

**EXPERIENCES OF FAMILIES LIVING IN RURAL AND REMOTE
BRITISH COLUMBIA WITH A CHILD
WITH A DISABILITY OR DEVELOPMENTAL DELAY**

by

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Abstract

The primary purpose of this study was to gain a deeper understanding and describe the unique experience of raising a child with a disability or developmental delay when the family lives in a rural or remote community, from the perspective of the parent. Symbolic interactionism theory served as the framework for the study that used ethnographic methodology to explore the experiences of parents in the distinct culture of rural and remote communities. Data collection included two face-to-face semi-structured interviews with eight parents living in four rural communities in BC. Data were categorized, and analyzed using a systematic approach. The analysis generated 13 subthemes that included exploration of topics such as: rural versus remote, the value of Interpersonal relationships, intense emotions, construction of disability, travel considerations and issues, financial burden, and service providers. These subthemes were then clustered under three broad themes which included: community experiences, parenting experiences, and family experiences.

The parents in this study raising a child with a disability or developmental delay identified their communities as small towns which included values such as opportunities to participate in outdoor, recreational experiences as well as the importance of strong interpersonal relationships with community members including the professionals that work with them and their child. The experience of having a child with a diagnosed disability or developmental delay was expressed as intensely emotional but the experience of parenting can be different if your child has a diagnosis versus the ongoing pursuit of obtaining developmental information. Distance to medical services plays a significant role in the experiences of these parents. Access to services impacts timely pre-natal and diagnostic information. There is an increase in the financial burden due to the necessity of

frequency of travel, increased costs to access resources and additional costs incurred when spending significant amounts of time away from home. Babies are born outside of local community and family separation may be prolonged if ongoing medical intervention is required. The local service provider, the Infant Development Consultant plays a significant role in creating a strong working alliance with parents as well as facilitating linkages to necessary services and supports.

Preface

This research was conducted as a part of this thesis was approved by the University of British Columbia Behavioural Research Ethics Board (BREB) under certificate number H10-01598.

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Chapter One: Introduction

Parental voices regarding issues of disability and developmental delay in rural and remote communities have been understudied and are under-represented in the literature. Of the limited literature on parents with children with disability the participants are most often living in urban centers (e.g. Baumbusch, 2009, Pighini, 2008) and the research uses quantitative approaches (Penz, D'Arcy, Stewart, Kosteniuk, Morgan, & Smith, 2007). Moreover, the experience of having a child with a disability or developmental delay is usually described as a burden, stressful, or a negative experience that requires remediation (Ferguson, 2002; Salvoviita, Italinna, Leinonen, 2003; Sen & Yurtsever, 2007). Because of the limited research on the parental experience of raising a child with a developmental delay or disability when living in a rural or remote community, the experience is not well understood. This limited understanding may lead to policy and practice that may not be responsive to or reflective of the needs of these families.

Key Terms

Disability. Disability takes on different meanings in different contexts. For the purposes of the present study a disability is “a substantial limiting physical or mental impairment which affects basic life activities such as hearing, seeing, speaking, walking, caring for oneself, learning or working” (Coleman, 2006, p.118).

Developmental disability. A developmental disability is described as “any physical or mental condition (such as mental retardation, cerebral palsy, epilepsy, an autism spectrum disorder, or a neurological disorder) that begins before the age of 22 years, causes the child to acquire skills at a slower rate than her peers, is expected to continue indefinitely and impairs the child’s ability to function in 3 or more

developmental areas, such as communication, learning and mobility” (Coleman, 2006, p. 112).

Diagnosed disability. As used in the health care and mental health care systems in British Columbia, diagnosed disability indicates that the disability has been diagnosed by a medical professional or other credentialed professional (e.g., psychologist).

Developmental delay. The term developmental delay describes an infant or young child who is not achieving skills in the typical pattern or within the age- expected time frames. The infant or toddler is not demonstrating skills expected at his or her chronological age. For some children the developmental delay is indicative of a particular developmental disability and the child will later be diagnosed with disability, while other children will eventually catch up to their typically developing peers (Coleman, 2006).

Parent. For the purposes of this study, parent is defined as the primary caregiver who lives with the child the majority of the time. This definition is inclusive of foster parents, adoptive parents, and grandparents among others. The “parent” in this study is a person who identifies as the primary caregiver for the child (or children) in the family. This designation is not gender- specific with both mother and father participants in the study.

Infant Development Program (IDP). The Infant Development Program of British Columbia is a home visiting, early intervention program that serves families with children who have disabilities or developmental delays under the age of three years.

