDP due to her own professional training and previous jobs within hospitals and health centres. Rather than completing the Ages and Questionnaires during consultation visits, Grandmother 6 chose to fill these on her own, and then mail them to the consultant, demonstrating her sense of ‘autonomy’ and ‘control’ –and these are the labels used in categories selected to code some of her responses.

Grandmother 6’s reassurance has also come from her family doctor’s support. Grandmother 6 trusts her doctor having had a long-term relationship as a patient. This doctor followed-up her children as they were growing up. The doctor has been, in fact, her main point of contact for both medical and developmental queries after Child 6’s discharge. Although both the Therapy and Supported Child Development Programs have included Child 6 in their caseload for monitoring, Grandmother 6 expresses she has not felt the need to contact them because Child 6 (quote) “is doing fine; he is a very bright little boy.” Grandmother 6 repeatedly states that she has no developmental concerns for Child 6; however, she mentioned a couple of recent referrals for Child 6 to have his depth perception assessed by a vision specialist. Grandmother 6 also obtained a referral for a neurologist to assess Child 6’s balance and motor coordination, since Child 6 tends to fall down frequently when he runs. Grandmother 6

quotes Child 6' complain: *"I can't run; I fall all the time."* At no point Grandmother 6 refers to (a) the physiotherapist's written recommendations for Child 6's follow up, given his low muscle tone previously observed, or, (b) the consultant's suggestion to monitor Child 6's visual perception during the later preschool years. (These observations are included in the Child 6's files, and Grandmother has been sent copies of these notes). Grandmother's account of Child 6's transitioning stages mainly revolve around the logistics of finding the appropriate program and/or caregiver, or one (a) providing Child 6 with quality care and stimulation, and, (b) being able to match or fit-in with her job schedule needs. This has been an issue since Child 6 turned 3 years, and she took more hours at work. Now, as he approaches 5 years old, and Kindergarten registration is approaching, Grandmother 6 has accessed the information and resources she needs through her community. Although she has not rejected the guidance and services offered by the Supported Child Development Program and BC Centre for Ability (closing Child 6's case, at the time of data collection), she has identified scheduling and transportation barriers to access their services, including a Kindergarten orientation meeting, and sees no need to access their services at this time. Moreover, Grandmother expressed her confusion between the two programs in terms of not being sure what the mandate was for each agency, and how had this referral come through for her. Her recollection of the discharge process with the IDP was that it concluded with their having a package for her with information about preschools and daycares in her area. Grandmother 6 acknowledges that, (quote) *"There were lots happening at the time...I could have been confused..."*

Summary of Findings from Focus Groups and Interviews

Overview

The findings above reported address the research topic posed in this multiple case study, “What are the parents’ perceptions of their experiences of early intervention on early child development, parenting, and/or family dynamics in families with a child at-risk for developmental delays, or diagnosed with developmental disabilities?” Participants’ responses addressed this, and the four subsequent questions, by representing their perspectives in their roles as parents included within the collective group, e.g., “parents who received early intervention services” (Stake, 2000). The findings herein summarized derive from this perspective. The viewing through the collective lens of this group of parents has allowed this researcher to identify consistent patterns in their accounts. Moreover, and as indicated earlier in this chapter, participant parents’ stories and the information retrieved through the children’s reviewed files are also consistent. The consistency of these findings resonates with research concerned with parents reporting on health-related issues pertaining to their children (Glascoe, 1997; 2000; Coleman, 2006). Moreover, the findings in the present multiple case study provide specific insights about how participant parents experienced early intervention services. These insights are made explicit through participant parents’ explicit and implicit connections between issues, situations, and events concerning the different programs accessed, the ways services were delivered, and the obstacles and barriers encountered in this process. The identification of insights and their connections confirm the instrumental purpose of this multiple case study (Stake, 2000).

The following statements summarize the findings of the present study, under the headings of the four specific research questions guiding this study. These statements combine the analyses of the participant responses across the four interview topics and the two focus group topics (see Table 4), with examples and quotes derived from participants' individual accounts. The headings represent the revised themes, and their associated categories. The revised themes combined elements from previous themes; at the same time, new themes emerged after analyzing and interpreting the analyses of the within-participant respondents' data, in conjunction with the previously organized and analyzed interpretations derived from the across participant respondents' data. This process will be further explained in the Discussion chapter of this study.

Summary of Findings by Research Questions

Research Topic: "Parents' Perceptions of their Experiences of Early Intervention on (a) Early Child Development; (b), Parenting, and/or, (c) Family Dynamics, in Families with a Child At-Risk for Developmental Delays, or Diagnosed with Developmental Disabilities?"

Theme 1: Family Centred Approach and Home Visitation Services

Participant parents reported their unanimous preference for a family-centred approach, and a home-based model of service delivery, in contrast to centre-based, and/or exclusively therapy-based and child focused services. The finding confirming parents' preference for a family-centred approach when receiving early intervention services is central in the present study. In fact, findings associated with each one of the four specific questions stem from this first finding. This finding supports parents'

perceptions and understanding of their experiences of early intervention services in terms of their value being one intrinsically related to the approach guiding the IDP Program professional practices. It is important to know that parents' responses revealed their differentiating between home-based services that followed the family-centred approach, in contrast to home-based services that were provided under a therapeutic or child-focused approach. This distinction is explored further ahead, within the findings addressing the specific research questions in this study.

In reference to service delivery models, all Stage One participant respondents' unanimously stated their preferences of home-based versus centre-based services. In the case of participants in Stage Two, parents also referred to home visits as an ideal component of the program, at least for the first couple of visits. For example, Grandmother 6, in Stage Two, expressed her satisfaction with the initial home visit consultation upon her grandson being transferred from a previous IDP program (with home-based visitation services), to the present one (with visits to the waitlist and monitoring groups). In contrast, participant parents in family 5 did not have this initial visit. These parents reported that they would have appreciated at least one home visit, and especially an initial one following the referral.

Overall, parents identified higher levels of comfort in having the first contact with consultants at home, in addition to making things "easy" for them through home visitation services during the early months following their child's birth. In reference to parents differentiating between family- vs. therapy- and/or child (as client) –centred approach, parents identified specific features that are listed next, under the heading of the second specific question (question b). It is important to note that the features

identified by parents corroborate previous research conducted by Dunst and collaborators (Dunst et al., 1998; Dunst et al, 2002), among other authors concerned with family-centred approaches in early intervention cited in the literature review of the present family. The participant family summaries provide additional support to this finding, through the in-depth review of participant parents' comments more in depth.

Specific Research Questions

Question 1): "What are the Individual Experiences of Developmentally At-risk Children and their Families Who Participated in the IDP in Terms of their Child Current Developmental Needs?"

Theme 4: Collaborative Consultation

Parent consultation, listening to parents, and empowerment. The findings of the study identified parents' priorities in their relationship and interaction with consultants. These priorities were summarized as follows: (a) Consulting with parents about their needs, concerns and ideas about issues pertaining to their child's development, health condition, and therapies to be provided; (b) respecting parents' preferences and choices with regards to scheduling visits; information and resource shared, and other referrals to be completed; (c) listening to parents, and providing them with the type of information and resources they need. The purposes were to learn more about their child developmental condition, and, access the resources they need to obtain the desired services. At the same time, participant parents reported the sense of empowerment gained through their having being listened – and attended to—their concerns by the IDP consultant. Mothers 1, 2, 3, 4, and 5, and Father 4 expressed how

effective this collaborative working relationship was for them in their attaining and/or enhancing their advocacy skills for their children when approaching their physicians, therapists, school administrators, or government agencies. Participant responses, and in particular, Mother 3's examples, clearly illustrated the existing power imbalance between her, as a mother of a developmentally at-risk child, and the doctors following up Child A and Child B. Her quote "Had it not been for the consultant's presence...my child would not have been diagnosed and got the label..." powerfully reflects her frustration in not being heard by these professionals for the past two years. The power imbalance with the medical profession is outwardly expressed by Mother and Father 5 in their account. In addition, Father 1's confrontation with the government's bureaucracy (Father 1, quote) "red tape," reinforces Mother 2's quote, "What is a priority" in reference to being denied services for her daughter with developmental disabilities. These examples comparing and contrasting the active listening encountered by parents with the IDP, with the obstructions or impediments found in their accessing medical, therapeutic or educational public services are further explored in the discussion chapter of this study. Mother 3's detailed account on the diagnosis and labeling processes of Child A and Child B raises the issues related to the "criteria" used for diagnoses - -and hence, labeling and funding for services—for developmentally at-risk children when the risk conditions are "suspected" and not "established."

Theme 5: Effective Knowledge Translation in Sharing Information and Resources

Sharing professional and community-based services information in a way is accessible for families (through effective knowledge translation) was identified as one

essential service among the many key services that IDP consultants provided to families. This unique feature of the IDP program made it possible for families to learn about their child's individual needs and options, based on the priorities they had identified in collaboration with the consultant's guidance. These findings came forward as the most salient of the specific findings. They represent a concrete example of how family-centred early intervention services can impact parents with developmentally at-risk children. The findings indicate that, on top of the high quality of the content shared, it was the ways in which the information was conveyed that helped parents gain a deeper understanding of their child's condition(s) and developmental progress. Thus, this information model ensured for parents that, at every stage during the first three years of their child, they could make the most appropriate decisions in order to address their child's current health, developmental, learning, in addition to their overall family needs. In addition, Mother 1 and Mother 4 reported having received useful information on community-based services and programs from the Supported Child Development Program's consultant, following their child's discharge from the IDP, and how the Supported Child Development Program consultant's taking time to explain the connection among agencies was important for her to obtain a clear understanding of what services her family could—or could not—access, and where would they access them. In sum, the availability of accurate information that was, in turn, presented in a professional manner confirmed to participant parents that their requests were being acknowledged.

Joint decision making. Parents reported that they were given control in the decisions regarding service provision for their child, or children (in the case of Family

3). This was also an important feature that complemented the sharing of information with the IDP Program consultant (discussed next). Joint decision making increased the flow of effective communication with the IDP Program consultant. According to responses, implementing this communication model within the structure of services being provided would have diminished the chances for confusion or misinterpretation reported by participant parents. For example, (1) Mother and Father 5 accounts on the overflow and disconnect among the professionals in the health and medical system following Child 5's birth; (2) Mothers 3 and 4, and Grandmother 6 confusion with the organization of preschool intervention programs and therapies. Mother 4 and Grandmother 6 particularly referred to the difficulties they experienced in differentiating between the services provided between one agency and another; and, (3) Mother and Father 1, and Mother 2, with the organization of support services in the school system. Instead, parents perceived they were being respected, and that they had the option to ask for more if and when needed while receiving services through the IDP. In reference to participants' suggestions, Mother and Father 4 specifically asked for a chart, with updated programs and services available, that would clearly describe each agency and programs. This, in their view, would increase the level of accessibility for families once their children were discharged from the IDP at age 3 years old. Similar comments were echoed by respondents in Families 1, 2, and 3 in Stage One. During the discussion in Focus Group 2, these families expressed their wish to have ongoing information (e.g., trainings) as well as visual and concrete information showing how system and services work).

Question 2): “What are the Individual Experiences of Developmentally At-risk Children and their Families who Participated in the IDP in Terms of Their Access to Resources and Programs?”

Theme 2: One to One Relationship with Consultant/Therapist

Parents identified having a one to one relationship with the IDP consultant over time as an important feature within the program model of services. Specifically, participant parents described this relationship as one that helps develop trust, and that ensures continuity of services and effectiveness in communication. This finding is articulated differently for (1) parents in Stage One, and, (2) parents in Stage Two. (1) Stage One participant respondents clearly articulated how special their connections were with their consultant. They used terms such as “trust”, “feeling comfortable”, and “friendship”, “wonderful.” This sense of trust helped parents in Stage One in their developing a collaborative relationship with the IDP consultant as their “case manager.” Allowing the consultant to undertake this role supported parents in their accessing, (a) other therapy services; (b) funding for respite care; (c) reimbursement for child-minding and expenses related to items and equipment they needed for their children; e.g., diapers, and a walker. Parents identified this “case coordinator” or “managing” role as crucial for them also because of the vulnerable stage they were at during the months following their child’s birth, and overall during the first three years of their child’s life, when the developmental and health needs of their children were the highest. All parents in Stage One provided specific examples of how the supportive and non-intrusive nature of the consultant’s approach in their offering different alternatives to programs, services and equipment helped them deal with the

more delicate –and grave—issues they were confronting during this stage of their lives. Parents commented the time it took for them to (a) assimilate the news of their children’s diagnoses, and, (b) understand the impact of the diagnoses on their development. Additional information on the importance of the consultants’ role in coordinating, or managing, parent participants’ cases is discussed within the findings presented under question 3 that deals with participant parents’ discharge from the IDP and transition to other programs. (2) Stage Two participant respondents reported less involvement of consultants in their accessing programs and services than Stage One parents. Nevertheless, the findings derived from Families 5 and 6 indicate their preference for monitoring consultation services with a non-rotating system of consultants for every visit. Neither Mother/Father 5 nor Grandmother 6 explicitly identified the impact of this rotation in their accessing programs and services. However, several examples implicitly referred to the different way referrals and other services were accessed, with the consultant taking a less prominent role in their case’s coordination or “managing.” The next set of examples illustrate the implicit references to differences between the ways of accessing services, when comparing the consultant rotating system vs. the continuous presence of a consultant. Example 1: Mother and Father 5 expressed their desire “to have one, maybe two consultants” during the waitlist/monitoring group consultations (Interviews #3 and #4), with whom they could establish a relationship. As mentioned earlier, these parents specifically articulated the importance for them to know that the consultant(s) following up on their child “really knows their child”, and that aspects of the information shared during consultations would not be lost between sessions once every couple of months; for

example, the fact that their child was bilingual, and that they (parents) believed this fact accounted for some of the expressive language delay observed by different consultants through a number of visits. Although parents were satisfied with the work their child completed with the speech therapist, the levels of trust and credibility that this service was one their child needed at the time would have been higher had they perceived a continuity along the consultant's reporting of Child 5 language slower acquisition and progress being influenced by bilingual learning. Example 2: It is interesting how Mother and Father 5 made several references about their ongoing consultation with the pediatrician to find answers to Child 5's unusual behaviours. At the same time, information about Grandmother 6's consultation with their family physician, followed-up by the referrals the neurologist was retrieved through these respondents' accounts. No references of these participants' concerns, and/or the consultations made to their doctors were included in the participant children's files. With (a) visits being more spaced --and hence, less frequent--for Families 5 and 6; and, (b) the rotation of consultants throughout the waitlist/monitoring groups, the role of consultants in Families 5 and 6 can be described as one where a monitoring role preceded the case coordination role, in contrast to what was reported from participant parents in Stage One. Further research is needed to find out more information about how this service provision model impacts on parents. Researching this aspect in the service delivery model for the waitlist/monitoring group is especially relevant, when considering instances like the following: (a) this mother expressed she would have consulted with the IDP on the unusual behaviour her child exhibited for a while, had she been aware she could re-contact the program for information, following the

family's discharge; and, (b) Grandmother 6 acknowledged the confusion she had experienced, as she was not made clear about the differences between the two preschool intervention and support programs for Child 6 after discharge. In addition, Grandmother 6 did not indicate an understanding of a connection linking the IDP physiotherapist's recommendation for monitoring, and the BC Centre for Ability social worker that established initial contact with Grandmother 6 for services with their agency following IDP discharge (Child 6's file with this agency was closed during the data collection process in the present study).

Theme 3: Inclusion of All Family Members

Findings indicate that parents were more inclined to access the services and programs offered through IDP (e.g., the Parent Child Mother Goose Program, physiotherapy, or speech therapy consultation in partnership with the health authority's speech therapist) because they were invited, through their consultants, to include other members of the family. This inclusion helped increased their accessibility of programs and services because the families' logistics were made easier for participant parents. Parents reported not having to deal with stressors; e.g., child minding, and /or multiple transportation issues that were identified as barriers elsewhere throughout the parents' accounts. At the same time, the inclusion of young siblings in the different programs accessed through IDP as well as in home-based consultation and therapy sessions were identified as a key feature for parents. This feature stems out of the IDP following a family centred approach. This finding resonates with the findings recently reported by McPherson (2007) on her research recently conducted with families whose children have experienced health-related risks.

The inclusion and participation of siblings in home-visits and therapies were highly valued by two of the participant families in Stage One; as Mother 4 expressed it “... *siblings are teachers too.*” Her comment resonates with previous research on family-centred practices conducted by authors including Ramey, Krauss, and Simeonsson (1989), as well as Ramey and Ramey (1998). This comment reflects the participant parent’s favouring of a family-centred model of services, where the inclusion of all family members shows the intent from the service provider to address and effectively meet families’ unique needs. At the same time, the effectiveness of these services in meeting their child’s developmental needs –and the family’s needs—is, in a way, measured in terms of (1) the level of voluntary participation of their child in the therapy and consultation session, and, (2) the added value of having the sibling in the role of collaborator, and an active participant in the family activities, as opposed to being excluded from (what parents perceived are) family activities.

Question 3): In what ways do the individual experiences Described in 1) and 2)

Relate to the Current Preschool/School Demands on these Parents?

Theme 6: Case Managing and Service Coordination

Role of consultant and service coordination following discharge. As explained in specific question a), the role of the consultant as a case manager is paramount for parents. This role is further appreciated by participant parents after the discharge process has been completed, since the consultant’s connection with the family had provided the elements for integration and continuity of services during the preschool years. After their discharge from the IDP, parents no longer have the consultant’s guidance and orientation. Participant respondents’ comments indicated how they came

into the understanding that in order to execute the service transitions from the IDP to other child development and intervention programs, they need to be pro-active, and follow-up on their own. Parents' comments on their perceptions of how these programs functioned indicated a working model that followed child-focused and therapy-centred approaches. Parents had mixed perceptions on these programs providing services at home, or being centre-based. At the preschool- and/or school-age stages, Mothers 2, 3, and 4 indicated their preference for services offered at their children's daycare, preschool or school settings, in terms of convenience for scheduling the therapy for their children. At the same time, Mothers 1, 2, and 3 reported the little contact maintained with the therapists or consultants since the communication was now channeled through the preschool, daycare or out-of-school care staff. In terms of the coordination of services required, including scheduling and follow-up, these models of service delivery are reported to demand more work by participant parents in Stage 1; Grandmother 6, in Stage Two, reported scheduling and transportation barriers to attend orientation and other meetings at the programs' headquarters during weekdays, in the evenings. In addition, Mothers 1, 3, and 4 reported the approach guiding the therapy services offered not always meeting the needs of participant families. Quotes from participant parents that illustrate their perceptions following the discharge process from the IDP include the following: (1) "You...are feeling as you have been dropped" (Mother 2); (2) "I'd want to be 'hand held' until the school years," and, "From here to there, I need a hand" (Mother 3). Mother and Father 5 and Grandmother 6 reported their experiencing of the discharge process with the IDP as a natural process. Participant parents in Families 5 and 6 noted

that there were infrequent appointments scheduled throughout the last year of waitlist/monitoring group consultations, after their children's second birthday. Participants identified the following issues: (a) the spacing of the consultation visits, and, (b) the reassurance received on their child meeting the developmental milestones to account in helping them to realize that these services may not be needed for too much longer. Nevertheless, an implicit desire for continuity of services appears to be present, in this mother's previous comment on re-contacting the IDP when they identified a need for more information. In contrast, Grandmother 6 spontaneously expressed how she had had a feeling that she could always ask for more information, and that she would have called the IDP had she needed to, after her child turned age 3.

Loss of support following transition to school. Parents in Stage Ones and Two identified the transition from preschool to school as the hardest transition (in comparison to the first transition from the IDP onto preschool/daycare programs). Stage One participant parents listed (a) the lack of centralized case management after the preschool years; (b) a shortage of professional resources –for direct services or therapies; and, (c) an insufficient contact with teachers/administrators at school as circumstances making this transition to school a difficult one for parents and children. Four out of five participant children in Stage One had already been enrolled in school for at least one year. Their parents identified the school support worker (or special needs assistant) assigned to each one of their children as the key contact person on an ongoing basis, as opposed to the classroom --or the resource-- teacher. Participant parents' designation of this staff member as a key contact was associated with the worker's level of availability, accessibility and their having a more individualized

relationship with child in terms of the child's achievements and performance on a regular basis (Mothers 1, 2 and 3). Stage Two participant parents found the registration to school process challenging, as they anticipated their children's Kindergarten entry within the next school year. Participant parents confronted the difficulties of having to make a decision over registration choices. Some of the issues encountered were transcribed as (quote) "Looking for the 'ideal' school program for child to start Kindergarten– where child fits in best" (participant mother in family 5); and, (quote) "deciding on the smaller school, the one that would be easier for child to transition" (participant grandmother, Family 6). Although concerns on their children's development or learning skills were not stated, these participants showed an anticipation –and expectation—for the school entry process. Parents revealed their hopes of their children experiencing a kind transition process; this anticipation implicitly denotes some of their ongoing preoccupation with additional needs showing up during the children's school years. At the same time, family logistic and scheduling factors played a role identified by participants; for example, consideration of what would be the most convenient location –that in turn would have easier access –and that would work fine with the family's work schedule and daily logistics, and especially for Families 1, 2, 3 and 6, would include having an after school child-care program available.