Rural and Remote. Rural refers to people living outside the commuting zones of larger urban centers. These centers are referred to by Statistics Canada (2009) as

Census Metropolitan Areas (CMA, population of 100,000 or more) and Census Agglomerations (CA, population of 10,000 -99,999). The current definition of rural states that rural is the population outside settlements with 1,000 or more population with a population density of 400 or more inhabitants per square kilometre (Statistics Canada, 2009). Statistics Canada also uses a more sophisticated measure of rural by considering not only the population but also the level of influence exerted by nearby urban areas by determining the percentage of the residents who commute regularly to the nearby urban center; this is called the MIZ (Metropolitan Influenced Zone) (Ostry, 2009). For the purpose of this study and ease of identification for participants and community agencies, use of the Statistics Canada (2009) designation of an “0” as the second identifier in the postal code, which is how Statistics Canada identifies rural and remote communities was used to identify rural and remote communities.

Purpose of the Study

Previous work in British Columbia utilized a retrospective, multiple case study approach to examine the experiences of parents with early intervention services in a large urban center (Pighini, 2008). Key findings indicate parents experience challenges transitioning across multiple programs, children without a specific diagnosis faced challenges in accessing services, and parents highly valued a close relationship with a knowledgeable service provider. This previous research was influential in the development of and served as a foundation for the present study.

The purpose of the present study was to gain a deeper understanding of the experiences of parents living in rural and remote communities in Northern and the Interior regions of BC currently receiving services from the Infant Development

Program (IDP) of British Columbia. The study explored parents' experiences parenting a child with a diagnosed disability or identified developmental delay

In this qualitative study not only was the parenting experience of raising a child with a disability explored but this experience was also explored within the context or "culture" of a rural or remote community. The research examined in this study was done within a geo-ethnocentric approach where living in rural and remote communities is often reported as a more negative experience than living in an urban setting. Also research on the experience of parenting a child with a diagnosed disability or developmental delay is often viewed as negative due to the perceived high stressors these families face and their possible need for specialized services (Smith, Humphreys, & Wilson, 2008). It is important to document through the voice of parents a fuller understanding of their experience parenting a child with disability or developmental delay in rural and remote areas.

Research Question

What are the parenting¹ experiences of parents living in rural and remote British Columbia who are receiving services from the IDP of BC because they have an infant or child under the age of three with a diagnosed disability or identified developmental delay?

¹ An attempt was made to include both mother and father participants in the study. However, ultimately there was only one father participant in the study. However, the term parent is used with the rationale for this decision detailed in Chapter 3.

Chapter Two: Review of the Literature

In this chapter the literature on parenting children with disabilities is examined. The parent stress and coping literature is highlighted to illustrate the importance of the social context of parenting, subsequently leading to an overview of Bronfenbrenner's socio-ecological theory. The study is situated within the literature on rural and remote context primarily derived from the health and education literatures. The chapter concludes with highlights of the literature on disability as a social construct.

Parenting Children with a Disability

Raising a child is one of the most challenging experiences in life. Most parents report feeling unequipped and stressed in dealing with the daily challenges of parenting, and comment that time and energy demands are strongest when children are very young (Crill-Russell, 2004; Dahinten, Timer, & Arim, 2008). This is particularly true for parents raising children with disabilities. Parents of children with disabilities often take on the responsibility of care for their child as well as creating friendships and building acceptance in the community (Hanvey, 2002). Children with disabilities are also more likely to be living in families impacted by poverty (Hanvey, 2002). Work force participation or career advancements are often limited due to extra demands including time away from work to care for their child. In addition, families of children with disabilities also face extra costs related to the needs of the child such as special equipment, special diets, medication, supplies, transportation and travel (Hanvey, 2002; Simpson, 2009; Valentine, 2001).

Parental reactions to having a child with a disability are described in the literature as shock, denial, suffering and depression followed by feelings of guilt, indecision, anger, and shame (Sen & Yurtsever, 2006). This wording is analogous to

wording used in the literature on grief and loss through death. A study conducted in Turkey with mothers with primary responsibility for 103 children with disabilities reported that their social lives, work lives, and family relationships were affected. More than half of the mothers reported feeling sad, overwhelmed, and angry. Two in five of these mothers reported being blamed by family members for having a child with a disability. The majority of the mothers reported that they received inadequate practical or emotional support (Sen & Yurtsever, 2006).

Mothers of children with disabilities report significantly more physical health complaints, higher levels of depression, stress, anxiety, and emotional distress than parents of non-disabled children (Hanson & Hanline, 1990; Hastings, Kovshoff, Ward, Espinosa, Brown & Remington, 2005; Kelso, French, & Fernandez, 2005; Pelchat, Ricard, Perreault, Saucier, Bethiaume, & Bisson, 1999; Trute & Hiebert-Murphy, 2005). While most of the literature addresses the impact on the mother who is parenting a child with disabilities, the literature also reports significant differences between the experiences of fathers and mothers. Reports of stress on fathers are more likely to be linked to the financial implications of caring for a child with disabilities (Pelchat, Ricard, Perreault, Saucier, Bethiaume, & Bisson, 1999). Several studies have indicated that a father's well-being is mediated or tied to the mother's state of well-being whereas the reverse has not been reported (Hastings, Kovshoff, Ward, Espinosa, Brown, & Remington, 2005). While considerable research focus is on the parental relationship and the physical and mental health of the parents other variables are also examined.