Question 4) “In what ways do the individual experiences Described in 1) and 2) Relate to the Demands from Other Family Members, and to Financial/Work Pressures?

Theme 7: Stressors that Become Barriers

Families with children who are developmentally at-risk experience a number of stressors on their daily lives (Poston et al., 2003; Turnbull & Turnbull, 1985; Turnbull et al., 1993). In the present study, participant respondents’ identification of these stressors specifically related to the ways in which these became barriers and obstacles to their actual carrying out of their daily lives activities. Some of the identified stressors originated from the children’s condition, and impacted on parent’s lives; others derived from external circumstances. These are listed in the next section that covers issues related to family logistics. Examples that illustrate the first group of stressors include the following: a) Mother 5’s account of Child 5’s complications at birth requiring an unexpected extended leave from work from Father 5 in order for him to support her spouse’s recovery, and to coordinate the many appointments and medical exams they were scheduled for Child 5 health monitoring and intervention for approximately one month, in addition to the recurrent visits to the pediatrician and other specialists; b) Mother 3’s descriptions of how Child B’s behaviour needs are so demanding they need to rearrange their furniture at home; at the same time, both children’s needs for routines are strict enough that any celebration or activity that steps out of the ordinary becomes an ordeal for the family in planning and organizing; c) Mother 2’s recalling on Child 2’s catching a virus or cold can end up in seizures, and therefore demanding from her and Father 2 to stay at home, by her bedside, to prevent

injuries; d) Mother 1 anticipating Child 1 going to school and being teased because of her needs for diapers at age 5 years old; and, d) Grandmother 6's dealing with court issues to obtain the custody of Child 6, and confronting Child 6's father for doing so – in addition to her ongoing dealing with issues related to her three adult children's special developmental and mental health needs and addiction problems.

Complexity of issues and logistics in families with developmentally at-risk children needs. Examples that include the second group of stressors include the following: a) the lack of available special needs placement in daycares forcing Mother 2 to exhaustively look for daycares that would provide the level of special needs care Child 2 requires; b) Mother and Father 4 giving up their full-time jobs for part-time jobs in order to be able to attend the special needs of Child 4, and of his sibling. Family 4 can only rely on their own family unit, since they have no extended family help; c) Grandmother 6 being limited to access services and programs for Child 6 offered in her immediate community. This respondent explained that she did not access a specific preschool program she would have liked to register Child 6, and did not consider attending school orientation services through the BC Centre for Ability due to the distance between her home and work-place, and the difficulties to access quality child-minding that can fit her schedule as a single parent.

Two factors surface that explain the reasons behind these stressors and the impact on families. The first factor is that these families basically count on the one- or two- adult parents or caregivers to manage and coordinate the logistics with their children. In the case of the participant respondents, the coordination entails an even more involved role with their dependents having special or unique needs. Therefore,

the risk of medical crises striking, and/or facing issues related to chronic disability is ongoing. The second factor refers to the issue of specialized childcare placements and availability --as well as the availability and affordability of quality child-minding-- is a prevalent one for Families 1, 2, 4, and 6. Even for Family 2 with grandparents being available to support these parents most of the times, should there not be specialized and quality child care day-time services would impact on these parents in maintaining their full-time jobs. This aspect is further discussed in the next section.

Health risks and disability, child care availability, and the impact on families' job and financial conditions. Demographic information collected through participant respondents' accounts revealed that all participant respondents had completed post-secondary education; e.g. college and/or university degrees. This was also true for Mothers 2 and 3's partners, who were the sole respondents for Families 2 and 3. In spite of their professional training, at the time of data collection, only Family 2's parents, Mother and Father 2 held full-time jobs, with the rest of participant parents holding part-time jobs. The remaining participant respondents indicated their being limited to hold part-time jobs given the specific demands of their children that required their ongoing presence, in the absence of alternative and/or reliable child care. The lack of reliable childcare impacting a high number of parents in BC has been reported (Kershaw, Forer, & Goelman, 2005). At the same time, research conducted in BC has documented the low-earning levels of families with young children, due to a combination of low salaries, child care costs and low tax reimbursement after incurring in these costs (Kershaw, 2007; Kershaw, Anderson & Goelman, 2007). The findings retrieved from participant respondents in the present study confirm these

issues are pertinent to them. However, these participant respondents held additional concerns. These concerns involve the perils that could result in the absence of specialized child care; e.g., lack of safety and children feeling unwell. Participant parents' accounts highlighted the unique characteristics of their preschool- and/or school-aged children, in terms of health, developmental, behaviour and/or temperamental needs. All participant respondents -but Mother and Father 2--had given up possibilities of full-time jobs at this stage of their lives in order to ensure the best care for their children. Not surprisingly, Mother and Father 2 represented the only family case with a full-time network of support, with day-time child care available and evening and weekend support from grandparents who not only offered their children with occasional child minding, but also provided them with cooked meals. Mother and Father 3 did have in-home part-time support and help from extended family for child-minding on an as-needed basis; however, the demands on the family were enormous with two young children with special needs, and Mother 3's immediate family living abroad. Childcare issues brought up by participant respondents were described elsewhere in this chapter. Nevertheless, the issue of in-home child minding was a recurrent one for participant respondents who had no extended family -or friends-- support; for example, Family 1, Family 4 and Family 6. The findings from this multiple case study confirm how having a network of support makes a difference on the lives of families with developmentally at-risk children. Mothers 2 and 3 repeatedly expressed their feeling fortunate because of this type of support; and how this support allowed them to participate in occasional social activities or celebrations; in contrast, Mother 1, Mother and Father 4, Mother and Father 5, and Grandmother 6 made

reference to the difficulties experienced as they had no one else to rely on –but themselves. These families reported having very little time to engage in activities other than their daily work and home routines. An important priority identified through the findings of this study was participant respondents’ preference to avoid, if at all possible, in-home child-minding (or respite care), unless the person taking care of their children was an immediate family member. This priority was explicitly identified for Mothers 2 and 3; and implicitly revealed by Mother and Father 1, Mother and Father 4, Mother and Father 5, and Grandmother 6 through examples provided during the interviews.

Summary

This chapter presented a description of the findings retrieved through file reviews, focus groups, and interviews. The reporting and interpretation of these findings was supported by memos and theoretical annotations that complemented the data collection and data analyses processes. The chapter included a section explaining the organization of these findings; this organization came as a result of a rigorous coding process that involved thematic analyses. The findings reported consisted of patterns observed across all participant families. The findings included unique features identified in each one of the six family cases. These patterns across families and the individual case features were related to the families’ experiences with the early intervention services provided to them by the IDP of BC between their child’s birth and age 3 years old. Additionally, the patterns and features related to the subsequent experiences of families, following their discharge from the IDP program, and until their children’s entry to preschool/daycare, and or to school. The findings of the

present study confirmed that the impact of early intervention services on developmentally at-risk children and their parents were experienced over time, and through multiple dimensions, stemming out of the program's solid grounding on a family centred-approach. The findings were deemed (1) trustworthy, as determined from data reflecting participant families' particular experiences and perceptions; (2) reliable, with an established inter-coder reliability of 95% or above; (3) valid, through member check sessions revising children's files and transcriptions of interview that confirmed verisimilitude among the different sources of data collection; and (4) representative of participants. Data was reported through narratives, summaries, and quotes from participant Mothers and Fathers, and summarized in tables that contained children's information from file reviews. A second set of member checks with participants confirmed the validity or truthfulness of these findings. Participant respondents concurred that the themes identified in the findings represented them in the following roles, (a) parents with developmentally at-risk children, and, (b) parents serviced by the IDP of BC. The final chapter in this study discusses the implications of these findings within the contexts of research, policy and practice in the early child development, special needs and early intervention fields.

Chapter V: Discussion

Introduction

This chapter consists of a discussion of the findings of the present study. The interpretation of the findings address the research topic on parents' perceptions of their experiences with early intervention on (a) early childhood development; (b) parenting; and/or (c) family dynamics in families with a child at-risk for developmental delays or diagnosed with developmental disabilities. The findings also address the four specific questions raised in this study:

- (1) What are the individual experiences of parents of developmentally at-risk children who participated in the Infant Development Program in terms of their child's current developmental needs?
- (2) What are the individual experiences of parents of developmentally at-risk children who participated in the Infant Development Program in terms of access to resources and programs?
- (3) In what ways do these individual experiences described in 1) and 2) relate to the current preschool/school demands on these parents?
- (4) In what ways do these individual experiences described in 1) and 2) relate to the demands from other family members and to financial/work pressures?

The organization of this chapter proceeds as follows: First, a discussion about the significance of the present study is presented. In this discussion, the relationships between the integrated findings of this study and the literature reviewed are

highlighted. Second, the relevance of these findings in the contexts of early intervention, early child development, and special needs education are discussed. Third, implications for practice are considered. These include examples relevant to training and program evaluation. Fourth, implications for policy are addressed. These comprise aspects related to early intervention systems that in turn guide inclusive models of intervention for all developmentally at-risk children and their families. The final three sections of this chapter encompass the limitations of the present study, the recommendations for further research, and a summary with conclusions about the study.

Significance of Study

The findings of the present study on the parents' perceptions of the impact of early intervention strongly resonated with the information collected through the literature reviews on previous and current research on early intervention, developmentally at-risk children, and their families. In this section, findings confirming the extant literature are highlighted, and specific topics in need of further research are noted. In both cases, the discussion expands on the meaning of these findings in relation to each one of the specific research questions and within the context provided by the themes and categories identified in chapter 4 of this study.

Unique Experiences of Parents about their Child's Current Developmental Needs

Criteria for children's referrals and their role in service provision. The first aspect examined refers to how the individual health and developmental profiles of the children in this sample are consistent with children's profiles cited elsewhere in the literature examining developmentally at-risk children, and reviewed in chapter 2 of

this study. The findings of the present study confirm that most children referred for early intervention services by their first birthday have a history of medical complications. These medical complications may or may not be associated with multiple developmental disabilities. The characteristics of the seven children's profiles, retrieved through file reviews, and further confirmed through interviews and member checks, provided extensive grounds for documentation. This documentation allowed for the retrieval of information focusing on their health and developmental progress during their first three - to seven- years, and the professional follow-up they received. It is important to note that the reason for referrals and overall children's health and developmental profiles obtained through the reviews of their IDP files match the information on the broader population of children served by the IDP of BC available through the program's biennial statistics (Office of the Provincial Advisor, 2004, 2006), as described in chapter 4. More specifically, this information refers to four of the children identified with established risks since birth, or soon after birth; two children with "suspected" risks; and one child with developmental delays, and with no recorded history of medical risks. This child's developmental delays were recognized at age 2 years. The four children with established risks had developmental disabilities in multiple areas, including congenital and/or genetic anomalies, consistent with the findings of Hanson (2004) and Hebbeler et al., (2007). Approximately 35% of all of the children referred to the IDP conform within the "diagnosed disability" referral category (Office of the Provincial Advisor, 2004, 2006) and are referred within birth and age six months. The degree of delays ranged between moderate and severe, as identified within the first four months of age (Hanson, 2004; Horowitz et

al., 2007). The child not fully meeting the medical criteria for “suspected” risks, but whose specific developmental delays were evident for his parents since his first birthday, matches the IDP referral category associated with developmental delays. The age at referral is usually around the child’s second birthday with motor and/or language delays identified by parents as their most frequent worry. Hebbeler et al. (2007) reported a small proportion of children’s referrals corresponding to mild to moderate developmental delays between 2 and 3 years old. The majority of children with developmental delays within the mild to moderate range of severity were confirmed between the ages of 3 and 5 years old (p. 2-7). These later referrals to early intervention services (e.g., after age 1 year old) coincide with the findings of this study, and they appear to be associated with the fact that “at risk” medical criteria continue to dominate the referral process. An interpretation of such findings is how family practitioners and pediatricians with little training on child development appear to be less sensitive to specific developmental delays in infants and toddlers, in spite of parents’ bringing these issues to the attention of the professionals, and in spite of their requests for further assessment of their children. Such issues included parents’ concerns related to observed delays in the language and social and/or emotional domains when their children did not fully meet the expected milestones of talking, maintaining eye contact, and/or engaging in play activities. The reason for referrals in the two children with “suspected” risks in this sample do confirm that these specific referrals to early intervention exclusively follow criteria associated with medical complications. Such criteria are based on the recommendations for early intervention made by clinicians and researchers monitoring children with a history of pre-, peri-,

and post-natal risks from birth to their school years. Examples of researchers reporting similar findings include Allen (2002); Chan et al. (2001); Chelsea, Lisonkova, and Synnes (2004); Rescnick et al. (1998); Connor and Stresissguth, 1996; Chudley, Conry, Cook, Looock, Rosales, and Leblanc, 2005; Synnes et al. (1994); Synnes, Lefevre, and Cake (2005); Synnes et al. (2006); and, Vergara and Bigsby (2004).

Parents' awareness of children's developmental needs after IDP discharge. It is important to note that the parents of children with "suspected" risks expressed no concerns about their children's current developmental milestones at the time of data collection. Nonetheless, these parents expressed heightened levels of awareness of their children's specific needs and performance during preschool. Two aspects illustrated parents' heightened levels of awareness. One referred to their apprehension regarding the possibility of their children exhibiting developmental and/or learning difficulties and or behavioural differences (e.g., in their attention and activity levels) during their school age years, as two mothers revealed. The second one referred to their apprehension about their children not adapting to the new public school system, and not feeling at ease in their school, as one father expressed. These findings suggest that parental levels of awareness and apprehension require attention on the part of clinicians conducting research on early intervention for children with "suspected risks," a topic in need for further research. For example, in their *National Longitudinal Study of Early Intervention*, Hebbeler and colleagues (Hebbeler et al., 2007) commented on mothers indicating their awareness of potential developmental, learning, and/or behavioural concerns for their developmentally at-risk children during their preschool years. Professionals in contact with these children referred to these

mothers as being extremely vigilant at the time. Later on, when children were identified with developmental or learning disabilities, clinicians and early intervention professionals reevaluated their perceptions of these mothers. They recognized, instead, the high levels of awareness demonstrated on their children's developmental characteristics. Not only does this example highlight the importance of listening to parents, and understanding their levels of awareness of their children's characteristics and needs, but it also indicates how relevant it is to further examine mothers' and fathers' diverse perspectives and responses on this topic. Recent studies have examined gender differences in parents' responses to interview questions regarding services provided for their medically and developmentally at-risk infants in intensive care units (NICUs). Results have confirmed a distinct quality of responses between mothers, and fathers (McPherson, 2007). Mothers and fathers indicated their preferences in the way professionals conveyed information to them. Fathers expressed their overall preference to interact with a male health professional; mothers indicated that they were more at ease when dealing with female nurses or physicians. Likewise, fathers and mothers with newborns hospitalized in NICUs have identified differences in their perceived roles during the time of hospitalization of their child (Albersheim, 2007; Arockiasamy, Holsti, & Albersheim, 2008). For example, fathers associated their roles as "providers," ensuring everything was in place for mothers not to have additional stress. Gender-based differences in fathers and mothers' responses about their awareness of their children's unique developmental characteristics were not purposefully examined in the present study. Nevertheless, this is a topic that requires further investigation, as mentioned further ahead in this chapter.

Meeting the developmental needs of children in the “grey area.” Two factors may have determined for the three children with “suspected” risk and the child with developmental delays to end up within the “grey area” for the purposes of referral to early intervention services (Glascoe, 1997, 2000; Gilliam et al., 2005; Horowitz et al, 2007). The first one refers to the children’s high levels of resilience (Sameroff & Chandler, 1975; Sroufe et al., 2005), following the risks identified at birth and/or the complications experienced soon after birth. The second factor refers to these children’s developmental patterns throughout their infancy meeting overall criteria of typicality according to physicians’ observations. Parental concerns regarding their infants and toddlers’ specific developmental issues did not appear to merit a full developmental pediatric assessment. Therefore, the physicians’ evaluations of children’s medical risk status, including pre-term birth and very low birthweight, and/or their developmental risk profiles, including chronic or ongoing medical complications, were used to determine whether these children met the necessary criteria for the levels of early intervention received before age 5 years old. Authors, including Hebbeler et al., (2007), Horowitz et al., (2007), and Goelman and The CHILDC Collaborative (in press), have also identified similar medical criteria used for early intervention referrals with young, at-risk children. These findings substantiate the findings of a recent study using data from the US-based Early Childhood Longitudinal Study (Rosenberg, Zhang, & Robinson, 2008). Rosenberg et al.’s (2008) study reported a 3% discrepancy between infants and toddlers qualifying for referrals to early intervention services because of developmental delays, and those infants and toddlers actually receiving these services.

Criteria for referrals and timing of interventions. The ways and the timing of referrals in early intervention services delivered to children and their families by medical criteria confirms previous research conducted by Hebbeler and colleagues in their 2007 national report on early intervention (Hebbeler et al., 2007). Specifically, these authors' descriptions of the type of early identification and referrals conducted for developmentally at-risk children fit the descriptions provided in chapter 4 in this study on children's specific medical tests, pediatric examinations, in addition to periodic screening, surveillance, and consultation during their first three- to five years of life. In addition, the types of services provided to these children do match with those cited in the literature related to the follow-up of at risk infants and children, including Butler et al., (1999); King and Meyer, (2006); and, McLean et al., 2004a). For example, researchers have examined children with similar health and developmental backgrounds to the children with established risks in this study. Authors, including Allen and Alexander (1999); Bailey et al. (2005); Baird et al. (2001); Bremberg & Lindstrom (1997); Gilliam et al. (2005); McLean, (2004); and Wald et al. (1996), have mentioned referrals conducted for the early screening and assessments of these children conforming to medical criteria for specific medical and developmental diagnoses occurring within their first six months, to two years of life. Because of their more compromised medical and developmental conditions, these children also obtained physician's referrals for further comprehensive assessments and early intervention services, in contrast to children described as in the "grey area". These findings are similar to Hebbeler and colleagues' (2007) observations. The results of their report revealed that referrals for children with specific developmental

delays followed concerns expressed by parents –e.g., “someone first has to notice” (p. 2-7). Such concerns, including motor and language delays, were not usually reported before ages 12 to 18 months. Reporting concerns did not necessarily lead parents to early intervention at that time. For many children, difficulties were identified after age 3 years, during their preschool years, with language and communication representing over 40% of all specific developmental delays (Hebbeler et al., 2007).

Issues of health related quality of life. A background aspect related to the timing of specialized services to children with “established” risks was their history of frequent hospitalizations during their first year of life associated with their medical conditions at birth, when compared to the number of hospitalizations and medical treatments of the rest of the children in this study. Researchers investigating the health and developmental trajectories of medically- and developmentally at-risk children have focused on their health-related quality of life; and, on the medical services utilization of these children (Houbé et al., 2004, among others). Current reports have confirmed a high proportion of illnesses and hospitalizations among children with established risks throughout their first year of life (Goelman et al., 2007, 2008). Many of these children were admitted to Levels II and III Neonatal Intensive Care Units (NICUs) (Chan et al., 2001; Donohue, 2002; Klassen et al., 2003; Goelman et al., 2007, 2008; Schiariti et al., 2007; Tideman et al., 2001; among others). This close contact between the medical and health professionals with children and their parents would have resulted in more detailed recording of the children’s progress, and in subsequent multiple referrals for these children. In turn, these referrals prompted the provision of medical and professional services between birth and three months of age,

as evidence in the children's reviewed files, with children's referrals to the IDP of BC occurring between one- and five- months of age. The specific case of one child referred by his parents at age 2 years¹⁶ related to the child not meeting the current medical criteria that refers to risk conditions associated with pre-term birth and very low- to extremely low-birthweight. These specific findings echo Bhutta and colleagues' (Bhutta et al., 2002) conclusions in their meta-analyses review on children born premature and low birthweight. The authors identified relevant research reporting poor developmental outcomes of children born with normal- or low- birthweight. In their conclusions, these authors call the attention of other researchers and practitioners examining the outcomes of infants born pre-term. Practitioners and researchers utilized the current risk criteria of birthweight categories as main proxies for risk influencing children's developmental outcomes. Therefore, Bhutta and colleagues caution medical and developmental practitioners not to utilize birthweight, associated with gestational age, as sole proxies to determine risk criteria in newborns undergoing medical complications. Recent research conducted by Schiariti and colleagues (Schiariti et al., 2007) has expanded on the topic of risk criteria for low- to normal-birthweight, and slightly preterm children.

The processes for the identification, referral, assessment, and follow-up for the two children with "suspected" risk in the present study were, in turn, different from the processes followed with the other four children with "established" risk, and to the child with developmental delays. This child had no recorded antecedents of health or medical risks due to his normal birthweight and resilience, according to his mother's account. The early referrals for IDP consultation under the "at risk" category did not

¹⁶Child A, of Mother 3

include, on the part of these children's physicians, a referral for a full developmental pediatric assessment between birth and age 5 years old, by the time of kindergarten entry.

Bridging early intervention service gaps through expanded referral criteria. In closing the discussion about the findings addressing the first specific research question on the children's current developmental needs, two main aspects come forward for reflection. One aspect refers to how the findings point to the need to re-examine the criteria for the identification and referral of developmentally at-risk children from a broader perspective of risk assessment. Regular clinical observations of infants and young children by family doctors and community health nurses, and, anecdotal reports from parents during these visits could yield comprehensive information on the developmental status of children. This combination of services could help bridge this gap between services needed and services delivered for children currently deemed in the "grey area." The second point derives from the previous one, and it consists of taking advantage of such expanded criteria for referrals to guide professionals in observing and documenting the characteristic of all children's development since their very early stages. The pioneer work in BC, Canada conducted through the Chilliwack Developmental Screening Project (Goelman & The CHILD Collaborative, in press) exemplifies a successful academic and community partnership. This project attempted to identify subtle as well as more obvious developmental disabilities in children, and used community capacity in the implementation of professional-and parent-completed tools.¹⁷ Moreover, research work conducted elsewhere in North America used family-

¹⁷ http://www.earlylearning.ubc.ca/CHILD/research_child_screening.htm

and children-based surveys (e.g., the PHDS or “Promoting Healthy Development Survey”) investigating parent’s needs for guidance and information from their physicians during “well baby” visits (Bethell, Peck Reuland, Halfon, & Schor, 2004; Kogan, Schuster, Yu, Olson, et al., 2004). Kogan and collaborators reported how parents identified their need to talk and discuss issues related to home and family, parenting and early child development, and with their physicians (Kogan et al., 2004). Bethell and collaborators identified four areas of care for children that need improvement (Bethell et al., 2004), including 1) anticipatory guidance and parental education, 2) screening for family psychosocial risks, 3) screening for smoking and drug and alcohol use in the home, and 4) provision of family-centered care (p. 1973). These examples of projects utilize frameworks based on the principles of universal screening and of ongoing developmental monitoring and surveillance from birth to kindergarten entry. Implications for practice and policy will include consideration on these aspects of referral, intervention, developmental screening and surveillance for developmentally at-risk children. A discussion of the findings on the topic of screening and assessment follows, through the comparison and contrast of the participant parents’ diverse experiences, in terms of the approaches taken by agencies delivering services to their children.

Unique Experiences of Parents about their Access to Resources and Programs

Family centred approach, collaborative consultation, assessment and early intervention practices. This section expands the previous discussion on aspects focusing on the discrepancies identified between the different children’s follow-up intervention activities since birth. These discrepancies are examined from the

perspective of the parents' perceived effectiveness of the two identified approaches to service delivery in early intervention described earlier in this study. These include the family-centred approach, in contrast to the professional-based approaches based on the medical model of services. The connections between these approaches to service delivery and the steps reported by current research that are usually followed by health and medical professionals in the early intervention process are highlighted. These connections refer to the following: First, the specific roles played by professionals in the health and medical disciplines, including family doctors, pediatricians, community health nurses, and hospital-based therapists, among others in the decisions around completing referrals are discussed. Second, the influence of such decisions on children and families are highlighted; and third, how the latter affected the way IDP consultants and other early intervention professionals delivered their services are presented.

Authors, including Hanson (2004) and Shonkoff (2000), have referred to a power imbalance between parents accessing professionals working under a hierarchical model similar to the medical model of services. Power imbalance manifests when parents attempt to access specialized consultation and services for their young children when these professionals do not acknowledge their needs. In Mother 3's case, medical specialists silenced her voice as a parent -- to the detriment of Child A's opportunities in gaining access to early intervention since age 1 year. The issue of professionals ignoring or dismissing parents' concerns about their children's health and/or development has been examined elsewhere (Glascoe, 1997; 2000; Hirschberg, 1999; among other authors). Authors Dunst and Trivette (1988) used the terms "learned helplessness" when referring to parents learning to comply with

professionals working under the medical model of services (p. 373). When professionals dismiss parents' intuitive knowledge about their children's developmental needs, they fail to recognize these parents' capacity to understand the specific developmental needs of their children. Guralnick, Neville, Hammond, and Connor (2008) have recently documented the specific attunement between mothers and children with developmental delays in natural home and play interactions and how this attunement reflects mothers' knowledge of their children's development, and their connection to their unique needs. The silencing of parents' voices when they transmit their concerns based on their anecdotal observations, and their intuitive knowledge about their children, resonates with the issue raised by Linda Tuhiwai-Smith in her book, *Decolonizing Methodologies*, where she discusses how current formal systems of knowledge silence other, less traditional, forms of knowledge (1999, p. 33).

In contrast to this silencing, the findings of this study reveal parents' insistence on the strength their voices gained through their work with IDP consultants. Parents used the advocacy skills consultants modelled for them during home visits, in order to gain access to services for their children, after their discharge from IDP. Parents also recognized the deep respect in both the consultants and physiotherapist's during consultation and assessment activities, throughout the question and answer processes utilized by consultants and physiotherapists to gather information about their child –in either home or in-centre consultations. The findings also point at parents' perceived empowerment when consultants shared their contributions of ideas and resources with other parents, thus creating a network of support among parents interested in sharing resources for their children. This sense of empowerment had its roots in the first

contact with consultants, when they were first introduced to the IDP Family Needs-Assessment Survey (see Appendix A). This tool guided parents' work with the consultant by identifying the strengths, needs, values, and beliefs of the family in terms of their perceived goals and objectives in working with their child. Needs-based assessments were conducted periodically with the family in order to ensure that the services offered continued to meet the family's needs, until the time of their discharge from the program. The use of this tool epitomizes the importance that IDP programs assign to working in partnership and collaboration with families. This joint exploration of families' strengths and needs evokes one mother's statement on her realization of her learning to draw from her own "family riches" through her work with the IDP consultant over the years. This, in turn, had provided her with a sense of strength and power she had held on to when the time came for her to voice her ideas during her daughter's first IEP meeting at school. The phrase "family riches" evokes Luis Moll and collaborators' term "funds of knowledge" (Gonzalez, Moll, & Amanti, 2005; Moll, 1992). In their research with Latino school-age children, these authors highlight --for teachers, administrators, and education policy makers-- the existing power and resources and that are present in each family. The authors conducted research with immigrant Latino families living in different urban and rural areas in the US. Their findings confirmed the importance for teachers to conduct home visitations; to learn to draw from the resources and rich traditions within these families; and to bring them as "assets" into the classroom and schools' curricula for the benefit of all children and families. The findings on families accessing their own strengths and their sense of empowerment have important implications for practice and for policy that will be

examined further ahead in this chapter.

Family centred approach and effective knowledge translation in sharing information and resources. The findings from file reviews and further confirmed through interviews indicate how the information exchange went both ways since parents completed the Family Needs Survey. Throughout consultations, parents acquired relevant information, and gained a better understanding of their children's development and learning processes. Such wealth of knowledge and information provided parents with a language that allowed them to talk about, to reflect on, and to elaborate on what they had observed about their children's skills and progress through this exchange process with the consultants. This two-way process supported them in making timely decisions related to the steps they ought to follow in order to address their children's unique needs. This process reveals how a cooperative, non-hierarchical working model steered an interactive and collaborative process of exchange of information that resulted in the construction of a solid platform where parents could stand with their children.

One way of interpreting this process is by associating the sense of empowerment parents gained with the consultants' sharing their sound knowledge on issues relevant to them. The ways in which sharing the information and knowledge occurred was also relevant. It combined modeling through shared observation, assessment and play sessions, facilitating, and/or, adding on resources and material upon parents' requests, and it will be discussed in terms of the implications for practice and training. Of particular relevance is the seeming relationship between the findings pointing to the importance of the process of information exchange for

participant parents and issues related to children's developmental screening and assessment. This ongoing observation and evaluation process is evocative of Meisels and collaborators' extensive work on authentic assessment practices; for example, Meisels et al., (2003), and Meisels, Liaw, Dorfman, and Fails Nelson (1995), with further implications for practice and training.

Family centred approach, case managing, and service coordination in early intervention services. The differences in service delivery early intervention models for the children in this study emerged through their dissimilar profiles in terms of different levels of complexity, consistency, and continuity in the information gathered through their first three years. Previously outlined recommended practices in using multiple tools include observation and assessments with different time occurrences; in a variety of settings; and in collaboration with an interdisciplinary team of early intervention professionals (Bailey, 2004b; McLean, 2004; Mc Lean & Crais, 2004; among others). Multiple methods of gathering information for assessment purposes are instrumental in obtaining and providing a more complete "picture" of children identified at-risk for developmental delays and their families. These methods need to include a combination of traditional assessment measurements, including standardized tests, (McLean, 2004; McLean & Crais, 2004, among others), and less traditional methods; for example, questionnaires, surveys, and interviews (Hirschberg, 1996; Lynch & Hanson, 2004; Klassen et al., 2003, among other authors). This integral representation, in turn, assists early intervention professionals to most effectively address the needs of children and their families with follow-up collaborative consultation and intervention practices, as proposed by Mahoney et al. (1998), Winton (1998), and, Winton and Bailey (1990).

Such practices were largely in place for children with established risks. The findings of the present study support these assessment and intervention practices; they also coincide with the recommendations of the existing literature on this topic (Allen & Alexander, 1999; Bailey, Skinner, & Warren, 2005; Baird et al., 2001; Bremberg, 1997; Gilliam et al., 2005; McLean, 2004). The discussion that follows expands on this topic and specifically on how assessment practices affect the type of early intervention services offered to the children and families.

Family centred approach and home visitation services. File reviews of children revealed differences in terms of their referrals for early intervention and the service delivery model experienced that were the result of assessment-led practices (McLean et al., 2004a). These findings coincide with Hebbeler and colleagues' report on the criteria for referral and the type of early intervention services delivered (Hebbeler et al., 2007). In the present study, the referral category placed these some of these children within the "suspected risks" group of children, and one child in the developmental delays category. None of the children had previous screening or pediatric developmental assessment reports. Consultations for children with "suspected risks" were carried out at the IDP centre, in contrast to the at-home services provided for children with established risks or with identified developmental delays. Chapters 3 and 4 of this study included a description of the process of consultation and monitoring for these children. Although the IDP program offered multiple levels of observation and assessment to all children, the information for children with "suspected" risks lacked the depth, complexity and combination of multiple methods of data gathering observed for children with "established" risks. One

reason behind this discrepancy might be associated with the difference in the number of observations and the time span between one observation and the next—for children with “suspected” and “established” risks. At the same time, the different models of service delivery favoured children with “established” risks in maintaining one consultant throughout the years. These families received steady home visitation practices that were convenient for parents and, especially mothers, of young children with multiple health and developmental needs. The relevance of this information heightens in light of how the findings of this study relate to current findings reported on family-centred assessment practices and their recommendations in using both multiple-tools of assessment, as well as repeated, ongoing observations (McLean et al., 2004, among others previously cited). Home visitation models of services could have also benefited children in the IDP in that they allowed for more frequent and consistent observations of the child in their natural environment, in combination with other standardized or informal assessment tools, and with the parent participation. At the same time, the findings in this study resonate with recommendations on family-centred early intervention practices, including the work conducted by Dunst and collaborators (Dunst, et al., 1986; Dunst et al., 1988), as well as Turnbull and Turnbull (1986, 1993, 1995, 2001), also cited earlier in this study. In this aspect, parents reported that the early intervention practices followed by IDP consultants were consistent with the family-centred approach for both home-based and centre-based consultations. This finding is extremely relevant for current early intervention practices that equate home-visitation and child-focused services with family centred-approach practices. According to parents, successful examples of family centred-

approaches (e.g., consultation and/or direct therapy services) were implemented within a collaborative framework, where information and resources were shared within a context of respectful listening to parents' needs and values, and where decisions were taken jointly. On the contrary, parents perceive services that do not incorporate these elements as less effective, sometimes bordering on being non-respectful of family needs and values. In the present study, four parents in three families rejected, discarded or not fully accessed services perceived as professionally driven, child-focused and therapy based. The children ended up not having services for an indefinite period.

In sum, the analyses of the information retrieved through file reviews and interviews revealed some of the reasons underlying the differences in the progress and follow-up of children with “established” and with “suspected” risks. Differences not only referred to in-home vs. in-centre service delivery models for participant families, as elaborated in chapter 4, but they also pointed to a higher frequency of contacts between parents and consultants. A more intensive contact between parents and consultants appears to have benefited families with children with “established” risks. In-home visits included naturally occurring observation activities; for example, playing and reading stories with the children and their parents. These promoted in-depth parent-consultant relationships established; and in the fact that only one- or two- (vs. several consultants) followed up these children over time. Finally, the types of assessment practices that consultants followed, and the complementary assessments from other professionals involved with the children resulted in obtaining information that is more comprehensive for children with “established” risks or with

developmental delays. Sustained follow-up occurred in terms of addressing the needs that these parents had identified for their children, when compared with the needs expressed by parents with children with “suspected” risks. This prolonged follow up was possible in spite of the service gaps that parents identified as parents of children with “established” risks or developmental delays transitioned, after their discharge from the IDP, and into other programs. A discussion of the implications of these findings examining the impact of early intervention practices on parents with developmentally at-risk children is included further along in this chapter.

Unique Experiences of Parents and Current Preschool/School Demands

Absence of centralized services and case managing coordination. The findings in this study revealed how hard transitions had been for parents once they were discharged from IDP. The sense of being “on their own,” “confused,” or to have “been dropped” after their child turned 3 years old may have derived from the reality these parents experienced of a conglomerate of programs and agencies. These programs offered either therapy services (e.g. the BC Centre for Ability), or out-of-school support services (e.g., the BC Supported Child Development Program) for their children. Agencies used slightly different service delivery models, including a combination of home visitation and in-centre service delivery models. Limited communication and information sharing was maintained among professionals managing their cases; for example, therapists and preschool teachers; or preschool teachers and parents, but rarely the three parties. Parents’ expressions of frustration are not surprising, especially when considering the activities they needed to coordinate for their children. These including the following: medical and health contacts, therapies,

(e.g. family therapy and Applied Behavioural Analyses), and preschool, and/or childcare arrangements. Some parents also needed to submit applications and requests for funding and/or reimbursement for medical expenses or specialized equipment for their children. Through files reviewed it was assessed that each parent with children with “established” risk or with developmental delays continued to deal with an average of five professionals and with at least three different agencies during the preschool and early school years. Parents with children with “suspected” risks had an average of two professionals, and two agencies or programs during this same period. By the time their children were 4 years old, no one was available to integrate all the information and services that were, or could have been, accessible for these parents (see chapter 4). Several parents had no memory of information received through the IDP at the time of discharge about preschools or support programs. Other parents could no longer remember the information they knew they had received at the time of discharge from IDP. Parents’ perceptions on the topic of service coordination and continuity gain more relevance in light of the findings of the present study revealing how emotionally daunting the experiences surrounding the birth of their children was for parents. Some of the initial comments shared by parents during the interview referred to how hard it was for them to recall these experiences and facts. One interpretation is how parents’ capacity to hold the information provided and to utilize this information diminishes once they do not have the support of a case-manager. At this point, parents need to assume this new role on behalf of their children. Accessing programs and handling information and resources appears to become an additional stressor in parents’ lives, and even more so, as their children grow older. Although

their children's disabilities remain the same, their needs change and may become more complex. These issues are further explored in the sections that follow.

Program access stressors and how they become barriers for parents.

Difficulties in service coordination in preschool support programs resulted in two of the parents missing invaluable resources available through a preschool support therapy program and on orientation sessions for kindergarten entry through this program. The lack of guidance on how to proceed with information about preschools and daycares after the IDP discharge resulted, for one parent, an immigrant to Canada, in missing out on the concept of "catchment areas." These catchment areas determined the availability and service provision of special needs preschool support. This situation temporarily affected the service provision for her child at the time he began preschool. Another mother, also an immigrant to British Columbia, indicated how she relied on acquaintances to find out about a preschool for her child, and how she longed for written guidelines that would describe this process, and that were relevant to her geographical location. Factors that increased parents' hardships in their children's transitioning from preschool to school included the following: Difficulties finding before- and after- school care; reduced direct therapy services and limited one-to-one support availability for their children following funding cuts in schools; and, the provision of preschool therapy services ending at age 6 years. Similar comments have been brought up in a recent report from the BC Children's Health Alliance for Special Needs (e.g., Pivik, 2008) by a group of parents and early child development and special needs service providers. Parents' testimonies in the present study acknowledge the role of the IDP consultant as critical in taking charge of service coordination that

included guidance and support in the completion of referrals and the interpretation of assessment reports for other medical tests and professional consultations. The discharge from the IDP at age 3 years signified for these parents the loss of specific early intervention consultation services. Parents also commented how difficult it was for them to access a wealth of services they perceived as too complex to manage on their own. Parents' responses are important, in that their reports reflect their satisfaction with these programs from a "consumers" perspective (e.g., Collins, Lemon, & Street, 2000). As consumers, the experiences of parents speak to their perceptions originating in their experiences with the IDP program. Their contributions support this study in the utilization of existing strengths and resources within the IDP program –and open the possibilities to expand these contributions onto other preschool early intervention and school support programs. Research on consumer satisfaction with social, health and educational programs is providing a voice to groups that have been traditionally underrepresented; for example parents of children with mental health issues (e.g., Godley, Fiedler, & Funk, 1998); teen parents (e.g., Collins et al., 2000), adolescents, (Stuentzer-Gibson, Koren & DeChillo, 1995), and children (e.g., Davie & Galloway, 1996). A recent study in British Columbia, Canada, entitled *Impact of Training and Counselling on Parents with Children in the Care of Welfare Authorities* sought to provide a voice to parents attending a parenting program.¹⁸ Many of these parents were living in poverty; their children had been identified by provincial government agencies as children living under social and environmental conditions that had placed them at-risk for apprehension from government authorities. Parents reported the benefits experienced through the agency's training and counselling

¹⁸ www.Swfs.ubc.ca/index.php?id=1175

programs. In spite of the support they received, parents identified poverty and abuse as the major barriers in attaining a sustainable lifestyle that would allow them to reunite their families. Results from this study, and the previously listed studies, provide unique examples of findings and recommendations drawn from the experiences of program-users, in contrast to recommendations generated from program-evaluators. In this sense, the rich and in-depth findings drawn from parents' voices in the present study address a key aspect in the research topic on parents' perceptions of their experiences of early intervention. These findings speak to how lack of coordination and service continuity equates to a barrier to accessibility of existing resources for parents. Therefore, parents' assessed the quality of services such as direct therapies for their children from their own family-centred perspective; for example, "Does this service acknowledge my child's current needs and strengths?" "Does the therapist include my other child (sibling) and us (parents) within the consultation and follow-up plan?" "Does the therapist share my/our vision of what we would like for our child in terms of programs and services?" These findings echo Hebbeler and collaborators' report (Hebbeler et al. 2007) about parents' expressing strong preferences for family-centred services, as opposed to child-focused services. Parents' questions are examples to be further explored in the discussion around implications for practice and training.

Summary: Effective services and joint parent-professional collaboration.