Type of disability, family income, and family structure are also examined in the family and disability literature. Researchers looking at the divorce rate of parents who have children with Down Syndrome, for example, raised a number of interesting

considerations. Urbano and Hodapp (2007) discuss the 'Down Syndrome Advantage', the idea that parents and families with children who have Down Syndrome cope better than parents and families of children with other disabilities due to specific qualities characteristic of a child with Down Syndrome. For example a child with Down Syndrome is assumed to be friendly and to have fewer challenging behaviours; also, the parents have access to extensive information about the disability as it has been widely researched (Stoneman, 2007). Parents of children with diagnosed disabilities report differing levels of stress as compared to higher levels of stress or dissatisfaction for parents who have a child without a diagnosis or child with externalizing behavioural characteristics (Wang et al., 2004). The more severe the disability, the lower the quality of life according to reports of parents' perceptions (Wang et al., 2004).

Urbano and Hodapp's (2007) research further examines family function as related to parent and family factors separate from the child. Family factors such as parental age, SES, and education levels were explored as well living in a rural versus urban area. As there is extensive literature that emphasizes the negative impact that having a child with a disability can potentially have on a family (Ferguson, 2002; Hastings, Kovshoff, Ward, Espinosa, Brown, & Remington, 2005; Kelso, French, & Fernandez, 2005; Pelchat, Ricard, Perreault, Saucier, Bethiaume, & Bisson, 1999; Trute & Hiebert-Murphy, 2007), it is important to carefully consider the framework from which the parenting experience is described as well as the underlying assumptions about disability. Research on parenting a child with a disability has historically focused on the negative implications, emphasizing parents sorrow, marital breakdown, and family instability. Turnbull and Turnbull (1993) have grouped this pathogenic focus into two general types: pervasive negative generalization (focusing on the negative,

dysfunctional or pathological elements of family life) and negative interpretation (attributing negative interpretation to positive findings). The researcher's construction of disability influences the approach and interpretation of the research.

Two studies reviewed use the phrase "between joy and sorrow" (Kearney & Griffin, 2001. p.582; Trute & Heibert-Murphy, 2002) to describe the experience of parenting a child with a developmental delay or disability. An Australian study utilizing qualitative interviews with six parents of children with significant developmental disabilities reported that while the parents experienced anguish and sorrow they also spoke of hope, love, strength, and joy (Kearney & Griffin, 2001). These findings are consistent with a longitudinal study by Trute and Heibert-Murphy (2002) with a random sample of 87 families with children with developmental disabilities using standardized self-report measures of family function and stress, initially taken when the children were five years old and again seven years later. The parents shared their own experiences that included both the positive and negative appraisal of their situations. A key finding in this study according to the author was the significance of the parental appraisal and perception of the situation: the parental perception of the situation greatly influenced the parents' experience.

There is research that speaks to the positive contributions that having a child with a disability has on a family (Abbott & Meredith, 1986; Hastings & Taunt, 2002; Stainton & Bessier, 1998; Summers, Behr, & Turnbull, 1989). A considerable amount of the research is anecdotal reports and family narratives. This research indicates that the person with disabilities gives the family strength, tolerance, faith, compassion and professional and personal growth and that having a person with disabilities created lives that were enriched and made more meaningful (Summers, Behr, & Turnbull,

1989). Turnbull, Behr, and Tollefson (1986, cited in Summers, Behr, & Turnbull, 1989) interviewed 18 parents who had children with disabilities and 10 parents who had children without disabilities. This study identified 14 categories of positive contribution that parents said their children with disabilities were either sources of or reasons for. The list included: greater happiness, greater love, strengthened family ties, strengthened religious faith, expanded social network, greater knowledge about disability, learning not to take things for granted, learning tolerance and sensitivity, and increased personal growth. Abbot and Meredith (1986) found that 88% of the parents in their study reported positive contributions by their child with a disability such as more patience, compassion and greater appreciation for the small and simple things in life; as well, this experience created a closer and stronger family.

Research by Green (2007) also discusses the valuable benefits to having a child with a disability. Green suggests that it is the socio-structural constraints associated with caring for a child with complex needs that places an additional burden on the mothering role, but most mothers perceive valuable benefits such as increased self-understanding and confidence. Green puts forward the idea that much of the research looks at the “subjective burden (emotional distress)” and de-emphasizes the “objective burden (socio-cultural constraints)” and the benefits of this experience. Green titles her paper, “We’re tired, not sad” indicating that research needs to be conducted within the context of social cultural beliefs around disability and the additional burden of perceived stigma regarding disability rather than pathologizing parental responses in isolation.

Stress and Coping Model

Extensive bodies of literature explore the variables associated with an individual's experience of having a child with a disability and his or her reactions and adjustments to what is considered a stressful situation. (Folkman, 1984; McConachie, 1994; Saloviita, Italinna, & Leinonen, 2003; Turnbull et al., 1993) While an exhaustive analysis of all the stress literature is beyond the scope of this review, a discussion of the Process Model of Stress and Coping originally developed by Lazarus and colleagues in the 1960s (Beresford, 1994) provides a useful framework for examining some of the important elements of stress and coping considered in this study.

The model illustrates the multiple stages of decision making that a parent goes through upon hearing that they have a child with a disability or developmental delay. The first stage is called "primary appraisal", where parents ask; What is the meaning of this event? How will it affect my well being? The model suggests three possible appraisals of the situation; irrelevant, stressful or benign-positive. If the parent appraises this situation as a stressful event they determine if is harmful or a challenge. This leads to the "secondary appraisal" stage where parents ask; What can I do? What will it cost? What do I expect the outcome to be? In order to answer the questions in the secondary appraisal stage, parents must access both personal coping resources as well as socio-ecological coping resources. This leads to engagement in problem-focused strategies or emotional focused coping strategies. When an outcome is obtained it is then reappraised with questions such as: Has the stress changed? and Am I feeling better?. This is a cyclical process that parents may engage in over and over according to the model.

The process model of stress and coping by Lazarus is frequently cited in the literature on parenting children with disabilities. (e.g., Beresford, 1994; Kelso, French, & Fernandez, 2005). As outlined, the model suggests that parents may see the birth of their child with a disability as irrelevant, stressful, or benign-positive. Research most often explores the experience of parents when they see this event as stressful. This researcher's review of the literature did not identify studies where parents state that the birth of their child with a disability is irrelevant. This may be because parents do not identify the birth of a child with a disability as irrelevant or it may be because it has not been researched. If the event of the birth of a child with a disability is seen as irrelevant, there may be implications for families in terms of accessing services and early intervention. The family may be happy about the birth of the child but the fact the child has a disability is seen as irrelevant. Consequently, the parents may not actively seek remediation or support services. Perhaps these behavioral reactions of the parents are then seen by others as denial but perhaps it is just a non-event or not a concern in this family's life. A parent's appraisal of the event also influences a parent's information-seeking behavior and this is described as one of the problem-solving strategies (Pain, 1999). Currently, there is a shift in the research that considers the possibility that parents may look at having a child with a disability as a benign-positive event (Helff & Glidden, 1998).

If the family identifies the birth of their child as a stressful event or interprets it as a threat with potential harm, the parents then start to access their personal coping resources as well as their social support resources. Accessing external support resources and accessing internal personal coping resources may then mediate the

family's secondary appraisal through exploration of questions such as: What can I do? What will it cost? What do I expect the outcome to be?

These questions and the subsequent answers are influenced by the internal coping resources of the family as well as the access to availability of resources within the community and the location of that community within a larger societal context. Uri Bronfenbrenner first introduced a model of ecological study in the 1970s (Bronfenbrenner, 1994) and articulated that there are levels of influence on family which impact a child's and family's development. Distinct differences exist because of where a family lives. Urban or rural environments provide different 'exosystems' and it could be argued that rural versus urban environments have distinct 'macrosystems' as well. These are terms used in Bronfenbrenner's socio-ecological model and explanation of the "spheres of influence" on individuals.

Ecological Influences on the Child and Family

A child and family do not develop in isolation (Goelman, Pivik, & Guhn, 2001). Bronfenbrenner (1994) suggests that in order to better understand human development one must consider the entire system where growth occurs. Bronfenbrenner explains human development as the progressively more complex interaction between a human being and the environment. There is a bi-directional reciprocity in interactions between humans and the environment which becomes increasingly more complex over time. His theory articulates the view that five socially organized sub systems are nested within each other and have influence on the developing human. He therefore refers to this model as the socio-ecological model of development (Bronfenbrenner, 1994).

The most proximal environment to the child is the microsystem, where the child and family live and where they have face-to-face interactions and influence

(Bronfenbrenner, 1994). For an infant or young child this environment consists of primary caregivers and other family members. For infants and children in this study, the microsystem includes not only the infant-mother-father triad, but also grandparents, siblings, the hospital setting and staff if the child requires further medical attention, staff at a child development center, and the early intervention staff in a home visiting program.