Through the findings of this study regarding parents' experiences in transitioning to other preschool- and school-based intervention programs, it became apparent that these early intervention services are accessible to some, but not all, children and

families; therefore, their levels of effectiveness drastically diminish, as their resources remain unused by their target population. These findings support the current idea for implementation of models in early intervention that address both global and specific needs; for example the “Response to Intervention Model,” under the “Recognition and Response System” (e.g., Coleman et al., 2006; Houbé, 2008). The RTI model’s illustration through a pyramid (see Appendix K) includes, at its base, high-quality services considered as universal; for example, screening and developmental monitoring; childcare, and preschool. The centre of this pyramid includes targeted group intervention services, including language stimulation programs (e.g., the Hanen Program¹⁹), and parent-child bonding programs (e.g. the Parent-Child Mother Goose Program²⁰). The tip of this pyramid includes specialized individualized services; for example, early intervention consultation and therapy services. The Recognition and Response System and the RTI model are being utilized as frameworks assisting program planners and policy makers in responding to parents’ requests for integrated services (Coleman et al., 2006; Houbé, 2008; Pivik, 2008). The findings in the present study indicate that while parents responded positively to the collaborative consultation and joint decision making that IDP consultants offered, the lack of response of provincial government agencies greatly affected and discouraged them when the time came to apply for different sources of funding. Parents labeled the official and bureaucratic language as confusing; for example, the terms “meeting the criteria” and “priority” took different meanings for three of these parents. Parents were disconcerted following three years of experiencing their case as a priority for the IDP

¹⁹ www.hanen.org

²⁰ <http://www.nald.ca/mothergooseprogram/>

program staff. Parents found themselves not ready to confront extended wait-times for services, and disheartening messages from government officials in terms of accessing special needs funding for their pre-school to school-aged children. Three parents expressed their frustration with the contradictions in the government system that acknowledged their case as “meeting the criteria,” given their children’s disabilities, but that also regarded them as “non-priority” cases when the time came to receive the funding for support requested. These findings add to the previous findings on parents’ identification of their children’s needs and their accessing services. They provide a clear example of how parents strive to address the specific and unique needs of their children, and how they keep trying to access services that best fit these changing needs. A clear message was how imposing models of service on parents fails to meet their needs. On the contrary, listening to parents (e.g., starting the intervention process with collaborative tools such as a needs-based assessment survey) has proven effective for them. Parents’ desire to share and contribute their experiences with other parents, and their wanting to provide their recommendations illustrates both their sense of ownership of their lives, and the thoughtful process of decision-making invested for their children’s best interest throughout the years. Important implications for practice, training, and policy stem from these findings.

Unique Experiences of Parents; Demands from Family; and Financial/Work Pressures

Confronting cycles of disability and anticipation. Participant parents of children with “established risks” confronted unique issues in trying to meet the physical, health, and developmental demands of their children that varied but did not

disappear with age. These parents' experiences were very particular to their children's unique situations, as described in chapter 4 through the Cycle of Disability and Cycle of Anticipation themes. The findings of the present study revealed that consultants supported parents in their learning to prepare for the next stage of demands they needed to address for their children through every transition, in turn linked to children's growth and developmental stages. This guidance and support occurred through an ongoing process with parents sharing these experiences, dealing with the individual situations revolving around them, and learning to understand what each one of these stages meant, in terms of the addressing the needs of their children. Their voices corroborate Diaz Soto and Swadener (2005) and Joao's (2004) reflections on the many languages of disability, when these authors refer to parents' voices assigning meanings to typical and atypical development. The information discovered in this study about the predicting expertise that participant parents gained through their unique parenting experiences does not undermine the obstacles they confronted, nor does it ignore the deep and complex emotional processes they experienced. Parents of children with "established" risks and with developmental delays reported how they gradually came to terms with the information about their children's frail health, and/or moderate to severe developmental needs; and, the long-term impact all of this would have on their families' lifestyle. Their accounts resonated with the stages of grief and loss described in early literature focusing on special needs and families (e.g., Ludder & Jackson, 1974; Turnbull et al., 1993) and further reiterated in more recent literature about bereavement (e.g.; Bonanno & Kaltman, 2001). Their testimonies on their perceptions about their children's dependency levels remaining the same and even

increasing with age portrayed their ongoing sense of preparedness to confront the upcoming stages in their children's needs. The experiences of these parents are unique in that their children's growth and development do not progress towards their independence, as typically developing children do. At the same time, authors have examined parents' capacity to overcome complex situations and crises. For example, Lynn Hoffman (1981) described how all parents learn to adapt to the different crises they may face through their family life cycle in her book *Foundations of Family Therapy: A Conceptual Framework for Systems Change* (1981, pp. 160-161). Findings from participant parents' accounts in the present study revealed that their priorities were to have systems that worked in place both at home and at work, and, ideally, they wanted to have network and support systems external to their nuclear family. When such systems were in place, parents appeared to cope with the daily challenges of their children's health and/or developmental conditions. These findings resonate with other authors exploring the coping mechanisms for parents with children with identified disabilities; for example, Dunst et al. (1988); Dunst et al. (2002); Margalit and Al-Yagon (2007), among other authors cited earlier in this study. For example, parents in Margalit and Al-Yagon's (2007) study with preschool children with Down's syndrome reported how they learned to adapt and find special to interact with their children. However, they identified situations like their children being ill as very stressful. Comparatively, the findings in the present study revealed that, when specific aspects of these systems failed, parents reported having more difficulty managing their stress and coping poorly during crises. Examples of these stressful situations referred to conflicting job schedules and childcare issues, especially for families with two

children. One of the fathers had a nervous breakdown and requested an extended leave from work when the demands of his job and his home escalated soon after their child (the youngest of two) was born. This child was extremely sick and frail during his first six months of life, causing great anxiety and ongoing sleep deprivation for both parents. This particular family had no support from other relatives at the time. The findings bring forward important issues at the policy level in terms of the imperative need to secure childcare, respite care, and, financial support systems for families with young children who are developmentally at-risk. Securing such systems could ensure the preservation of the health and integrity of these families; otherwise, their risks for breakdown could increase. These issues surface again in the section examining implications for practice and policy.

Parents of children with “suspected” risks reported worrying about sequels of the medical risks associated with their children’s pre-, peri-, or post-natal complications. Parents’ anxiety related to the possibility that their children would receive a medical or developmental diagnosis throughout their school years. Notwithstanding the reassurance provided from IDP staff and from their physicians, parents’ fears were not appeased. None of these parents could find a final explanation, or a solution, for the neurological and or behaviourally based concerns they brought up to their physicians. Parents reported that their present level of concern has diminished, but not totally disappeared. One parent expressed her preoccupation with this comment: “[I’m] trying to find what could come next, at the turn of the bend.” These findings indicate that even if parents are not explicitly voicing their concerns to their physicians, they may continue to question and worry about unexpected

behaviours or atypical events with their children. Parents' comments revealed that they continued to ask questions of other parents, and/or would try to find answers through internet surfing. It is important that physicians find ways to address such concerns. This may require documentation from professionals that would complement parents' observations. Such ongoing observation and recording process, described earlier in the chapter, could result in helping parents understand the nature of the unexpected or atypical events they have observed. Issues on developmental monitoring are expanded upon in the section discussing implications for practice and for training.

Stressors and family issues from the perspectives of fathers and mothers. The findings in this study revealed that fathers' responses were more informative, fact-based, or opinion-led in nature in their experiential accounts about the IDP, when compared to mothers' responses. Mothers' responses primarily referred to aspects related to the well-being of their child, and to anticipating other needs. Mothers also referred to how their relationship with the IDP consultant, and/or with the IDP physiotherapist supported them in address their ongoing worries and concerns. Gender differences in responses were less apparent for the one single parent (Grandmother 6). Her account seldom mentions the aspect about relationships. This parent's account stresses, instead, on the effectiveness of services received and on the obstacles encountered along the way regarding childcare and family issues. These findings indicate the importance of examining gender differences and roles played by parents when examining parents' perceptions of their experiences of early intervention services. A recent study (McPherson, 2007) examined gender differences in parents'

responses to interview questions about services provided for their medically fragile and developmentally at-risk infants in intensive care units (NICUs). Reports confirmed distinct quality of responses between mothers, and fathers. McPherson reported that mothers and fathers indicated their preferences in the ways professionals conveyed information to them. Fathers expressed their preference to interact with a male health professional when responding questions about the well-being of their child and the services received at the hospital. In contrast, mothers expressed their being more at ease when dealing with female nurses or physicians. Fathers and mothers' responses in McPherson's study (2007) bring forward the predominance of women (over 95% of consultants) providing IDP consultation services for families (D. Brynelsen, personal communication, July 9, 2008). Consultants, in turn, predominantly relate to women (mothers) usually staying at home with their infants and young children. Participant fathers in the present study indicated their appreciation for the program and described their connection with IDP consultants. Still, mothers included comments that related to more personal feelings and perceptions around their work with the consultant(s) throughout the years. This information is important and extremely useful in understanding some of the limitations in this study in having a predominance of mothers as sole respondents among the two-parent participating couples. For example, three of the couples decided that only the mother would talk to the interviewer and researcher (another woman), with one mother expressing "[within our couple] I do more of the talking." Likewise, researchers focusing on fathers and mothers with newborns hospitalized in NICUs have identified differences in these parents' perceived roles during the time of hospitalization of their child (Albersheim,

2007; Arockiasamy, Holsti, & Albersheim, 2008). For example, fathers associated their roles as “providers,” ensuring everything was in place for their partners, and indicated their awareness of their partners’ exhaustion, now wanting them to suffer additional stresses.

Issues for couples and family-related issues. The topic of stress following birth complications was brought up by one of the mothers with a child with “suspected” risk. This mother reflected on the strain that couples with a child with medical conditions and developmental disabilities could suffer when they had little or no family relief or support over an extended time of duress. The present study purposefully asked parents to comment on aspects related to their own family dynamics. However, other aspects surfaced during the interview sessions. One aspect referred to parents’ concerns with their other child not receiving the attention needed as a consequence of ongoing family stress and the focus on the child with delays or disabilities. This aspect has been documented by authors, including Crnic et al. (1983); Deal, Trivette, & Dunst, (1988); Dunst et al. (1997); Hirschberg 1996); and Lobato (1980), and needs further attention within the context of parents receiving early intervention support. Another aspect referred to the presence or absence of support by other relatives. Parents’ with such support commented on the help this support represented. A powerful example refers to the two parents in one family referring to their estrangement from other relatives. Parents’ comments indicated how hard it was for them to have their children grow apart from grandparents and other relatives who had alienated them. These parents implicitly referred to their child’s disability as the cause for such estrangement. In another example, parents with relatives far away in

other provinces or countries expressed their sadness about their children not spending time together with relatives, and for the family not being able to receive their support. Examples illustrating parents' reliance and need for support from other relatives and community members are important for training and policy considerations within the ecological framework of early intervention practices already described in the present study; for example, Bronfenbrenner (2005); Garbarino and Menzel (2006); and Sontag (1996).

In contrast, issues related to couple dynamics when parenting a child who is developmentally at risk tended to be more implicit than they were explicit among the interviewed parents. It is important to recognize that these issues need further attention and examination, and that parents did not readily identify them at the same level they did, for example, with the daily family logistics, childcare, and financial issues. More specifically, the examples provided by parents around family logistics indicated that in these couples with young children, issues related to couple relationship seemed to take background stances with childcare, job and financial issues taking over. These findings resonate with authors examining issues pertinent to family cycles and family stages (e.g., Brannen, Moss, & Mooney, 2004; Hoffman, 1981). For example, Brannen et al.'s (2004) multi-generational case studies on families described the issues confronted by English couples, living in the last quarter of the twentieth century, and their being caught in the middle of childcare demands for their young children. Later on, these same couples ended tending their parents, while confronting the stresses of work and financial hardships for both members of the couple.

Parenting over a lifetime. Authors, including Turnbull and Turnbull (1995,

2001), have examined the issues described earlier among couples with children with disabilities. For example, as they transition through their life-cycle stages, these couples may not experience the “empty nest” stage because some of their children will most likely need some level of assistance as adults –a concern expressed by three parents in the present study. At the same time, the findings in the present study about couples and long-term family issues confirm what other authors have reported over decades, about families with developmentally at-risk children needing guidance and support throughout the years (Bailey, 2004a; Dunst et al., 1997; Morningstar, et al., 1997; Turnbull & Turnbull, 1985). This support may be needed in different capacities, over time, as families’ needs change throughout the different stages. Authors, including Turnbull and Turnbull (1995, 2001), have examined these issues among couples with children with disabilities. Such findings point at the need for further examination of this aspect within the context of early intervention training and program practices in their consulting work with parents. With children as young as age 3 years old, these parents are already worrying about their future as adults in need of care. This level of involvement in parenting also calls for a reflection on parents’ sense of feeling different and being treated differently by other parents and members of their community. Parents’ dual feelings of inclusion and exclusion, and a mixed sense of belonging within their family and broader communities call for further research. For example, a study within the ethnographic tradition of inquiry could examine the meaning(s) of the sense of belonging and of feeling included through the experiences of parents with developmentally at-risk children (e.g. Tedlock, 2000).

Implications for Practice and Policy

Introduction

Participant parents' responses portrayed their perceptions of early intervention process, including the activities done in conjunction with the IDP consultants, and the impact these experiences had had throughout the years. It is important to note that, throughout their accounts, participant respondents mentioned but did not stress outcome measures of performance as the essence of the success of early intervention programs with their children. Quite the contrary, although parents were keen to observe changes in their children acquiring, developing and/or enhancing motor, language, cognitive, self-help, language, social, and emotional skills, they did not adjudicate such changes as the direct result of the early intervention services received. Instead, they focused on their own journeys of discovery had led them to better support their children's developmental needs through the guidance provided by the IDP consultants. This journey was unique for each participant family. It involved, for participant respondents, obtaining accurate and in-depth knowledge of their child's condition and developmental progress; and the resources available to address his or her needs. Above all, it meant a collaborative process of reflection and decision making that ultimately led them to attain the goals they had first identified for their children. Examples of such process are discussed throughout this section.

Implications for Program Practices and Training

The above-described findings suggest that IDP programs could benefit from a formal evaluation of their screening, assessment, and follow-up practices, including the evaluation of the rationale and operating system supporting these practices for both

levels of services (e.g., in-home and in-centre). One objective for this evaluation is to achieve maximum effectiveness in service coordination for families with children who require ongoing follow-up attention. The second objective is to enhance current screening and assessment procedures for infants and young children. In reference to service coordination, this objective acknowledges the essence of participant parents' responses captured under the closing theme "the desire to share and contribute." A clear message from participant parents refers to their hopes that their expressions could translate into practices that favour integration, as opposed to fragmentation of services. Parents also insisted on the timing of direct therapy services or equipment assistance for their children, and the negative impact of extended wait-times to access these services for their children. Service coordination through an integrated case management system that does not stop passed the age of 3 years is a focal point for these parents. The recommendation for the IDP to establish an early contact with families, e.g. "since their time at the hospital" (Mother 5) requires acknowledgment at management and organizational levels of planning and programming. An early point of contact at the hospital for parents whose children spent extended time at a Neonatal Intensive Care Unit could make a difference for parents. Parents could learn about the resources available for them in terms of information, guidance and support, and above all, knowledge translation of the medical system and language identified as challenging for several parents. An initial contact that is hospital-based could also save parents mobilization or transportation after they have just dealt with critical times with their infant. The aspect of mobilization presented some resistance for two parents in one of the participant families (Family 5) after an extended stay at the hospital with

their child. This mother expressed how she did not want to go anywhere for a consultation once they were home with their child, echoing other parents' preferences.

Enhancing methods of screening and assessment signals another focal point for evaluation. This refers to the necessity to re-examine the current tools selected for screening infants, toddlers, and preschoolers. Authors have recommended a combination of tools and methods of assessment in order to rule-out suspicions for developmental delays, especially for infants and young children with delays ranging in the mild- to moderate- degrees of severity (e.g. Ford & Dahinten, 2005), whose needs are more complex to identify. The challenge of developmental assessment during these young ages given the difficulties with sensitivity and specificity of the current developmental assessment tools available has been identified by authors including Ford and Dahinten (2005); Frankenburg (2002); and Gilliam and Meisels (2005); among others.

Nonetheless, the findings of the present study may contribute in this regard with suggestions for targeted screening and evaluation practices in the IDP. These could include a further examination of the selection and the administering of the assessment and screening tools currently utilized in this program. At the same time, in keeping in line with the Program's current family-centred practices, implications for training refer to maintaining and enhancing current consultation practices based on systematic observation and collaborative documentation, the two principles behind authentic assessment (Meisels et al., 1995). Informal screening tools based on these principles; for example, "The Ounce" (Meisels et al., 2003), could help parents incorporate specific vocabulary that describes their children's specific skills and

behaviours. Similarly, enhancing consultants' skills around the language of observation in infant and child development could enhance knowledge translation practices, as parents develop a keener and more refined sense of their children's development and specific needs. Training components for consultants to share with parents could include the following: Combining observation (e.g., The Ounce), informal screening tools (e.g., the Ages and Stages Questionnaire), standardized tools (e.g. the Battelle Inventory, among others), and, sharing and exchanging specific descriptive developmental vocabulary with parents. Such enhanced training could further support parents in identifying areas of strength in their children, and those needing further assessment and intervention. Moreover, it would ensure a common language used by parents and professionals alike when sharing developmental information about their children's progress. In order for the sharing of information to be effective, this training component would expand to health, medical and therapy-based professionals following up children in the IDP, according to the reviewed files. Presently, developmental reports are shared among professionals examining and/or providing medical or therapeutic treatment to children in the IDP. Nonetheless, the findings of the study indicated a pressing need for these professionals to become attuned to the more subtle characteristics of infant and child development –and especially for the language, social and emotional domains. Knowledge sensitivity towards these areas of development could result in a deeper and more accurate understanding of the needs of young children. It could also be translated into these professionals (e.g., general practitioners, nurses, pediatricians, physiotherapists, occupational therapists, and speech and language therapists, among others) assisting in

providing timely intervention before the children's entry to kindergarten.

Through the interpretation of parents' voices, the findings in this study confirmed the importance of maintaining and enhancing the IDP Program's current collaborative, across-disciplinary and highly professional practices, all of these highly valued by participant parents. These practices included consultants' sharing of relevant information on children's developmental milestones and on their developmental needs, as well as consultants providing parents with access to further resources during their children's preschool years. An immediate need participant parents identified was the maintenance of developmental follow-up and monitoring activities of their preschool- and school- aged children. This was particularly relevant when additional complications, concerns, or new "red flags," became apparent for these parents –from concrete needs including finding equipment for their growing children, to learning about precursors, or indicators of Asperger's or Attention Deficit Disorder, as identified in chapter 4 of this study. Practical implications for consultants in order to address these issues brought up by participant parents reflect the previous suggestions for training. First, the ongoing clarification with parents about the meaning of developmental and diagnostic terms by drawing on "the riches" of parents' background knowledge, or their "funds of knowledge" (Gonzalez, Moll, Floyd-Tenery, Rivera, Rendon, et al., 1993; Gonzalez, Moll, & Amanti, 2005) as described earlier on in this chapter. Second, using the parental common or intuitive knowledge evidenced by parents throughout their accounts, and already explored by authors including Guralnick et al. (2008). Expanding on parents' intuitive knowledge could complement the screening and assessment activities by elaborating on the meaning

and relevance of each developmental item explored within the overall developmental context of their child.

A key finding to take into account referred to the pro-active role of consultants. Consultants take an important role as advocates for children. Furthermore, they become parents' allies by providing parents with the necessary tools and resources to access programs and services. Future and long-term initiatives for program planning and expansion in the IDP and other early intervention agencies for preschool-aged children may utilize this information for further training and program implementation. At the same time, the issue of the existing restricted criteria for identification and follow-up of children within the "grey area" brings forward the necessity for universal screening (e.g., Houbé, 2008) through the implementation of health monitoring (Kogan et al., 2004; Roberts, Behl, & Akers, 2004), and developmental surveillance practices (Bethell et al., 2004; Halfon, Uyeda, & Inkelas, 2004). Such practices could assist in identifying areas that may require further evaluation and follow-up as children move on to their preschool and school years. Routine developmental monitoring examples were cited earlier with initiatives described in the Chilliwack Developmental Screening Project (Goelman & The CHILd Collaborative), and the use of the PHDS Survey (Bethell et al., 2004). These initiatives could be implemented for young children during regular medical check-ups and vaccination visits at the family physician or community health office (Goelman & The CHILd Collaborative, in press). These types of initiatives respond to a broader framework of intervention for all infants, young children, and their families through universal screening (Houbé, 2008). Targeted screening would reach children needing a closer follow-up because of

observed delays, as expressed by parents and/or caregivers, and pre-, peri-, and or post-natal medical or environmental antecedents. Such antecedents include considerations about parents' lifestyle and teenage pregnancy, as it was the case for Child 6 (Infant Development Program of BC, 2004).

A current project that stems out of this multiple case study has incorporated the preliminary findings of the pilot stages of the study into a series of deliverables. These deliverables aim to support parents and service providers in the identification and follow-up of developmentally at-risk children with "established" and "suspected" risks. This project is entitled "Social Inclusion for At-Risk Children and Families" (Goelman, Brynensen, Hertzman, El Khatib, & Pighini, 2007; Goelman, Brynensen, Synnes, Houbé, Hertzman, et al., 2007).²¹ The deliverables component of the Social Inclusion Project aims at parents with developmentally at-risk children from birth to age 6 years old, and service providers working with these families in British Columbia's Lower Mainland. Resources include multi-lingual questionnaires and online and printed resources intended to validate parents' and service providers' concerns for developmentally at-risk children and, to provide them with geographically- and locally- relevant information regarding early intervention programs; for example, the IDP, the Supported Child Development Program, the Aboriginal Infant Development Program of BC, and the BC Centre for Ability, among others. The health unit within each family's specific geographical area of residence is identified as the main point of access for resources parents, and other service providers including preschool and daycare teachers, can access. The IDP Program reports the community health nurses, or CHNs, as their main source of referrals in their program

²¹ See www.earlylearning.ubc.ca/sdpp.htm

(Office of the Provincial Advisor, 2004, 2006). At the same time, current models of early intervention cited earlier in this study; for example, Bremberg and Lindstrom, (1997), support a first connection with community health nurses, as parents' first points of access from the time of the birth of their first child. In countries like Sweden, community health nurses (CHNs) provide continuous surveillance from birth and through school, and high school (e.g., Guldbrandsson, Bäck, & Bremberg, 2005). This type of points of access and continuing contact for parents gains more relevance in light of the findings of this study. As previously mentioned, parents repeatedly expressed how hard it was to recall the many events at the time their children received early intervention services. By the time children moved to preschool, and later on when they attended school, this sequence of events was hard to retrieve for parents. Key information on their child's development, assessments conducted, and referrals completed for specific tests and/or treatments may be forgotten. Paperwork might be difficult to retrieve. A centralized point of access could ensure the integration of the information, and the continuity of services through case managers' coordination that works across agencies, regions and even provinces. In turn, this could increase the chances for children and families to maintain the services they require with a full documentation of their health, developmental, and educational profiles. Current research initiatives in British Columbia are working towards the implementation of linked database models using anonymous ID numbers matching the children's health and education unique registration numbers. These authors include Chan (2007) and Goelman et al. (2007, 2008).

In terms of the pragmatic usefulness of this multiple case study, the study

addressed a missing component in the early intervention research literature about the parents' perspectives on the developmental, health and educational paths of developmentally "at-risk" children between birth and their school age years. In re-examining the current criteria for referrals, the utilization of such frameworks could provide effective alternatives to the current criteria for referrals. Frameworks include information collected from parents and from professionals in different communities. These are alternatives that could potentially free the existing referral system of the above described constraints. Constraints seem to originate in pre-determined levels of developmental risks, and, in turn, limit referrals for early intervention, and exclude children in the "grey area." Looking at specific issues raised by a selected number of participant parents revealed key information on the roles played by the relationship between IDP consultants, the children and their families, and on the nature and quality of service provision of the IDP for this specific sample of at-risk children and their families. This information is relevant and highly informative to similar programs elsewhere in Canada and North America in terms of practicality and efficacy in service delivery. Moreover, it provides context and describes the existing gaps in the service provision and service continuity for families of developmentally at-risk children –some of them also mentioned in recent reports in British Columbia (e.g., Pivik, 2008) and elsewhere in North America (Hebbeler et al., 2007). Developmental differences included children with established developmental disabilities, and children in the "grey area," whose diagnoses, and/or labels for special needs funding (Gilliam et al., 2005; Horowitz et al., 2007), partly depended on the ongoing support and advocacy of the consultants working in collaboration with these participant parents.

This study is unique in covering the experiences of parents with developmentally at-risk children in interpreting a range of developmental differences through a multiple case approach. The multiple case study approach allowed this researcher to conduct a thorough and exhaustive investigation on the topic of parents' perceptions on their experiences of early intervention by maintaining the individuality of each participant. At the same time, patterns were drawn about common issues among the participant families. This dual characteristic observed through the findings of the present study resonates with Stake's description of the intrinsic and collective purposes of case studies (1994, 1995, as cited by Berg, 2001, p. 229). Although this multiple case study looks primarily at the instrumental and collective aspects of the case of parents in the IDP of BC (see chapter 2), the above-described findings yielded unique traits and characteristics of each family within the participants of this study. Such unique traits deserve further attention in research concerning families receiving early intervention services.

In terms of the service gaps already identified in this study, the necessity for a case coordinator that follows the child and family throughout their later childhood, and adolescent years stands out. Previous research with authors examining the importance of ongoing family support for parents of children with developmental disabilities has reported the long-term needs of these families (Dunst et al., 1997; Morningstar, Turnbull, & Turnbull, 1995; Turnbull & Turnbull, 1985; Bailey, 2004a, among others). An initiative is currently being piloted in British Columbia's Lower Mainland in response to a similar need in mental health (e.g., Ford, Cohene, & Stewart, 2008) where families are followed up through the different stages, from their preschool, into

their school and high-school years.

In the section that follows, the policy implications of the findings of the present study are discussed.

Implications for Policy

The findings above discussed contribute to the current shift in the focus of “evidence based practice” for policy makers (e.g., Guhn, in press). For example, results of school-based research reveal that primary evaluative practices currently in place aiming at program funding and development originate in quantitatively based evaluative processes. Such processes tend to rely exclusively on externally administered measurement tools used to periodically assess the effectiveness of programs (e.g., Elias, Zins, Graczyk, & Weissberg, 2003). The findings derived from the interpretation of participant parents’ responses support, instead, recent initiatives for sustainable and systematic evaluation practices. Examples of these research initiatives include studies that have also been conducted in school settings (Greenberg, Weissberg, Zins, O’Brien, Fredericks, et al., 2003; Ross & Ben Jaafar, 2006; among others). The issues these authors raised are, nonetheless, common to contexts and settings involving children and parents, as it is the situation with early intervention programs. Participant parents’ voices in the present study represent an important contribution to reframe evaluative practices in adding an essential qualitative component to this research. The methodology followed in this study supports the theoretical framework guiding these current initiatives (Greenberg et al., 2003; Guhn, in press). Authors including Elias and collaborators (Elias et al. 2003) have identified the use of this strength-based approach as key in promoting competence in programs

focusing on enhancing social and emotional developmental outcomes. This strength-based approach uses natural occurrences within the context of study. Such approach characterizes the context supporting the present study as it utilized the voices of parents in the IDP of British Columbia, and was conducted following research collaborative practices with the Program's staff and its Provincial Advisory Committee. As such, this study may become one of the first examples from where to explore sustainable aspects in the evaluation of early intervention programs including the IDP, and in particular, on the parents' and consultants' perceptions on their experiences of early intervention (Greenberg, Weissberg, Zins, O'Brien, Fredericks, et al., 2003). The parents' stress on the relevance of the interaction between processes, persons, contexts, and time added an essential component to this in-depth exploration. Such exploration fits within the ecological framework supporting such evaluative practices within the context of developmentally at-risk children and families (Bronfenbrenner, 1980; 2005; Shonkoff, 2000, 2004; Sontag, 1996). This framework could support the IDP of BC in sustaining their integrated, interdisciplinary and inter-agency early intervention program practices that clearly reflect parents' necessities to address their children's needs. Therefore, early intervention programs' services targeting families will have a higher likelihood to attain the levels of effectiveness they aspire. Examples that could inform program practices and policy makers in conducting such evaluative practices in early intervention include recent mixed-methods evaluative research on programs fostering social and emotional development in schools (e.g., Schonert-Reichl Smith, Zaidman-Zait, & Hertzman, under revision). These authors have successfully reported adopting the "consumer oriented" methods

of data collection earlier described. Researchers examined teachers and children's rating of these programs. Additionally, they asked teachers and children to provide their comments on their perceptions of the effectiveness of such programs. The strong validity of their findings, together with the high across-coder reliability ratings attained confirm the importance and necessity to incorporate their evaluative lens to the "evidence based practice" models earlier described. These aspects focus on the importance of including all family members of parents in the IDP to participate in group discussions. The inclusion of children's voices is a key aspect in the examination of the perceptions of the experiences of early intervention, and deserves attention and further research. Children's voices could profoundly affect decisions undertaken at a policy level; for example, funding for services impacting on wait-times, availability and accessibility of services; and, legislation that follows the guidelines of evidence based-practices (Guhn, in press) and favours family-centred services over services that are professionally-based, and child-focused services.

Limitations of the Study

Limitations encountered in this multiple case study related to recruitment and data collection procedures; these included the following: Working with a specific targeted sample of English speaking parents; confronting the risk of attrition and discrepancy between number of mother and father respondents; incomplete or inconsistent demographic information; and, excluding children from interviews and focus groups. In terms of working with a specific targeted sample, the challenges in working with a targeted sample referred to two main issues: One was the restricted criteria utilized in order to identify, locate, and contact the selected families. These

criteria restricted the possibilities for sample selection; for example, families with English as a second language whose adult members have little or no spoken English language were not recruited. These families comprised, approximately 2.5% of the IDP program caseload (Office of the Provincial Advisor, 2004, 2006). Hence, the recruitment procedures followed in the present study potentially excluded a number of families not meeting this criterion. This researcher intends to follow up with studies that include participants experiencing language barriers –in terms of not being able to communicate and/or understand English. This research initiative takes a higher priority in listening to the participant respondents' voices as they urge service providers to continue to be inattentive to the needs of families with English as a second language (Office of the Provincial Advisor, 2004, 2006). Families with little or no English encounter two barriers. One may be shared with English speaking immigrant families, as it was the case with four parents in three families participating in the present study. Parents were unfamiliar to the different systems and programs; the second one is the language barrier as an obstacle in communication; for example, lack of vocabulary and, many times, not having similar terms or concepts in their language of origin. Therefore, the difficulties of immigrant families related to their experiencing trouble in finding about, contacting, and/or accessing the early intervention programs, and transitioning from one program to the next. The English as a second language topic also relates to issues in first and second language acquisition to be explored in the recommendations for further research, and further inform training practices for early intervention professionals.

In terms of recruitment from one specific IDP program, this restriction ended

up being beneficial in terms of the consistency observed for families in their accessing resources and programs located within the same geographical jurisdiction; however, it also limited the number of families potentially reachable through other programs, in different locations of the Province. This is an important point to highlight, given that some of the experiences shared by parents in terms of specific models of service delivery, or of agencies and programs accessed are somewhat bound by their geographical location, in a large urban setting in British Columbia's Lower Mainland. The experiences of parents receiving early intervention services through IDP in other regions of the Province, and in particular, in rural contexts requires of further examination. This aspect is of particular relevance when considering that some of the existing hubs in smaller locations in British Columbia may try to connect some of the health, child development, family services, and education resources, and how these connections would determine differences in case management (e.g. Brynelsen & Pace, 2005). However, in these locations, access to specialized resources; for example, health, could be limited (Chan, 2007; Goelman, et al., 2008; Sankaran et al., 2002; Synnes et al., 2006; Synnes et al., 2008). A preliminary study described parents in families receiving IDP services in a rural setting in British Columbia being approached about their perceptions on the help received through this program. The findings of this pilot study mentioned themes including "isolation" and "feeling lost" in terms of access to programs and resources (Verdiel, 1995). These preliminary findings draw additional questions to be explored in the section discussing recommendations for further research.

In terms of confronting the risk of attrition/ discrepancy between number of

mother and father respondents, no sample attrition was reported throughout the pilot or during final data collection stage. However, a discrepancy between the number of participants and the number of respondents was noted. The proportion of respondent Mothers over Fathers call for an explanation, particularly when all parents/caregivers had given their full consent to participate in the study. Five out of eight participants in the pilot stage were also respondents during the interviews. Of these five respondents, four of them were mothers. The limited participation of fathers 1, 2, and, 3 during the interviews limited the collection of data, in terms of missing these fathers' voices in Families 1, 2, and 3's accounts. In retrospect, the lower number of participant Fathers was understandable in the present study. This statement is based on the analyses of specific findings where participant mothers revealed the following: Mothers held the most solid and continuous relationship with consultants –all women as well--during the first three years of their child's life; and mothers were responsible for the logistics involved in finding most of their children's programs and services. When faced with the possibility of commenting on their experiences with the IDP, and subsequent programs, these two factors would have provided mothers with more familiarity with the topics explored in this study.

In terms of the low attendance for Focus Groups discussions, two mothers and one father were involved with the focus group discussions. Low numbers of parents during the two focus groups affected the style of conduction of the groups and shaped the discussion format into a discussion between two – to three- parents. Low numbers in the focus groups also led this researcher to use the introductory and final questions in the first, and second group, respectively as part of the interview sessions for

participants who did not attend these groups. Other reasons were behind the lower number of two of the participant fathers not being in the focus group discussions. These were explained in chapter 3, and further commented in chapters 4 and 5 of this study. Further research examining gender issues could explore aspects related to fathers and mothers perceived roles while receiving early intervention services with the IDP and during the subsequent transitions to other programs. This research would build on comments previously shared by participant mothers about what they defined as their assigned roles within each couple, following on recent research conducted with fathers and mothers of at-risk infants (e.g. Arockiasamy et al., 2008). It is important to note that at the time they were contacted, participant parents did not indicate that one of the members in their couple would not be respondents in group or interview meetings. Nevertheless, the complications encountered in scheduling for the focus group discussions confirmed that these families' weekdays and evenings were generally booked with family and work commitments. Therefore, even if they indicated their interest in taking part on these discussions, these group sessions could not represent a priority for them. Evening or weekend meetings would have added to their already heavy load as families, as they identified in their accounts (see chapter 4). An important aspect is that, given the characteristics of the discussions held, the structure of these focus groups did not include the children and their siblings. The findings of the present study revealed that, overall, participant parents were more inclined to participate in group-based activities that included their children. Even if child-minding was available (at home, or at the focus group session site) this was not identified for participants to be their first option at any time; the findings indicated, in

fact, that parents preferred no child minding at home, unless it was by a relative. Considering families' priorities in terms of attending groups where their children were also involved, future studies with parents and children in the IDP would involve family group situations that would include all members of the family. This limitation speaks to the exclusion of children in focus groups and interviews, discussed next.

As mentioned in the criteria for recruitment, this study did not contemplate conducting interviews and/or focus groups that included children, given the nature of the questions posed in finding out their parents' perceptions of their experiences of early intervention on child development and their parenting experiences. Two considerations guided this decision: One was the young age of some of the children's young age (between 2 years and 10 months, and 5 years old, in Families 4, 5, and 6). The second one was how the nature and severity of their delays would represent a challenge for some of the other children to understand and/or respond to the questions posed, and especially for children in families 1, 2, 3, and 4. Nonetheless, the inclusion of children's voices in research concerned with perceptions of experiences of early intervention, and examining the impact of these experiences. Therefore, it is important to provide a better understanding of the experiences and needs of these children and those of their siblings. Examples of related research include studies focusing on chronic health and/or developmentally at-risk children. In these studies, researchers have asked participants' about their perceived health and quality of life (Donohue, 2002; Schiariti, Klassen, Houbé, Synnes, & Lee, 2008; among others). Other studies have examined children with physical disabilities and asking participants about their perceived levels of inclusion and participation in family, school and community

activities (e.g.; Pivik, MacComas, & Laflamme, 2002). The findings from these works have provided invaluable insights on these children's perceptions on health, development, and/or inclusion issues. The inclusion of children in research examining the perceived experiences of early intervention is an aspect discussed in the recommendations for further research.

In terms of limitations with demographic information, these referred to about children retrieved through files was not always consistent, and information about families was limited. This researcher was aware that files with date of birth before 2002 had had the children and family's information manually entered, and stored in different file formats. Nevertheless, during the file review sessions, and two- to three-sets of member check sessions following interviews, participant respondents clarified inconsistent and/or missing information. This included demographic information about parents, including their age range (e.g., under-age or minor, adult, senior), marital status, level of education, first and other languages spoken at home (whether or not they were immigrant parents), and job status. Only Child 6's biological parents were under age – however, they were not Child 6's caregivers at the time of data collection, with Child 6 being under permanent custody of his paternal Grandmother.

Recommendations and Suggestions for Future Research

The findings of the present study raise issues in the identification, referral and follow-up for developmentally at-risk children. In terms of identification, one such issue is the consideration for a universal screening system for infants, toddlers and preschool children that uses highly specific and sensitive tools (Gilliam & Meisels, 2005; Ford & Dahinten, 2005; Frankenburg, 2003). Support for this consideration is

growing with current research in B.C., Canada, pointing at the benefits of universal screening (e.g., Houbé, 2008). In reference to the particular findings of this study, this system would contribute to drastically reducing the possibilities of missing the identification and assessments for similar cases to the ones illustrated in the present study, at critical times in their development. Systematic planning (e.g., Halfon et al., 2004) and not 'luck' --as expressed by one of the participant parents-- should guide servicing infants and young children (Brynelsen & Pace 2004). The findings of the present study concur with researchers, clinicians, professionals, and community practitioners stating the necessity to implement a primary level intervention system, based on universal screening (Coleman et al., 2006; Houbé, 2008). This system works with parents and service providers in probing and supporting their needs to identify what are areas in their children's health and development in need of follow-up, as well as how to address those immediate needs. In this regard, the results of this multiple case study contribute invaluable information to the design and implementation of a current population-based longitudinal study on the health, developmental, and educational trajectories of a cohort of children in British Columbia. This population-based study compares the health, developmental, and educational trajectories of "at-risk" vs. "non-risk" infants and children (Goelman et al., 2006, 2007, and 2008). The study, entitled *An Interdisciplinary Study on the Trajectories of At-risk Infants and Children* aims to link developmental and educational information of at-risk children from birth to age 9 years old. At the same time, the study takes a closer look at the similarities and differences in service provision for developmentally at-risk children and families through the different urban and rural communities in British Columbia.

Preliminary findings of the population-based study, and preliminary findings drawn from the pilot stage of the multiple case study have already contributed in the development of deliverables for a major project funded by Social Development Canada, described earlier in this chapter. The project comprises both the population-based longitudinal study and the present multiple case, retrospective study.

Finally, the findings of the present study open further questions for research. One area of research refers to the examination of Child A's specific "case" in terms of his late referral to the IDP and within the sample in this multiple case study of children with "established" and "suspected" risks. This case clearly illustrated how current criteria guiding referral for assessment and early intervention may mask the developmental needs of children with serious consequences for children and families. In this sense, the findings of the present study resonate with the findings of previous research conducted elsewhere (Rosenbaum & Stewart, 2007; Simeonsson, Leonardi, Lollars, Bjorck-Akesson, Hollenweger, et al., 2003; among others) about the advantages of utilizing the World Health Organization's International Classification of Functioning, Disability and Health for Children and Youth (World Health Organization, 2001). This system complements the Response to Intervention system described in chapter 2 of this study (RTI, Coleman et al., 2006). It focuses on children's functional abilities, documented through parents and ongoing service providers' reports; for example, early interventionists and teachers. The ICF strives to utilize both medical diagnoses and descriptions of the developmental status of the children that complement their diagnostic conditions. Two premises support this system. The first one is that the inclusion of both components ensures that referrals to

early intervention do not solely depend on medically driven criteria, but also on parents' and service provider's observations and assessments. The second one refers to service providers obtaining stronger and richer evidence about the children's needs for specific intervention and support services, a topic reiterated in the conclusions of the present study. Moreover, the specific "case" of Child A invites further exploration in reference to the service delivery models in place, and to the roles of IDP consultants. IDP consultants act as driving forces in supporting parents to address their concerns. These findings are consistent with those of the pilot study conducted elsewhere in British Columbia (Verdiel, 1995), reporting on 11 interviewed parents in a coastal, logging area in British Columbia. These parents consistently described the role of the IDP consultant as a crucial one in their obtaining assessment, diagnostic and therapy-based services for their children. Similar to Child A in the present study, parents insisted that the presence of the consultant ensured their children did not miss services they required at the time. These findings suggest the need for the conduction of further research investigating the experiences of consultants in their daily early intervention practices. Moreover, a specific topic of research could focus on enquiring on the interaction and mutual influence between of parents and consultants; for example, how these interactions shape parents' perceptions on their children's development, and how do parents' experiences on these interactions shape, in turn, consultants' practices. Such research would add an important component to the literature on reflective practices in family-centred, early intervention practices; for example, Santos (2005); Scarborough et al. (2004); and Wadbsy et al. (2001), among others. Moreover, investigation on these aspects looking at the different interactions

between parents and consultants, and children has the potential for important contribution within an ecological framework of training and professional practice.