Surrounding the microsystem is the mesosystem which includes the interactions between the various microsystems that the child participates in (Bronfenbrenner, 1994). The mesosystem for families in this study includes the child-care centers which support the child and family. Families may be involved in local church or charity organizations and these organizations may help them raise money to travel to specialized services. Surrounding the mesosystem is the exosystem. The exosystem includes factors in less immediate social or political settings where a person may not have an immediate role can nevertheless experience a significant but indirect influence (Bronfenbrenner, 1994). For example when living in a rural community where the economy is based on the declining forest industry, one parent may need to work away from home yet the absent parent has a direct influence on the family life. A parent with a child with a disability may need to quit work to take care of the child. Surrounding the exosystem is the macrosystem encompassing the attitudes and beliefs of the culture such as religion, ethnicity, or living in a conservative or liberal political environment (Bronfenbrenner, 1994). The parent may not play an active role in the macrosystem but is directly influenced and impacted at all levels. For example, the current government's (macrosystem) cutbacks to social programs reduce services to families with children with disabilities; consequently, the family may need to move into the grandparent's

home for assistance with childcare and respite. As the grandparents age, the mother may take on more responsibility of caring for the grandparents, increasing her responsibility. All are impacted by the 'chronosystem'. Bronfenbrenner uses the term chronosystem to describe the pattern of processes and transitions over the lifespan (Bronfenbrenner, 1994). This chronosystem is the bi-directional reciprocity of interactions between and amongst the systems across time.

The socio-ecological model of development provides a useful framework to explore the complex variables that exist for families who have children with disabilities or developmental delay. It is important to remember that families develop within complex and interconnected systems. Seligman and Darling (1997) refer to families raising children with disabilities or developmental delays as 'ordinary families with special children'. As highlighted earlier in this review, the literature on experiences of families who have children with disabilities or developmental delay has been primarily conducted with parents living in urban centers. The present study will focus on parents residing in rural and remote communities. Review of research conducted in rural and remote settings begins to provide a context within which to place the experiences of these families.

Understanding the Rural Context

Given the earlier discussion of the socio-ecological model it is important to explore the literature on rural and remote life for the purposes of this study. The social context is a contributing factor in providing coping resources for parents which in turn influences their secondary appraisal of having a child with a disability, according to the process model of stress and coping (Beresford, 1994). There is limited literature on

rural and remote life and sometimes contradictory evidence of the experiences of parents in rural and remote communities.

There are competing definitions of rural and remote depending on country and purpose of the study. Between 19 to 30 percent of Canada's population live in rural areas depending on the definition (Statistics Canada, 2009). The definition of rural is based on land outside of urban areas that are sparsely populated or those areas with a population concentration of less than 1,000 and a population density of up to 400 per square kilometre (Statistics Canada, 2009). Classification of rural using the Metropolitan Influenced Zone (MIZ) considers the influence of the larger urban center on the population by determining the percentage of people that commute to the urban center on a regular basis (Ostry, 2009; Statistics Canada, 2009). Any community with fewer than 40 residents commuting is considered remote. It is important to consider the definition in light of what is being studied.

Thomlinson, McDonagh, Crooks, and Lees (2004) acknowledge that there is no consensus for the definition of rural but suggest that rural regions differ from urban centers in geography, distance from markets, population density, and reliance on primary resources. Their ethnographic study using semi-structured interviews with 55 persons ages 19 to 84, examined the participants' beliefs, values and practices related to health in two rural regions of western Canada. Participants defined health as a "holistic relationship between the physical, mental, social, and spiritual aspects of one's health" (p. 259). Residents in the study were more likely to engage in fewer health seeking behaviors meaning they only went to the doctor after they had been sick for many days, and tried traditional methods to treat themselves. Family, friends, and neighbors were reported as major sources of support as were grandmothers,

community elders, prayer and bible study groups at church. These researchers found that rural dwellers tend to view health from a “role performance perspective” meaning that if one is able to meet the ongoing family obligations and are still able to work then one is healthy. (p. 259). Further, participants strongly emphasized that professionals who listen to and respect family choices were valuable resources. The other illuminating finding was the participants’ definition of rural as a way of life, “that’s who I am and that’s what I have been all my life” (p. 262) rather than a geographic location. A review of rural-urban health status differences within Australia, New Zealand, Canada, the USA, the UK and other western European nations stated that, “rurality per se does not necessarily lead to rural-urban disparities, but may exacerbate the effects of socio-economic disadvantage, ethnicity, poorer service availability, higher levels of personal risk and more hazardous environmental, occupational and transportation conditions” (Smith, Humphreys, & Wilson, 2008, p. 56).