Further to this research topic, an additional focus for research would include an in-depth examination of the specific differences between the IDP home visitation and the in-centre waitlist/monitoring service models. This examination would include an investigation on the lenses of parents on the differences that emerged in the present study regarding the specific characteristics of developmental screening, assessment and follow-up consultation from these two perspectives. For example, this study pointed at the diversity among children and families, and at their unique needs for services. Parents of children with “established” risks needed ongoing, direct service, and consultation that not only guided parents, but also that helped to implement – and/or to coordinate—current and future services. Parents of children with “suspected risks” indicated their satisfaction with having a professional and trustworthy ‘space’ where to formulate their queries and questions on their child’s development and milestones, and on the unique developmental needs at each stage of their child’s growth during the first five years of life. Finding out how and in what ways parents understand the information provided, however, is a key issue for further research. A crucial aspect in the exchange and transmission of information refers to the consideration of cross-cultural contexts in the research in early intervention (Ball, 2007; Bradsher, 1997); for example, families encountering barriers related to minority cultural backgrounds, and/or families facing challenges with spoken –and understood– English. In at least two regions in British Columbia, Canada, children speaking a second language at home sometimes outnumber children with English as their primary

languages by the time they enter kindergarten (e.g., Statistics Canada, 2001).

Exploring issues related to the perception of the experiences of early intervention with families representing these groups could yield important findings in addressing these families' needs for their children. The benefits of this information would surpass, by far, the challenges that might be encountered in conducting such research. A final consideration refers to families with more than one language, and the sense of loss experienced by parents including Mother 3 after she received instructions to speak in English to their children, both of them with multiple developmental disabilities, and not to use her first language. This mother's reflections of how hard it was for her, a second language speaker, not to teach their children, and talk to them in her mother tongue was interpreted in terms of the effect this recommendation had on this parent. The choice for the English language would ensure for their children that they would communicate with their father and with members of their immediate community, given the children limited understanding and oral language command, in general. At the same time, not learning their mother's first language implicated, for these children, an additional distancing from their mother's heritage, in addition to the limitations imposed by the physical distance from their mother's relatives in her country of origin. Additional investigation on cross-cultural and cross-language topics in early intervention is needed to further understand this topic.

Summary and Conclusions

This study addressed the issue of parents' perceptions of their experiences of early intervention program(s) in different aspects related to child development, program access, and issues related to work and family. In doing so, this study sought

to determine whether examining this issue would affect early intervention program development. The approach selected in order to meet this objective was to engage participants in commenting on their experiential issues with the IDP, and with subsequent early interventions, therapy-based, or support programs. These issues focused on topics including: program accessibility, and services availability; transitioning between programs; and, family issues that related to the participants' experiences with early intervention. This researcher anticipated the following: It would be meaningful for participant parents to relate to these experiential issues; and parents' accounts would provide insights to the research questions posed on their specific experiences with early intervention. The findings obtained through the interpretation of the participant respondents' accounts, the subsequent data triangulation, and the member check sessions completed have addressed the purpose and objective of the present study.

The principles of action-based research (e.g., Tedlock, 2005; Turnbull et al. 1998) have guided this ethnographic study (Miller et al., 2005). The research conducted through this study responded to an existing university and community collaboration, and partnership, with the IDP of BC (Goelman et al., 2005; Goelman & The CHILD Collaborative, in press). During the consultative process completed during the planning stages of the present study, representatives from other provincial agencies expressed their interest to conduct similar studies in order to gain specific insights into their programs practices. These agencies provide early intervention; preschool and/or school support services in BC. They include the Aboriginal Infant Development Program (AIDP), the BC Centre for Ability, and, the Supported Child

Development Program. Representatives from these agencies considered the potential for such research to influence their future program planning, and, eventually affect the policies related to their planning and service implementation (IDP Steering Committee, personal communication, January 25, 2005).

In closing, it is important to recognize how the findings of the present multiple case study are bound by time in their historical context (e.g., Brannen et al., 2004). At present, parents with developmentally at-risk children in different communities throughout British Columbia continue to advocate to their local government authorities for early intervention services that are more accessible and integrated from their children's birth and into their school-age years (e.g., Pivik, 2008; Representative for Children and Youth, 2008). Perhaps the issues raised by the participants this study suggests the need for further research concerned with early intervention practices and families across this Province, and elsewhere in Canada, and North America. At the same time, these findings coincide with the launching of a new provincial cross-agency theoretical framework guiding birth to school special needs legislation (Representative for Children and Youth, 2008). This initiative embraces the International Functional Classification of Disabilities (World Health Organization, 2001). As previously described, such classification is an alternative to the current system of labeling based on diagnostic categories for children with developmental disabilities. In its pilot phases, the proposed framework is currently targeting children with "established" risks and developmental delays. The framework moves away from the current system of label-driven funding based on medical-specific diagnostic categories. The provincial government agencies' adoption of such criteria would

enable the implementation of some of the collaborative principles of the Recognition and Response system (Coleman et al., 2006). In terms of the educational, child, and family services components, however, the proposed framework promotes a child-focused approach. Such approach moves away from the family-centred collaborative principles guiding the intervention models strongly supported by the findings of the present study. Family-centred collaborative principles are at the core of the innovative intervention models in early- and school-based intervention described earlier (see Appendix K). Departing from these principles at a time when research-based practices indicate their importance and effectiveness in the success of early intervention practices could potentially be a setback in the progression of service delivery for developmentally at-risk children and their families in British Columbia.

The concluding thoughts of this study are directed to the collaborative work conducted with the IDP program and the Office of the Provincial Advisor. The systematic “member checks” for validity purposes were carried out throughout each one of the stages of this study. These sessions, consisting on discussions and presentations, ensured the integrity of the data collection, preliminary data analyses and interpretation of these findings. Finally, the researcher would like to acknowledge the parents who contributed to the present study through their personal accounts. As a researcher, I am deeply indebted to the parents in sharing their very personal views and, in their doing so, opening their feelings and emotions with profound honesty. This level of closeness throughout the interviews allowed parents to reveal how they perceived their experiences of early intervention, and provided examples on how these experiences had an impact on their lives. Deep love and unconditional commitment to

their children guide these families in confronting their daily experiences and overcoming struggles, as expressed in their stories. This is the essential lesson learned throughout the present study. This is also a message parents intended to share. Parents expressed their hopes that their contributions would influence program planning and policy decisions around funding family-centred early intervention programs that, in turn, integrate subsequent preschool and school support programs. Their voices need to be heard loud and clear.

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APPENDICES

Appendix A: IDP Family Needs Survey

- The following checklist includes needs that are commonly expressed by parents of young children with special needs.
- Mothers and fathers often have different needs so we recommend that both parents each fill in the checklist if possible.
- Please read each statement.
- If it is definitely not a need for you circle #1.
- If you are not sure whether you want help in this area circle #2.
- If it is definitely a need for you at this time circle #3.

- Some of the needs you have may be met through your Infant Development Program or through other community resources recommended by the Infant Development Program. Some needs may be met by your family, friends or other community contacts, such as parent groups.
- This list can help you and your Infant Development Consultant to plan and to set priorities to meet your needs.

1: I Don't Need Help 2: Not Sure 3: I Need Help

NEED FOR INFORMATION

- (1) I need more information about my child's
- (2) condition or disability 1 2 3
- (3) I need more information about my child's behaviour 1 2 3
- (4) I need more information about how to teach my child 1 2 3
- (5) I need more information on how to play with or
- (6) talk to my child 1 2 3
- (7) I need more information on services that are presently
- (8) available for my child 1 2 3
- (9) I need more information about services that my child
- (10) might receive in the future 1 2 3
- (11) I need more information about how children grow
and develop 1 2 3

Appendix A (continued)

NEED FOR SUPPORT

- (12) I need to have someone in my family that I can talk to more about problems. 1 2 3
- (13) I need to have more friends that I can talk to. 1 2 3
- (14) I need to have more opportunities to meet and
- (15) talk with other parents of children with special needs. 1 2 3
- (16) I need to have more time just to talk with my child's
- (17) teacher or therapist. 1 2 3
- (18) I would like to meet more regularly with a counsellor
(psychologist, social worker, psychiatrist)to talk about problems. 1 2 3
- (19) I need to talk more to a minister who could help me deal
with problems.1 2 3
- (20) I need reading material about other parents who have a child similar to
mine. 1 2 3
- (21) I need to have more time for myself. 1 2 3

EXPLAINING TO OTHERS

- (22) I need more help in how to explain my child's condition
to his/her siblings. 1 2 3
- (23) I need more help in explaining my child's condition
to my parents or my spouse's parents. 1 2 3
- (24) My spouse needs help in understanding and
accepting our child's condition. 1 2 3
- (25) I need help in knowing how to respond when

Appendix A (continued)

(26) friends, neighbours, or strangers ask questions
about my child's condition. 1 2 3

(27) I need help in explaining my child's condition
to other children. 1 2 3

COMMUNITY SERVICES

(28) I need help locating a doctor who understands

(29) me and my child's needs. 1 2 3

(30) I need help locating a dentist who will see my child. 1 2 3

(31) I need help locating babysitters or respite care providers

(32) who are willing and able to care for my child. 1 2 3

(33) I need help locating a day care centre or preschool

(34) for my child. 1 2 3

(35) I need help in getting appropriate care for my child in our

(36) church or synagogue nursery during church services. 1 2 3

FINANCIAL NEEDS

(37) I need more help in paying for expenses such as food,
housing, medical care, clothing or transportation. 1 2 3

(38) I need more help in getting special equipment
for my child's needs. 1 2 3

(39) I need more help in paying for therapy, day care,
or other services for my child. 1 2 3

(40) I or my spouse need more counselling or help
in getting a job. 1 2 3

Appendix A (continued)

(41) I need more help paying for babysitting or respite care. 1 2 3

(42) I need help paying for toys that my child needs. 1 2 3

FAMILY FUNCTIONING

(43) Our family needs help in discussing problems

and reaching solutions 1 2 3

(44) Our family needs help in learning how to support

each other during difficult times. 1 2 3

Our family needs help in deciding who will do

household chores, child care, and other family tasks. 1 2 3

Our family needs help in deciding on and doing

recreational activities. 1 2 3

(45) **G. COMMENTS**

Adapted with permission from material prepared by Rune Simeonsson, Ph.D. and Don Bailey, Ph.D., Chapel Hill, North Carolina.

Appendix B: IDP Closing Information Form

Date: _____

Name of Parents: _____

Name of Infant: _____

Address: _____

DOB: _____

Age Referred to IDP: _____

Telephone: H _____ W: _____

Age on Leaving _____

Diagnosis at referral: _____

Diagnosis on leaving: _____

Assessments Done Service to Family Initiated by IDP

Date Assessment Used Done By _____

Future Consultation will be provided by: _____

Telephone: _____

Follow-Up Plans _____

Preschool Choice by Parents: _____

Reason for Choice: _____

Staff Signature: _____

Post survey sent: _____

Need a closing file procedure listed for your agency _____

Need a closing office procedure for your office _____

Appendix C: IDP Post Service Evaluation

Questionnaire

31

PARENT SURVEY 2 WHEN CHILD AND FAMILY LEAVE PROGRAM

1. The Infant Development Consultant (IDP) supported my family in developing and maintaining a positive relationship with my child.
1 No 2 Some 3 Great Deal
2. My knowledge of my child's development as a result of participating in the IDP:
1 Remained the same 2 Grew some from the information received 3 Grew a great deal above what I already knew
3. My awareness of other services in my community for my child and family as a result of participating in the IDP:
1 Remained the same 2 Grew some from the information received 3 Grew a great deal above what I already knew
4. My ability to help my child learn:
1 Did not improve 2 Improved some 3 Improved a great deal
5. The quality of services provided by the IDP to my family was:
1 Poor 2 Fair 3 Good 4 Excellent
6. The skills of the IDP Consultant were:
1 Poor 2 Fair 3 Good 4 Excellent
7. The Consultant was sensitive to the needs and wishes of my family:
1 No 2 Some 3 A great deal
8. To what extent did you feel you had control over the help you received from staff and / or the Program. Please indicate the amount of control you felt you had:
0 1 2 3 4 5 6 7 8 9 10
No Control A great deal of control
9. My privacy was respected by the agency / program:
1 No 2 Some 3 A great deal
10. What I liked best about the IDP? _____

11. What could we improve? _____

Infant Development Program of British Columbia
Policy and Procedures Manual 2004

Appendix D: Contact Letter(s) and Consent Form for Participants

Vancouver, _____, 2007

Dear Parent or Guardian:

This letter (*will*) follow(s) Ms. Dana Brynelsen's introductory letter letting you know about "Multiple Case Studies of the Children and Families in the Infant Development Program of British Columbia". This study will look at several children and families who participated in the Vancouver Infant Development Program of British Columbia between the years of 1997 – 2005, with children born between 1997 and 2002, and their experiences throughout these years. The purpose of the pilot study is to study the experiences of the children and their families while in the Infant Development Program. We hope that the results of this study will help to convince policy makers to invest more resources into IDP and to inform more parents about the benefits of the IDP.

In order to conduct this study we will, with your permission, collect different kinds of information using different methods. These will include interviews with individual parents; focus groups discussions with groups of parents; accessing children's IDP files in order to better understand the kinds of services and interventions different children received. If you agree to participate, Dr Hillel Goelman and Ms Mari Pighini, the researchers in this study, will review your child's IDP file, and you will be contacted through the Vancouver IDP to participate in a series of 3-5 interviews of approximately 30 – 45 minutes each, and to participate in a maximum of three focus groups with the researchers, other participants in this study and IDP staff. ***Please be assured that all information will be held in the strictest confidentiality and no identifying information on the children and families in this study will ever be revealed, including Ms. Pighini's doctoral dissertation that will be based on this study.*** Your case will be assigned a random Study ID so that personal information is always protected. In terms of data storage, all of the data collected will be kept in a locked file cabinet, and the data stored on protected computer files. You will be reimbursed for transportation (bus fares) and/or child care expenses that you may have incurred during your participation in the interviews and /or focus groups sessions.

You will receive an overview report of the study upon its completion. At no time will individual information about you or your family be shared with others and the results of this work will be published in a way that confidentiality will be completely protected. We would be very grateful if you would give us your consent to participate in this study by signing the attached consent forms for the researchers to have access to your child's IDP file (Consent Form (a)) and for us to contact you for interviews and focus groups (Consent Form (b)).

*Page 1 of 2, Contact letter
Version August 20, 2007*

Appendix D (continued)

We would like to stress that your participation is completely voluntary, and you can decide at any time to withdraw from the study and you without prejudice to your children's present or future involvement in the IDP. You may request at any time to have your information removed from our files, before, during or after the completion of this study. We are grateful for any information you feel able to give us.

If you agree to participate in this study, please complete and sign the attached consent forms (a) for your child's file and (b) for your own participation, and mail it back to us in the enclosed self-addressed and self-stamped envelope as soon as possible. If you do not wish to participate, please do mail the forms indicating your refusal to participate in this study so that we know you have received this request.

If you have any questions or concerns with regards to the contents of this letter and/or the consent form, please do not hesitate to contact Mari Pighini at (604) 827-5513 during office hours (collect); you may also leave a voicemail message on this phone number at any time (day/night). Please do leave a detailed message with a call back number where you can be reached. Mari can also be reached via email at mpighini@interchange.ubc.ca

If you have any concerns about your child's rights as a research subject, you may call the Office of Research Services at the University of British Columbia, at 604-822-8598. We realize that as a parent you are busy and have many responsibilities and your time will be limited. We are very grateful to you for agreeing to take the time to share your experiences and knowledge with us to help us improve our work with other families. Thank you very much.

Sincerely,

(Signed)

Principal Investigator:
Hillel Goelman, Ph. D.
Director, The C.H.I.L.D. Project
Senior Scholar
Human Early Learning Partnership
University of British Columbia
440-2206 East Mall
Vancouver, B.C. V6T 1Z3
Telephone: (604) 822 5232

(Signed)

Co-Investigator:
Mari Pighini, Ph.D Candidate
Research Coordinator,
The C.H.I.L.D. Project
Human Early Learning Partnership
University of British Columbia
440-2206 East Mall
Vancouver, B.C. V6T
Telephone: (604) 827 5513

Appendix D (continued)

Study Title: Consortium for Health, Intervention, Learning and Development (CHILD): A Study of the Children and Families in the Infant Development Programs of British Columbia – A Pilot Study

CONSENT FORM – Family (a)

Principal Investigator: Co-Investigator:

Hillel Goelman, Ph. D. Mari Pighini, Ph.D Candidate
Director, The C.H.I.L.D. Project, Research Coordinator,
Senior Scholar The C.H.I.L.D. Project
Human Early Learning Partnership Human Early Learning Partnership
University of British Columbia University of British Columbia
440-2206 East Mall 440-2206 East Mall
Vancouver, B.C. V6T 1Z3 Vancouver, B.C. V6T 1Z3

(PLEASE KEEP THIS PORTION FOR YOUR RECORDS)

I/ We have also kept copies of both the letter describing the study and this permission slip.

_____ Yes, I/ We give my permission to Dr Hillel Goelman and to Ms Mari Pighini, of The CHILD Project, to examine my son/daughter IDP files between the years of 1997 – 2005 for the exclusive purposes of this Study.

_____ No, I/ We do not give my permission to Dr Hillel Goelman and to Ms Mari Pighini, of The CHILD Project, to examine my son/daughter IDP files between the years of 1997 – 2005 for the exclusive purposes of this Study.

I/ We understand that by signing this form: a) I/we agree to participate in this study, b) I/we understand that my/our participation is completely voluntary, and that c) I/we can decide at any time to have my/our information removed from your files before, during or after the completion of this study.

Parent 1 Name: _____

Parent 1: Signature: _____

Parent 2 Name: _____

Parent 2 Signature: _____

Name of Son/Daughter: _____

Date of Birth of Son/Daughter: _____

Date signed: _____

Appendix D (continued)

PLEASE COMPLETE AND MAIL TO STUDY COORDINATOR IN SELF-ADDRESSED, SELF-STAMPED ENVELOPE (ENCLOSED)

I / We have read and understood the attached letter regarding the study entitled Consortium for Health, Intervention, Learning and Development (CHILD): A Study of the Children and Families in the Infant Development Programs of British Columbia (IDP of BC)

I/ We have also kept copies of both the letter describing the study and this permission slip.

_____ **Yes**, I/We give my permission to Dr Hillel Goelman and to Ms Mari Pighini, of The CHILD Project, to examine my/our son/daughter IDP files between the years of 1997 – 2005 for the exclusive purposes of this Study.

Parent 1 Name: _____

Parent 1: Signature: _____

Parent 2 Name: _____

Parent 2 Signature: _____

Name of Son/Daughter: _____

Date of Birth of Son/Daughter: _____

Date signed: _____

I/ We understand that by signing this form: a) I/we agree to participate in this study, b) I/we understand that my/our participation is completely voluntary, and that c) I/we can decide at any time to have my/our information removed from your files before, during or after the completion of this study.

_____ **No**, I/We do not give my permission to Dr Hillel Goelman and to Ms Mari Pighini, of The CHILD Project, to examine my/our son/daughter IDP files between the years of 1997 – 2005 for the exclusive purposes of this Study.

Please print your name(s): _____
(Please do not sign)

Appendix D (continued)

Study Title: Consortium for Health, Intervention, Learning and Development (CHILD): A Study of the Children and Families in the Infant Development Programs of British Columbia – A Pilot Study

CONSENT FORM – Family (b)

Principal Investigator: Co-Investigator:

Hillel Goelman, Ph. D. Mari Pighini, Ph. D. Candidate

Director, The C.H.I.L.D. Project,
Senior Scholar The C.H.I.L.D. Project

Human Early Learning Partnership

University of British Columbia

440-2206 East Mall

Vancouver, B.C. V6T 1Z3

Research Coordinator,

Human Early Learning Partnership

University of British Columbia

440-2206 East Mall

Vancouver, B.C. V6T 1Z3

(PLEASE KEEP THIS PORTION FOR YOUR RECORDS)

I/ We have also kept copies of both the letter describing the study and this permission slip.

_____ Yes, I /We agree to participate in this study and give my/our permission to Dr Hillel Goelman and to Ms Mari Pighini, of The CHILD Project, to contact us for interviews and for participating in focus groups for the exclusive purposes of this study.

I/ We understand that by signing this form: a) I/we agree to participate in this study, b) I/we understand that my/our participation is completely voluntary, and that c) I/we can decide at any time to have my/our information removed from your files before, during or after the completion of this study.

Parent 1 Name: _____

Parent 1: Signature: _____

Parent 2 Name: _____

Parent 2 Signature: _____

Name of Son/Daughter: _____

Date of Birth of Son/Daughter: _____

Date signed: _____

_____ No, I /We do not agree to participate in this study and do not give my/our permission to Dr Hillel Goelman and to Ms Mari Pighini, of The CHILD Project, to contact us for interviews and for participating in focus groups for the exclusive purposes of this study. Please **print**

name(s): _____

(Please do not sign)

Appendix D (continued)

PLEASE COMPLETE AND MAIL TO STUDY COORDINATOR IN SELF-ADDRESSED, SELF-STAMPED ENVELOPE (ENCLOSED)

I / We have read and understood the attached letter regarding the study entitled Consortium for Health, Intervention, Learning and Development (CHILD): A Study of the Children and Families in the Infant Development Programs of British Columbia (IDP of BC)

I/ We have also kept copies of both the letter describing the study and this permission slip.
_____ **Yes**, I/We give my permission to Dr Hillel Goelman and to Ms Mari Pighini, of The CHILD Project, to examine my/our son/daughter IDP files between the years of 1997 – 2005 for the exclusive purposes of this Study.

Parent 1 Name: _____

Parent 1: Signature: _____

Parent 2 Name: _____

Parent 2 Signature _____

Name of Son/Daughter: _____

Date of Birth of Son/Daughter: _____

Date signed: _____

I/ We understand that by signing this form: a) I/we agree to participate in this study, b) I/we understand that my/our participation is completely voluntary, and that c) I/we can decide at any time to have my/our information removed from your files before, during or after the completion of this study.

_____ **No**, I/We do not give my permission to Dr Hillel Goelman and to Ms Mari Pighini, of The CHILD Project, to examine my/our son/daughter IDP files between the years of 1997 – 2005 for the exclusive purposes of this Study. Please **print** name(s): _____
Please do not sign)

Appendix D (continued)

Vancouver, February 25, 2008

Dear Parent or Guardian:

This letter is in reference to a research project where you participated between the years 2005 and 2006. The title of the project is “A Study of the Children and Families in the Infant Development Program of British Columbia – Pilot Study.” The purpose of the pilot study was to study the experiences of the children and their families while in the Infant Development Program.

At this time, we are asking for your permission to conduct an additional file review of the file pertaining to your child with year of birth 1999. (The file revision session during the first stage of the study covered only the file with date of birth 2001). Once this file is reviewed, we would also schedule a visit session of approximately 45 minutes to one hour to go over the information collected. This is called a “member-check session.” The purpose of this meeting is to revise the accuracy of the information retrieved from the second file. In our initial contact letter we mentioned how this study would collect different kinds of information using different methods. Therefore, we would “match” the information collected through the interviews with the information retrieved from the files.

Please be assured that all information will be held in the strictest confidentiality and no identifying information on the children and families in this study will ever be revealed, including Ms. Pighini’s doctoral dissertation that will be based on this study. Please note that although confidentiality cannot be guaranteed in focus groups, all participants will be asked to keep information discussed confidential.

For this stage of the study, you will, once again, receive an overview report of the study upon its completion. At no time will individual information about you or your family be shared with others and the results of this work will be published in a way that confidentiality will be completely protected.

We would be very grateful if you would give us your consent to participate in this study by signing both attached consent forms, so that the researchers have access to your child’s IDP file (Consent Form (a)) and for us to contact you for file revision follow-up meeting, (Consent Form (b)).

If you do wish to give your consent to participate in this second stage of this study, we do need both consent forms (a) and (b) signed. If you do not wish to participate, please mark an X besides the “No” statement, indicating your refusal to participate in this study. In either case, please mail the forms back in the self-addressed and self-stamped envelope, so that we know you have received this request. (Please do not sign the forms should you decide to refuse to participate in this study.)

*Page 1 of 2, (re) Contact letter
Version 1, February 7, 2008*

Appendix D (continued)

We would like to stress that your participation is completely voluntary, and you can decide at any time to withdraw from the study and you without prejudice to your children's present or future involvement in the IDP. You may request at any time to have your information removed from our files, before, during or after the completion of this study. We are grateful for any information you feel able to give us.

We would also like to let you know that there is a possibility that we may want to re-contact you within the next 5 years for periodic updates regarding the study. Should this be the case, we will follow similar steps and procedures to ask for your consent to be involved at that point in time.

If you have any questions or concerns with regards to the contents of this letter and/or the consent form, please do not hesitate to contact Mari Pighini at (604) 827-5513 during office hours (collect); you may also leave a voicemail message on this phone number at any time (day/night). Please do leave a detailed message with a call back number where you can be reached. Mari can also be reached via email at mari.pighini@ubc.ca

Should you have any concerns about your child's rights as a research subject, you may call the Office of Research Services at the University of British Columbia, at 604-822-8598. We realize that as a parent you are busy and have many responsibilities and your time will be limited. We are very grateful to you for agreeing to take the time to share your experiences and knowledge with us to help us improve our work with other families. Thank you very much.

Sincerely,

Principal Investigator:

Hillel Goelman, Ph. D.
Director, The C.H.I.L.D. Project, Senior Scholar

Human Early Learning Partnership
University of British Columbia
440-2206 East Mall
Vancouver, B.C. V6T 1Z3
Telephone: (604) 822 5232

Co-Investigator:

Mari Pighini, Ph.D Candidate
Research Coordinator, The C.H.I.L.D.
Project
Human Early Learning Partnership
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440-2206 East Mall
Vancouver, B.C. V6T 1Z3
Telephone:(604) 827 5513

*Page 2 of 2, (re) Contact letter
Version 1, February 7, 2008*

5

Name of Program

[illegible]

391

Appendix F: IDP Referral and Waitlist Contact and Consultation Forms

133

☐ Must be on agency letterhead ☐

REFERRAL FORM

FAMILY INFORMATION

Name of Infant: _____
 D.O.B. _____
 Age at Referral: _____ Gender: _____
 Mother's Name: _____
 Father's Name: _____
 Address: _____
 Telephone (H) _____ (W) _____

Siblings

Name: _____ Age: _____
 Name: _____ Age: _____
 Name: _____ Age: _____

REFERRAL DATA

Date of Referral _____
 Referral Source: _____
 Reason for Referral _____

BIRTH INFORMATION

Hospital: _____
 Birth Weight: _____
 Gestational Age: _____

Agencies Involved

Foster Child: Yes _____ No _____
 Name of Agency _____ Name of Worker _____

Diagnosis / Additional Information

Assessments	Type	By Whom	Date

Physicians Medical Concerns

Does the family require an interpreter? Yes: ____ No: ____ Language: ____
 Are there any cultural or religious observances of which we should be aware?

Do you have any information that may indicate a potential risk to a home visitor?

Additional Comments: _____

Parent is informed about the IDP and wishes to participate.

Parent has been given the Parent Information Package. This consent is reviewed annually.

IDP Consultant Signature _____

Parent Signature _____

Appendix F (continued)

(Name of Program)

INFANT DEVELOPMENT PROGRAM INITIAL WAITLIST CONSULTATION

PRIORITY FACTORS ASSIGNED: _____

NAME: _____ D.O.B.: _____

AGE AT VISIT: _____ CONSULTANT: _____

DATE OF VISIT: _____

DIAGNOSIS: _____

PREGNANCY: _____ DELIVERY: _____

MEDICAL HISTORY: _____

MEDICATION: _____

IMMUNIZATIONS: _____

HEARING: _____

VISION: _____

FEEDING: _____

SLEEPING: _____

BEHAVIOUR: _____

OTHER AGENCIES INVOLVED; SERVICES CURRENTLY BEING PROVIDED:

PARENT'S CONCERNS : _____

OBSERVATIONS: _____

SUGGESTIONS:

REFERRALS, ETC. _____

OUTCOME: _____

Appendix F (continued)

IDP Waitlist Consultation and Contact Letters

Date: _____

Dear _____,

RE: _____

DOB: _____

It was a pleasure to meet with you for a Waitlist Consultation on _____
where you met with an

☐ Infant Development Consultant

☐ Consultant Pediatric Physiotherapist

We are confirming that you will be sent the The Ages and Stages Questionnaire to monitor your child's development every 2 months or as appropriate. You will have the opportunity to return to a waitlist session for review of your child's progress and [name of Infant Development Consultant], will be available by phone at. The I.D.P. Newsletter will be mailed to you and you will have the opportunity to register for and participate in any of the IDP group programs offered.

We will see you again at the Waitlist Session in _____.

Sincerely,

[signature]

Infant Development Program

CcIDP file

Referring Person _____

Appendix F (continued)

Date: _____

Dear _____,

RE: _____
DOB: _____

It was a pleasure to meet with you for a Waitlist Consultation on _____
where you met with an

☐ Infant Development Consultant

☐ Consultant Pediatric Physiotherapist

We are writing to confirm that you will be contacted by an Infant Development Consultant who will be available to begin seeing your child on their regular caseload. Every effort will be made to contact you by phone as soon as possible to schedule an initial home visit.

Additional
Information: _____
Sincerely,

[signature]
Infant Development Program

CcIDP file
Referring Person _____

Appendix G: Home Visitation Record, Family Contact Summary and Waitlist and Monitoring Group Summary

159

☐ Must be on Agency letterhead ☐

HOME VISIT RECORD

Name: _____ Date: _____

Progress on Current Program: _____

New Activities: _____

Materials Left: _____

General Remarks: _____

Follow-up: _____

Consultant Signature: _____

Infant Development Program of British Columbia
Policy and Procedures Manual 2004

FAMILY CONTACT SHEET

[illegible]**Ph: Phone****HV: Home Visit**

Phy: Physio

Oth: Other

Appendix G (continued)

(Name of Program) INFANT DEVELOPMENT PROGRAM WAITLIST CONSULTATION	
DATE:	
NAME OF PARENT/GUARDIAN:	
NAME OF CHILD:	AGE OF CHILD:
PARENT COMMENTS (Interests, needs or concerns)	
I.D.P. CONSULTANT:	
CONSULTANT SUGGESTIONS MADE:	
PHYSIOTHERAPIST SUGGESTIONS MADE:	
REFERRALS INTO COMMUNITY:	
PLEASE INDICATE (✓) IF YOU WOULD BE INTERESTED IN:	
<input type="checkbox"/> ANOTHER WAITLIST GROUP	
<input type="checkbox"/> ANOTHER CONSULTATION WITH THE PHYSIOTHERAPIST	
<input type="checkbox"/> OTHER	

Appendix H: Scripted Questions for Parents Interviews and Focus Group Discussions

Interview # 1:

Topic: What are some of the different experiences lived for the children's families in terms of access to resources and programs while in the Infant Development Programs?

Please elaborate on the following:

What were your experiences /have your experiences been through home visits with your consultant(s)? (E.g. establishing contact with your consultant(s); visiting schedules/time frames; level of comfort with relationship with consultant; asking/receiving for information, what type of information,asking/receiving additional therapies/services (link with question 2))

The type of support obtained to access other professionals (e.g.,*pediatricians, speech language pathologists..?*

Other programs, like Centre for Ability, Alan Cashmore Centre...?

Other related experiences that you can think of...(e.g. advocacy for respite care, support to access social assistance)

Interview # 2:

Topic: When transitioning from IDP to other programs,

What were some of your experiences in terms of obtaining information and support/assistance? (e.g., From other program(s) consultants? Given by Preschool teachers? Given by daycare staff? Given by Neighbourhood Houses/Family Places)
And,

Appendix H (continued)

What kind of therapy/support have you received/ have continued to receive throughout the preschool years and up to Kindergarten? (e.g. *Supported Child Development Program, Gateway society, Variety Child Centre...*)

Can you think of specific examples re: in what ways does this type of support has /has not been helpful for your child, your family -Why would you like/not like for it to continue?

Interview # 3:

Topic: More recently, when transitioning from Preschool/Daycare to school entry --Kindergarten and Grade 1,

What kinds of experiences do you recall in terms of accessing/understanding/working with the school system? (e.g. In terms of the relationship and support with your child's teacher; in terms of the type of support received from the Administrator; contact and linking with other support staff – classroom support worker/aide; in terms of referrals for screening/ assessment; in terms of follow up with individualized educational programs (IEP)

What kind of therapy/support have you received (and/or continued to receive) throughout Kindergarten and Grade 1? Eg Use similar examples to above re: contact and linking with other support staff – classroom support worker/aide; in terms of referrals for screening/ assessment; in terms of follow up with individualized programs (IEP); or help in requesting disability/special needs tax break.

Appendix H (continued)

Interview # 4

Topic: Coping

How would you describe the way your family has coped/continues to cope with all of these transitions/changes throughout these years? *(e.g., in terms of your child current developmental needs; given your present preschool/school demands; the demands from other family members)*

(How would you describe the way your family has coped/continues to cope) with the financial/work pressures that are linked to parenting a child at risk for developmental delays/ learning disabilities or diagnosed with developmental delays?

Appendix H (continued)

Focus Group #1

1. Introductions and comment: Dr Hillel Goelman (supervisor role), Mari Pighini (student role), parents (presently with IDP/have left IDP) *(Note: May have a separate focus group with IDP staff if the need arises for clarification in identified issues)*
2. Some background: Who are we and what are we doing with this study?
 - Our interest, previous work and collaboration, and commitment with/to IDP
 - What do we envision with this study
 - Mari Pighini's dissertation will be based on this study (explain/elaborate on the meaning of the term "dissertation")
 - Ensure privacy and confidentiality of all material discussed in this group
 - Sharing a written summary of what was discussed with the group after we finish the sessions

Questions for focus groups discussion:

- In what ways will/would it be...
 - meaningful
 - empowering
 - challengingfor parents who are working /have worked with IDP, to participate in a pilot study about parents' experiences with the IDP?
- In what ways do parents who have been involved with IDP share similar backgrounds?
 - For example: How/In what ways do parents with young children who are at risk for developmental disabilities get involved with IDP?
(Note: Not using the term "IDP Parent(s)" to avoid the risk of falling into "groupthink", according to Fontana & Frey, 2000)
- What would be some examples of the impact of the IDP program on families* working with the IDP (eg., *home visits, relationship with consultants, information shared.*) * Parents, siblings, extended family members
- How are/were these examples important/relevant
 - For families who are now participating in the IDP
 - For families who have already left the IDP
- Would you like to participate in a second focus group
 - to discuss, compare/contrast expectations vs lived experiences while participating in individual interviews with the researcher(s)?
 - to voice, discuss, compare and contrast interests/concerns/ideas and suggestions for further research in relationship to parents'/families' experiences in working with IDP
- Closure and thank you!

Appendix H (continued)

Focus Group #2

1. Welcome back!
2. Connecting and sharing about 'what's up' in the last few weeks / month/couple of months?

Questions:

- How were some of the experiences of individual interviews with [the researcher]?
 - In terms of sharing/thinking about/recalling these experiences?
 - Similarities/differences among parents experiences?
- In hindsight, as participants of this study, what would be some
 - interests
 - concerns
 - ideas
 - suggestions , to be discussed
 - in terms of further issues to examine about this study among current/former parents working with the IDP?
 - in terms of some other aspects that you consider meaningful/useful/ relevant to find out more about...?

3. Closure:

- Re-cap
- Reassure confidentiality/ group summary of the case study to be sent to their program as soon as it is finished
- Thank You!

Appendix I: File Reviews and Comments to Reviewed Files

	File Reviews: Families (Stage One) and Child A			
	0001	0002	0003 Child B	0004
			0003 Child A ²²	
Referral source	Pediatrician	Community Health Nurse	Community Health Nurse (Child B) Parents (Child A)	Pediatrician
Identified condition	Prenatal condition-syndrome	Medical congenital condition	Medical/developmental condition (Child B) Developmental delays (Child A)	Medical congenital/genetic condition
Medical history	Full-term baby; Ongoing medical/physical complications; treatments for medical conditions; conditions impact on physical well-being & developmental progression	Full-term baby; Required surgery and frequent hospitalizations; ongoing medical/physical complications; treatments for medical conditions; conditions impact on physical well-being & developmental progression	Small for gestational age baby; required neonatal intensive care hospitalization (ICU); medical complications required ongoing pediatric follow up (Child B) Full-term baby; normal birth-weight (over 3500 g); Peri-post natal complications; hospitalized for severe cold/infection; torticollis (physiotherapy) – by age 1 year. (Child A)	Full-term baby; required medical attention immediately after birth; medical complications; ongoing pediatric and other specialists follow up for medical, physical and motor concerns
IDP intake/Wait time	7 months (Wait time 3 months)	7 months (Wait time 2 months)	4 months (wait time 2 months) (Child B) 2 months (Child A)	2 months (wait time 1 month)
Developmental status	Moderate to severe developmental delays; identified special needs	Severe to profound developmental delays; medical concerns first identified at birth; parents concerns: motor development	Moderate to severe developmental delays; identified special needs by age 3 (Child B) Moderate to severe language, social/emotional delays, identified by age 3 (special needs by age 5) (Child A)	Moderate to severe developmental delays; identified special needs
IDP home visitation	Monthly, in addition to telephone conversations	Monthly (through IDP physiotherapy home consultation services)	Monthly, in addition to telephone conversations (Child B) Every 3 – 4 weeks , in addition to telephone conversations (Child A)	Monthly, in addition to telephone conversations
Therapy/ies	Physiotherapy	physiotherapy; Occupational Therapy	physiotherapy, (Child B)	physiotherapy

²² Files reviewed in Stage Two; Information from Interviews during Stage One.

Information fields	File Reviews: Families in Stage One			
	0001	0002	0003 Child B	0004
			0003 Child A	
Other Programs	Mother Goose Program	Hanen Language Program (language stimulation)	Parent –Infant Program (0-3); family program for parents and children with similar developmental condition (Child A, Child B)	Parent –Infant Program (0-3); Messy Art; sign language; Agency specialized in condition research program
Other Referrals	Speech and Language	BC Children’s (other specialists)	BC Children’s & Sunny Hill Health Centre,	Agency specialized in condition*; Vision, Language
Other Services	Therapy Program for SLP	Occupational Therapy (feeding)	Occupational Therapy (Child B) , Applied Behavioural Analyses, Speech (Child A, Child B)	sign language; occupational therapy*
Assessment	Gessell Developmental Schedules –overall gains (between 24-36 mos skills) at discharge	AIMS (Alberta Infant Motor Screening) 16-21%ile; Ages and Stages Questionnaire – increased awareness of surroundings by age 3; BC Children’s Report (Discharge)	Ages and Stages Questionnaire; psychological assessment – diagnosed condition (Child B and Child A)	OT ; Bayley scales; SLP- skills acquisition noted in all areas
Transition	Supported Child Development Program; identified “special needs”	Therapy Program; no daycare/preschool (until age 4)	[3-12]Program; identified “special needs”; Therapy Program; Social Worker; inclusive preschool	[3-12]Program; identified “special needs”; Therapy Program; inclusive preschool
Discharge	At age 3	At age 3	At age 3 (Child B) At age 3 yrs, 10 mos (Child A)	At age 3

Information fields	File Reviews: Families in Stage One			
	0001	0002	0003 Child B	0004
			0003 Child A	
Excerpts: Consultant's comments	"a delight" [re child]; "delightful" [re family]ll. Key words used in Home Visitation Records: "consult", "coach" "suggest", "strengthen"	Home visitation records reflect training and consultation re physical/motor domains	<p>N/A (Child B)</p> <p>Very positive comments about family's commitment to child and working in partnership with consultant (Child A)</p>	All home notes included greetings to family; Consultant 2 home visits include positive Individualized and personalized descriptors re consultant's joy to share child's skills and progress intertwined with a thorough description of developmental skills and follow up skills in addition to reflecting the parent(s) goals, eg: "parent appears to focus on <i>language development at this time</i> "; ongoing telephone visit record with updates
Family feedback:	Consultant's role: not an expert, but a collaborator; including sibling in process commending the staff for excellence	No letter with family feedback (refer to Response to reviews and artifacts sections)	<p>N/A (Child B)</p> <p>IDP Post Service Questionnaire (high ratings overall)</p>	N/A
Artifacts	None	Mini card-photo album; yearly Xmas pix; welcome back pix to consultant	N/A	N/A
Family profile (memo)	Family involved regularly with IDP consultant and physiotherapy services	Family involved with physiotherapy services through IDP. Perceived stress of family with medical condition; (parents did not pursue final diagnosis) Note family not involved in other groups or services, language, preschool	Family involved regularly with IDP consultant and physiotherapy services	Family involved regularly with IDP consultant and physiotherapy services