Access to health care is an issue for rural residents and includes lower levels of screening and delayed diagnosis that contribute to poorer health outcomes (Smith, Humphreys, & Wilson, 2008). This research demonstrates that living in rural and remote communities provides individual and families with unique and distinct micro, meso, and exo systems within which they develop.

Canadians living in rural and remote areas generally have less favorable perceptions of their health than their urban counterparts (Statistics Canada, 2003). Dahinten, Timers, & Arim (2008) found that mothers but not fathers who live in the Northern Health Authority region of B.C. reported less stress than parents living in other health regions.

In a study of nursing practices in rural and remote Canada, rural was defined in terms of issues of distance, weather, and limited resources (Macleod, Browne, & Leipert, 1998). A focus was on the high percentage of First Nations families who live in rural and remote communities. Findings indicate that issues of health provision and health care access were exacerbated by the disproportion of low health outcomes for First Nations children and families such as poorer health status, higher incidence of poverty, higher unemployment, lower levels of educational attainment, and poor nutrition were factors. This is an important consideration when discussing experiences of families living in rural and remote communities with children with disabilities and developmental delays. A high percentage of families with young children who live in communities designated as rural or remote are Aboriginal.

Access to services is impacted by geographic, economic, and cultural factors. Hanlon & Halseth (2005) discussed implications for health care delivery within the context of an ageing or “greying” resource based economy for the communities in Northern British Columbia. Of significance for the purposes the present study is that the communities are indeed ageing so that limited health and social resources there are increasingly going to caring for the ageing population rather than families of young children in these communities.

Disability as a Social Construct

One can define disability in terms of specific genetic conditions, physical limitations, or medical conditions. It can also be suggested that the concept of disability is a social construct in that it is not the genetic or medical condition alone that has the most significant impact on the individual, but it is how that disability is understood and experienced within the social world that creates meaning for the individual. Such

meaning is socially constructed. Within western culture there is an assumed and shared understanding of what the term disability means. Often the word disability is associated with negative attributes and behaviors or with deficits. Understanding and attributions to disability influence how people interpret and make meaning of any conversation or dialogue regarding children with disabilities or developmental delays and their families. It is only through a discussion and exploration of the construction of this meaning, that we start to unpack our current understandings of disability. A researcher needs to be aware of his or her own constructions and values regarding the term disability. This awareness will influence not only the approach one takes in researching this topic, but also influences every interaction one has with participants in the research, the analysis, and the reporting of the findings (Crotty, 1998; Wolcott, 2005).

The ongoing exploration of the social construction of disability is reflected in the research on the experiences of parents raising a child with a disability. It is crucial to have an understanding of the construction of social beliefs regarding disability within a historical context. Historically, in North American society, disability has been seen as “deviant” and not acceptable. Until the 1970s most children born with disabilities were institutionalized so parents had little home experience with their children with a disability. Consequently, it was not widely researched. The language used in a research article from 1961 was reflective of the social milieu at the time regarding disability; the article was entitled: ‘Mourning and the birth of a defective child’ (Ferguson, 2002). The early literature also focused on the burden of having a child with a disability and created the stigma of parents who were seen as being martyred by having what was perceived as an unfortunate event (Ferguson, 2002). Due to

institutionalization, people with disabilities were not seen in the community and had little or no opportunity to socialize with others. They were institutionalized and given inadequate or no intervention and stimulation and were often thought of as vegetative. Based on this, we can assume that most people growing up prior to the 1980s had a very limited and potentially distorted concept of what it means to have a disability.

With the advent of better medical technology disability was seen (and to some degree continues to be seen) through the medical model (Albert, 2004). The disability is something that is to be cured; parents were to take advice from the professionals who knew best, and parents and the children were dis-empowered and once again marginalized, although these children were now living at home and considered to be “included” in community. It is only within the last few years (Albert, 2004) that we have begun to look at disability on the continuum of the human condition. With the Canadian Charter of Rights and Freedom (Department of Justice Canada, 1982), increased disability advocacy, and greater awareness, disability must be re-constructed and discussed as a different reality. It is not the individual but the society that puts the label of disability on the individual. Disability is not only about labeling one’s health status, but also includes the consequences of labeling which lead to discrimination and social exclusion imposed by social, cultural, economic, and environmental barriers (Albert, 2004). This brief history is pertinent to the further discussion of the literature of disability, the influence of the environment and further exploration of the construction of understanding of disability.

In a meta-analysis of the family adjustment literature of raising a child with a disability Helff and Glidden (1998) reviewed 60 articles across 3 time periods: 1971-1975, 1983 and 1993. In this meta-analysis the change or shift in societal beliefs about

disabilities as seen with the implementation of the Individuals with Disabilities Education Act (IDEA) legislation and school integration in the United States was explored. The analysis was conducted, in part, to determine if researchers made the shift in approaching research from a more positive or less negative concept of families with children with developmental disabilities. While they discovered there was less negative concept of families with children with developmental disabilities from the 1970s to 1983, there was no increase in positivity and the balance of negative and positive remained stable from 1983 to 1993. While there was change over these years, most researchers have continued to explore and view family adjustment in a predominantly negative tone (Helff & Glidden, 1998).

Summary and Need for the Proposed Study

This review of the literature provides the framework for the present study. The literature on parenting a child with a disability consistently indicates the stressful life experience this is for families. Indicated in the stress and coping literature is the importance of the parental appraisal of this situation as demonstrated by the Process Model of Stress and Coping (Beresford, 1994). The parental attribution of the situation influences how parents access social supports and resources which are determined by the geographic location of where the families live. The literature on rural context provides an illustration of the unique mesosystem and exosystem that the families are living in. The discussion of the social construction of disability and the historical context of disability provides further evidence that exploring the experiences of parenting a child with a disability or developmental delay in a rural or remote community needs to be approached from a holistic perspective. A social constructivist epistemology and the ethnographic methodology of using face-to-face interviews with families provide the

necessary framework to fully and sensitively explore these experiences. The next chapter will outline the theoretical perspective, the procedures, data collection, and data analysis.

Chapter Three: Methods

Overview

In this chapter the theoretical perspective and epistemology, rationale for the study, and method are explained. The purpose of the study is outlined and the main research questions are identified. In addition, the setting where the study was conducted and the participants are described.

Theoretical Perspective and Epistemology

This proposed research study is based in social constructivist epistemology. Constructivism suggests, as described by Crotty (1998), that meaning comes only by our interaction with the world and it is through this interaction that we construct meaning. Meaning is not just discovered. Social constructivism further dictates that meaning-making comes from social interactions and conventional means. The assertion is that this is an interactional process, that one's understanding or meaning-making of the world comes from interaction with the world. The world is constructed by cultural beliefs and practices and these are the basis for much of our behavior. It is only through an examination and exploration of these behaviors that we can gain a greater understanding of the underlying cultural beliefs and practices. We can gain insight into what the meaning-making for individuals may be and it is only through this examination and exploration that we may potentially influence meaning-making and conversely change cultural practices or beliefs.

Defined in various ways, culture is often described as the habits and traditions that guide our behavior (Crotty, 1998). Culture consists of beliefs, behaviors, norms, attitudes, social arrangements, and forms of expression such as language that create

predictable and describable patterns in the lives of members of that collective (Richards & Morse, 2006). Crotty (1998) further suggests that “culture is best seen as the source rather than the result of human thought and behavior. It is a set of control mechanisms- plans, recipes, rules and instructions for governing behavior” (p.53).

Symbolic interactionism within the social constructivist epistemology, supports the use of symbols that are meaningful to the participants involved. Understanding is derived from the shared interaction through use of culturally shared and understood symbols such as words and meaning. The use of interviews as a data collection method is then consistent with a symbolic interactionism theoretical perspective.

An ethnographic methodology is situated soundly within a symbolic interactionism perspective as well as the social constructivist epistemology because ethnography approaches the participants’ lives within their “culture”. This methodology requires that the study takes place within the world of the participants and seeks to uncover meaning and perceptions based within that context. .

Often referred to as fieldwork, an ethnographer immerses oneself into the community and lives of the participants. This researcher had an emic perspective on rural and remote communities having lived that lifestyle for 15 years in Northern British Columbia. This was an advantage in the initial stage of the research as the researcher negotiated entry, adapted to the culture, and provided relational experiences easily (Richards & Morse, 2006). A challenge was maintaining an objective perspective as a researcher. This researcher was also at an idic position with the culture of parents who have a child with a disability or developmental delay. The fieldwork came from visits to rural and remote communities as well as visits to the homes of the families. The communities and the family homes provided rich information and artifacts.

Setting

All families lived in rural and remote communities of the Northern and Interior regions of British Columbia. All but one interview was conducted in their homes and communities. Two communities were in the North Region of BC and two communities were in the Interior region of BC. One interview took place at Easter Seal house in Vancouver because the parent and child were attending appointments in Vancouver and this worked best for their schedule.

Procedures

Recruitment. This study was situated within a larger research project, *Including all Children and Families – Expanding Partnerships* (Goelman, 2009) on social inclusion of children with special needs and their families. As a result, community contacts and visits were for multiple purposes. Prior to the start of this study, community visits were made with both local service providers of early intervention services as well as with parents who had previously utilized local early intervention services and these individuals served as key informants. The key informants provided direction as to what approaches, questions, parental experiences, and service provider's experiences should be explored further within this research.