File Reviews: Families in Stage Two		
	5	6
New/old file <2002>	>2002	>2002
DOB yyyy/mm	23/01	2003/07
Gender 1 (Male), 2 (Fem)	1	1
Contact parent or guardian F, M, other	F & M	Other -grandparent (guardian); File revision session: Before Nov 2005, biological mother (IDP 1 program)
Date of referral yyyy/mm	23/04	01/11/2003 (to IDP 2); IDP 1 referral soon after birth (File revision session)
Reason for referral	Post natal complications: hypertonic, hyper-reflexic	Concerns re prenatal drug exposure/ file revision session: Mother's young age at birth (15 years old)
Referred by (name of Agency)	physiotherapist at Provincial Children Hospital	Ministry for Children/Families to IDP 1; IDP 1 to IDP 2 transfer (file revision session)
Age at Referral	2 months	4 months (IDP 2); IDP 1, 1 month old
Age at Intake	3 months for Waitlist group Monitoring (Wait list group); May_2003. Status according to SLP assessment report: Regular visits age 1, monitoring age 2-3 with IDP	4 months, transfer from another IDP program in the Lower Mainland (1 - 3 mos. In IDP 1)
On Waitlist Y/N	Y - Monitoring ongoing	Y - Monitoring ongoing
Wait Time	1 month for Waitlist (monitoring) group	1 month for Waitlist group group at IDP 2 program (Clarification after file revision session: Program's name used to be referred to as "monitoring" and/or " Waitlist group" at time)
Diagnosis at referral	None	None
Parental Concerns	Mostly gross motor development. At age 2; additional concerns re language development (expressive only) 18 mos asq: number of words ("maybe")	File revision rewording: No concerns expressed by biological parents when referred to IDP 1. Grandmother, at 4 months old (ASQ) noted: "jerkiness" [File revision session: Jerkineess concern associated with risk for epilepsy, running in paternal family.] Concerns arising through year 1: diet issues (reactions from certain foods) [file revision session: was not chewing food, as if chunks were too big when they weren't.; thumb inclusion; difficulty (pain?) swallowing; health conditions (fever reported a couple of times)years 2-3; hearing (loud); speech/language not always intelligible[file revision: to Grandmother 6 was intelligible but not to consultant; once [child] started to talk, he used full, clear words, no ' baby talk' words; would like vision tested even w/no concerns; falls sometimes (depth perception concerns/reason for testing confirmed during file revision session) (grandmother) -normal vision test results
Diagn. condition	N/A	N

File Reviews: Families in Stage Two		
Degree of diagnosed condition	Not reported	N/A
Prenatal Health Status	No concerns (file revision)	Exposed to drugs though pregnancy; exposed to cigarette smoking as well (no alcohol)
Gestational age in weeks	36	39 weeks [checked info in first IDP file]; Gestational age may have been after 39 weeks (39 weeks reported); labour had to be induced for over term - File revision session; discrepancy with file re over-term.]
Birthweight in grams	2930* (see medical interventions, file revision)	3850
IDP related services progress reports dates/ notes	Varied between 2003-2006: 2003 - average of once every three weeks; 2004: average of once each month (family away for 6 weeks); 2005: 5 times during year; 2006: discharged (March) *	Jan 10/04 (1st) Oct 01, 05 (2nd) July 17, 2006 (3rd) (refer to assessment results), Age 5 1/2 months- first consultation: suggestions re overall gross motor coordination and balance skills Age 26 months: suggestions for developing jumping skills - everything else at par with age expectations
Y/N IDP Screening	Yes	Yes
Screening Tool (IDP), e.g. Ages & Stages Questionnaire (ASQ)	Yes	ASQ
Screening dates (IDP)	ASQ	Jan 10, 04/ 4 months Ages and Stages Questionnaire (ASQ) April 3, 04/8 months Ages and Stages Questionnaire completed by grandmother (sent home 10 month Ages and Stages Questionnaire) July 10, 04/12 months Ages and Stages Questionnaire completed by consultant. Oct. 2, 04/14 mos Ages and Stages Questionnaire completed by grandmother Dec 4 04/16 months Ages and Stages Questionnaire - follow up with mailed 27-mos Ages and Stages Questionnaire Sept 30, 05/ 27 months Ages and Stages Questionnaire completed by grandmother Feb 19, 06/ 30 months Ages and Stages Questionnaire completed by grandmother Feb 25, 06/ 33 months Ages and Stages Questionnaire completed by grandmother August 5, 06/36 months Ages and Stages Questionnaire completed by grandmother [file revision: most times seen by a different consultant; several times program coordinator]

Y/N IDP Assessment	June 2003: ASQ (4 months corrected age); Feb. 04: ASQ 10 months corrected age; June 2004 14 month ASQ (15 month corrected age); Sept 2005, ASQ 18 mos. corrected age; Feb 2005, 24 & 27 mos. ASQ (at 22 mos. corrected age)	IDP physiotherapy (at least two physiotherapy consultants]
Assessment Tool (IDP)	physiotherapy assessment only	not identified (parents – no information file revision)
Assessment Dates (IDP)	AIMS	July 2006
Summary-IDP Developmental progress report/results	July 2003 AIMS (Alberta Inventory of Motor Skills) April 2003 (has records of skills attained in October 2003 and February 2004) 33%ile scoring	Mild motor delay (gross motor) associated with low muscle tone - Recommended: support from OT[File revision: GM 6 does not recall this information being transmitted to her]; vision check re possibility of difficulties with depth perception (would impact balance) =[file revision session: testing: normal results]; availability of services: SCDP Program upon family's request
Medical Status at Birth	Exchange transfusion at 36 weeks; Blood group incompatibility. Hyperbilirrubemia (jaundice). Re-admitted to hospital (respiratory condition); hypertonic/hyper reflexic.; at age 2 months (1 month chronological age (CA)) (this info in medical history only, file reviews revisions)	suspected re effects from prenatal exposure to drugs (crystal meth); exposed during first two trimesters but not during last trimester to drugs) - file revision session [younger sibling born with full NAS, instead]
Medical History & Interventions	File review revision added: Birthweight lowered to 2500g within 24 hours. Re-admitted to hospital (respiratory condition); hypertonic/hyper-reflex at age 2 months (1 month CA); monitored for cp and kernicterus due to high tone; File review revision added: CT scan at hospital at age 2 mos, normal results; MRI scheduled as of Feb 2004 (not completed- file reviews revision session); hearing tests: File review revision added: 1st hearing test with sensors on the back of [child's] head conducted at age 2-3 mos; follow-up hearing test conducted between ages 1-4 (results: normal) (Information update during file reviews revision session, March _ , 2008)	IDP referral for vision screening at age 36 months; see hearing referral; Referrals through GP (to Provincial Children's Hospital) for EEG - re concerns for epilepsy and vision checkups (regular checkups) + to rule out difficulties with depth perception
IDP Home Visit Frequency/Average	N/A, except for initial physiotherapy visit/assessment (File review revision added: Parents clarify: no HV at all; mismatch of info with child's file. Clarify info mismatch w/Coordinator)	N/A

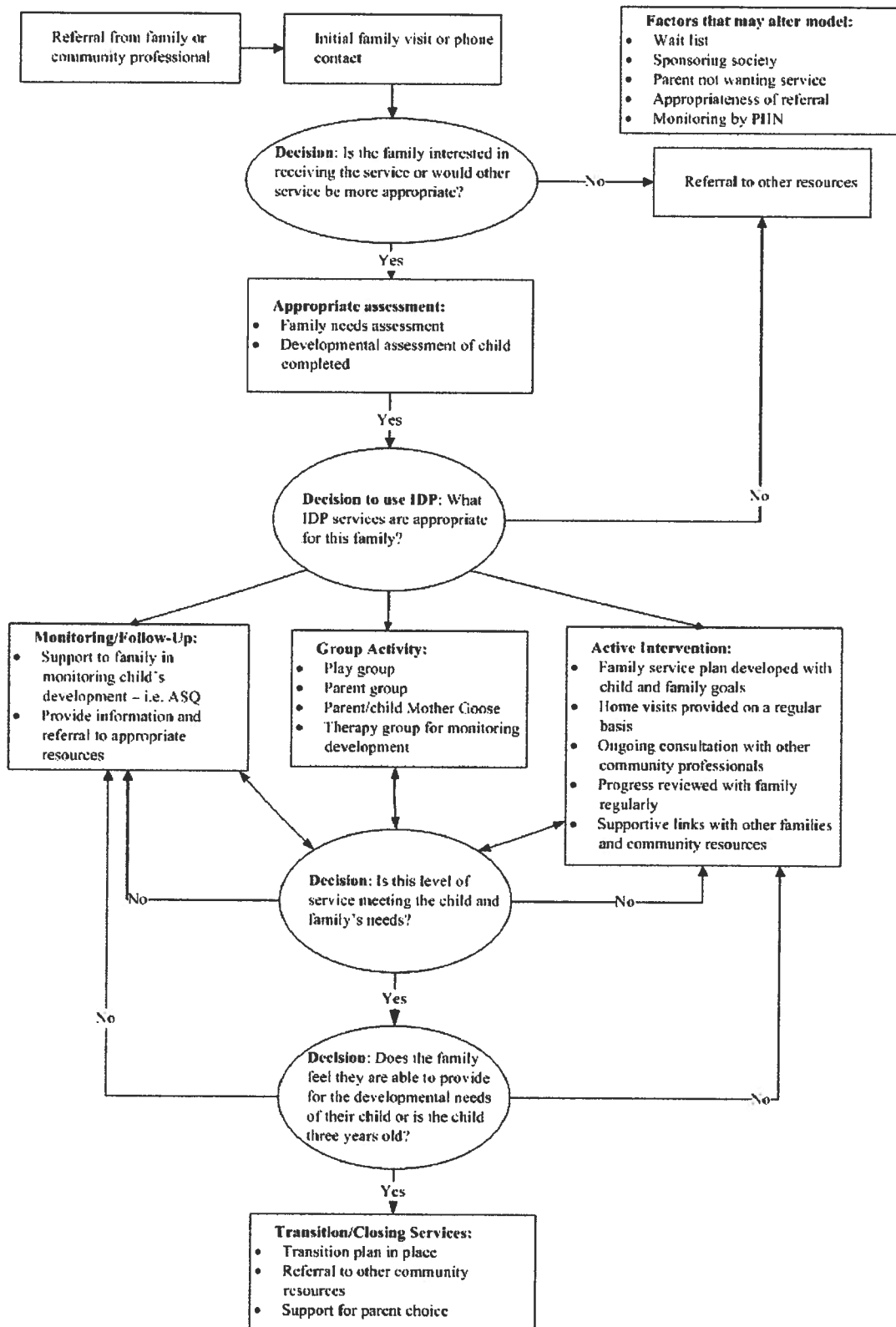
File Reviews: Families in Stage Two		
IDP Home Visit Information	N/A File reviews revision session - Move this section to next section entitled "Other IDP Related Services provided" as there were no HV	N/A File reviews revision session - Move this section to next section entitled "Other IDP Related Services provided" as there were no HV
Other IDP related services provided	Family attended Saturday Waitlist Groups (IDP consultant and physiotherapy). 1. physiotherapy assessment conducted at age 5 months corrected age for prematurity (6 mos. CA)(File reviews revision – deleted "home"); 2. 2nd and last physiotherapy consultation with Consultant # 5 (PT # 2) conducted Oct 2005. Summary (IDP Consultant # 5): Updated records re SLP visits; attending daycare; developmental skills within typically expected range ("normal limits"); physiotherapy report of home visit notes normal tone; recommendations for parents re exercises and get good quality shoes with support (exchanged "support" instead of "insole" and added "'good quality", (file rev. session)	Physiotherapy consultations for several Waitlist group consultations
Frequency of IDP related services	Varied between 2003-2006: 2003 - average of once every three weeks; 2004: average of once each month (family away for 6 weeks); 2005: 5 times during year; 2006: discharged (March)	Monitoring-approximately 1-2 per year (including final assessment)
SN support category and services	N	Not requested by family; SCDP Program contacted and recently closed file(discharge) see memo from interview 3 & 4; agreement was made that should child require services he would be followed up by SCDP Program/BC Centre for Ability, on an as-needed basis (refer to interviews)
Infant Monitoring Questionnaire 3+ Y/N?	N	N
Transition to school	N	N
Ministry Designation	N	N
Special Needs (SN) support category and services	N	N/A

Family composition	Father, Mother	Clarifying: Father, mother (child does not live with parents since he is 3 mos. old). Living with grandmother and 19 year old uncle; sees father/ uncle regularly; GM has custody.(File revision)
(SN)Family Members Y/N/	N/ Note re :Paternal uncle stutters	Y-father - suspected attention deficit disorder; history of epilepsy in paternal family; mother: drug use reported
Parents level of Education	Post secondary – university (F & M)	FILE REVIEWS REVISION session: Post-secondary – University (GM)
Income assistance Y/N	N	Child care and cihr subsidies
English first language Y/N	F – Yes; M- No	Y
Feedback/ \Comments/ Notes from Consultant re Home Visits/Waitlist Groups	Consultants and physiotherapy (PT) notes documented initial follow up re motor concern and during year two, re language concern and include reports from PT and SLP. Please refer to itemized list of visits re number of visits/consultants. Contact with same physiotherapist over time – except for a couple of visits while PT on holiday).	Consultants and physiotherapy notes indicate overall typical development; with specific notes on: motor skills (tone, balance, gross motor coordination); language development (speech fluency); attention- eye contact (and possibility of difficulties re visual perception)
Feedback, Comments, Artifacts (e.g. Notes/cards/pictures etc) from family after IDP discharge	N/A	N/A
Researcher's reactions to Home Visit/Waitlist Group Notes	Waitlist Group consultations reassuring In terms of child progress, especially in the area of motor development; there appears to be a concern with language development (re whether or not bilingualism interferes with child's language acquisition. File revision session added context to these comments. There are different styles in notes taken by the different consultants (seven); there appears to be some information overlap (e.g. telephone call records following up with families)	There is a sense of preoccupation with prenatal antecedents seen over notes; "mild" developmental concerns throughout are evident; no follow-up after 3 recommended -- yes suggested in physiotherapy assessment (confirmed file revision). There appears to be sense of heightened awareness from consultants with regards to certain areas of child's development, e.g., activity level and attention level. File revision and interview sessions revealed that guardian is aware of child having a high activity level, but to consider it within the expected levels for a child his age.
Researcher's reactions to Notes, Comments, Artifacts	N/A	N/A Clarification re notes and records with Program coordinator to ensure proper understanding of material to be transcribed (Feb 13, 2008)

Information fields	Comments to Reviewed Files					
	Families by Case Number					
	Stage One				Stage Two	
	1	2	3 (A and B)	4	5	6
Family profile (memo)	Family involved regularly with IDP Consultant and physiotherapy services	Family involved with physiotherapy services through IDP. Perceived stress of family with medical condition (still undiagnosed/ parents have not pursued) note family not involved in other groups or services, e.g. language, preschool	Family involved regularly with IDP Consultant and physiotherapy services	Family involved regularly with IDP Consult. and physiotherapy services	Family attended the Waitlist Monitor. groups for three years regularly w/ consultation and physiotherapist follow-up; Ages Stages Questionnaires completed with parents between and 4 times each year. Connection with Speech and Languages services from the health department in place.	Family first referred to IDP location where they received home visitation services. Upon transferred the present location of the IDP, guardian and child attended the Waitlist Monit. groups for three years regularly. Grandmother completed Ages & Stages Quest. between three and four each year . Occasional visits w/ physio-therapist follow-up
Responses to reviews	Home visit records reveal empowering/ proactive interactions between Consultant/ parents/ children information shared re child's syndrome, medical conditions, access to programs and resources and overall collaborative model of intervention services. Relationship between family Consultant/ program appears have been very close/attuned to family needs & wishes on Consultants' end parents growing	Family's connection with IDP through pictures and cards somehow reflects the relationship of trust nurtured and created with the IDP consultant while the family received IDP services; through interviews it was also learned that Mom, has also been in telephone contact with the IDP Consultant, keeping in touch & checking re tips and	Overwhelming number of medical-related information for this case: 3 specialists; in-depth/ consistent assessment process: combination of screening and formal assessments. Complex process of referrals and gathering documents for different programs and agencies –they are all in place; successful referrals/ intakes	Contrast between Consultant 1 and observed: although notes are very similar in content, i description of skills, resources and follow-up and both styles reflect family-centred care in their way of offering information and suggesting resources, Consultant 2 notes indicate a closer and more personalized relationship with family and their needs. From the notes and documentation on the file it appears that the main focus is on the child's month by month progress rather than more formal	Waitlist Group consultations reassuring In terms of child progress, especially in the area of motor development; there appears to be a concern with language development (re whether or not bilingualism interferes with child language acquisition) File revision session added context to these comments. There are different styles in notes taken by the different Consultants (seven); there appears to be some information overlap (e.g. telephone call records following up with families)	There is a sense of preoccupation with prenatal antecedents seen over notes; "mild" developmental concerns throughout are evident; no follow-up after 3 recommended suggested in physiotherapy assessment (confirmed file revision). There appears to be a sense of heightened awareness from Consultants with regards to certain areas of child's development, e.g., activity level and attention level. File revision and interview sessions revealed that guardian is aware of child having a

	to feel open and comfortable w/ Consultant/program as they discovered their child's needs. An equal partnership relationship where more than resources and skills where shared--in personal growth for the family and the Consultant	advice re other available resources and services. A first reaction for me is the confirmation of a relationship based on trust between the family and IDP		developmental assessments (except for motor and language development, concurring with parents' main concerns)		high activity level, but to consider it within the expected levels for a child his age.
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Appendix J: Model of Service for IDP of BC



Appendix K: Three-Tier *Response To Intervention* Model (RTI)

Appendix K, the “Response To Intervention Model” has been removed because of copyright restrictions.

The figure depicting the Response To Intervention Model consists of a three-tiered pyramid, with lights of shade from lighter (bottom) to darker (top). The pyramid is contained within a circle. Two arrows contour this outer circle. The three-tiered pyramid includes three captions. Starting from the base of the pyramid, Tier 1 “High Quality Teaching Environments;” Tier 2, “Group Interventions,” and Tier 3, “Individualized Interventions.” The circle surrounding the pyramid includes three captions, one on each side of the pyramid, and a third caption at the base of the pyramid. The caption “Recognition” (bolded, top), “Screening, Assessment, Progress & Monitor” (listed underneath) is on the left side of the pyramid. The caption “Response” (bolded, top); Research based Curriculum, Instruction & Interventions, is on the right side of the pyramid. The caption “Intervention Hierarchy” is included at the base of the pyramid.

The two contouring arrows around the circle and pyramid, in two hemispheres, include the caption “Collaborative problem-solving with teachers, parents and specialists” on both hemispheres. The arrows are also shaded from lighter to darker from the end to the tip of each arrow.

Source: The National Association of State Directors of Special Education, as cited by M. R. Coleman, V. Buysse, & J. Neitzel, J. (2006) In: Recognition and response: An early intervening system for young children at risk for learning disabilities. Chapel Hill, N.C. University of North Carolina, Frank Porter Graham Child Development Institute, p. 12. Available at: <http://www.ldonline.org/article/11394>

Appendix L: Ethics Certificate

Page 1 of 1



The University of British Columbia
Office of Research Services
Behavioural Research Ethics Board
Suite 102, 6190 Agronomy Road, Vancouver, B.C. V6T 1Z3

CERTIFICATE OF APPROVAL - AMENDMENT & RENEWAL

PRINCIPAL INVESTIGATOR: Hillel Goelman	DEPARTMENT: UBC/Education/Educational & Counselling Psychology, and Special Education	UBC BREB NUMBER: H05-80088
INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT:		
Institution UBC		Site Vancouver (excludes UBC Hospital)
Other locations where the research will be conducted: For data collection (file reviews and focus groups, similarly to data collection procedures in the original application) IDP Program (Vancouver Program Office Address: 3455 Kaslo Street Vancouver, BC V5M 3H4 p: 604-435-8168 f: 604-709-4563 Contact: Bonnie Barnes, Program Coordinator email:bbarnes@develop.bc.ca		
CO-INVESTIGATOR(S): Marl Pighini		
SPONSORING AGENCIES: British Columbia Ministry of Children and Families - "Consortium for Health, Intervention, Learning and Development (CHILD): A Pilot Study of the Children and Families in the Infant Development Program of BC" Social Development Canada - "Consortium for Health, Intervention, Learning and Development (CHILD): A Pilot Study of the Children and Families in the Infant Development Program of BC"		
PROJECT TITLE: Consortium for Health, Intervention, Learning and Development (CHILD): A Study of the Children and Families in the Infant Development Program of BC		

CERTIFICATE EXPIRY DATE: February 22, 2009

AMENDMENT(S):	RENEWAL AND AMENDMENT APPROVAL DATE: February 22, 2008	
Document Name	Version	Date
Consent Forms: Feb 8 IDP re- contact letter_version1_.doc	Version 1	February 8, 2008
Consent Form B IDP Study_revSept 2007, Version4_Feb808.doc	N/A	February 8, 2008
The application for continuing ethical review and the amendment(s) for the above-named project have been reviewed and the procedures were found to be acceptable on ethical grounds for research involving human subjects.		
Approval is issued on behalf of the Behavioural Research Ethics Board and signed electronically by one of the following:		
<p>Dr. M. Judith Lynam, Chair Dr. Ken Craig, Chair Dr. Jim Rupert, Associate Chair Dr. Laurie Ford, Associate Chair Dr. Daniel Salhani, Associate Chair Dr. Anita Ho, Associate Chair</p>		