A preliminary letter (Appendix A) was sent to all the Executive Directors or supervisors of the sponsoring agencies of the Infant Development Programs in the North and Interior regions of BC. The letter outlined the anticipated requirements for family participation in the proposed study. As a result of this agency recruitment, a letter of support was received from nine agencies.

An Agency Information Letter (Appendix B) describing the proposed study was sent to the executive director or designated contact person from each agency that

submitted a letter of support for the project. The Agency Information Letter outlined the eligibility criteria for parents to participate in this study. The agency was asked to mail Parent Information Packets to each parent or family that met the eligibility criteria. Of the nine agencies that provided initial letters of support, eight indicated that they had families that met the study eligibility criteria. Across the agencies that agreed to distribute the Parent Information Packet, a total of 164 parent letters were sent to the agencies for distribution to parents.

Recruitment was initially very challenging due the timing of the initial mailing in early November. Follow-up conversations with agency contacts indicated that late fall was a busy time of year for them and by the time they received the letters and started distribution it was December and parents were busy with holiday preparations. Continuous follow-up with agency contacts were required and often questions arose regarding clarification of inclusion criteria, process for distribution, etc. These conversations with the service providers provided a rich context for further understanding of the complexity of the lives of families living in rural and remote communities.

The Parent Information Packets, which included a Parent Introduction Letter (Appendix C) and a Parent Response Card (Appendix D), were provided to the agencies in stamped envelopes for the agency to distribute via mail to parents. The Parent Introduction Letter described the proposed study and outlined the expectations of the parents consenting to participate in the study. Parents interested in the study returned the Parent Response Card if they wanted to participate in the study or if they wanted more information regarding the study.

Participants

Ten parents returned the parent response card. These parents were contacted directly by the researcher by phone. This initial phone contact had three purposes: 1) to determine if parents met the eligibility criteria for the study; 2) to review with parents what was involved in participating in this study; and, 3) to schedule the initial interview. All 10 parents met the eligibility criteria (See Appendix F). Scheduling difficulties prohibited the participation of one parent who was moving to Alberta. One response card was received late in the process and data analysis was already in progress so they were not included. Eight parents participated in the study. Demographic information of the parents is provided in Table 1.

Table 1: Sample Characteristics

Interview Number	Parent Name	Parent Age	Parent Education Level	Age of Target Child
1	Nancy ¹	32 yrs	University Degree	2 yrs
2	Don ¹	31 yrs	University Degree	2 yrs
3	Sally	36 yrs	University Degree	2.7 yrs
4	Wilma	36 yrs	Some College	3 yrs
5	Cindy	29 yrs	High School Degree	2 yrs
6	Ally	37 yrs	Some College	4 yrs
7	Tala	35 yrs	Some College	4 yrs
8	Betty	41 yrs	Some College	3 yrs

¹ Interviewees 1 & 2 are married to each other and the initial interview was conducted together.

All the participants in this study were married to or in common-law relationship with the other biological parent of their child. In addition, to the summary above, a brief

description of the participants follows, in the order that the participants were interviewed.

Pseudonyms were assigned to all participants and their children to protect their anonymity. Every attempt was made to invite the participation of both mothers and fathers for this study. However, only one father agreed to participate. The research decided to include the father in the present study and not include only mothers in the study. In some instances the mothers who participated shared experiences of the fathers, from their perspective. Thus, the term parent perspective, and not just maternal perspective, was selected for the study with an acknowledgement that paternal perspectives are limited in this study.

Nancy. Nancy is a 32-year-old woman, married to Don and mother of Erica. Nancy has a post-secondary education and works part-time. She has lived in their community for over 5 years. Family ties and work brought them to their community but Nancy loves living in their community, which she defines as “remote”. Erica was recently diagnosed with a very rare genetic condition and has significant developmental delays.

Don. Don is a 31-year-old man, married to Nancy and father to Erica. Don operates his own business and has a post secondary education. He has lived in their community for over 5 years but was born and raised in the area and his parents live in a nearby community. Don loves the active outdoor lifestyle his “rural” community provides for him and the time it allows him to be with his family.

Sally. A 36-year-old married mother of three boys, Sally’s youngest child is 2 ½ years old Jack. Sally has post secondary education and works full time in a very specialized and demanding job and has been living in her rural community for over 11

years. Her husband is a rancher and grew up in the community. Her husband's family lives in the community while Sally's family lives elsewhere. Jack was prenatally diagnosed with a rare genetic condition and has developmental delays.

Wilma. Wilma is a 35-year-old married mother with four children, Beth, her youngest daughter is 3 years old. With one year of college education, Wilma works part time in the local elementary school. She was raised in a rural community and moved to this remote community 6 years ago for her husband's work in trades. His family lives in the area. Beth has a developmental delay.

Cindy. The mother of 2 daughters, Cindy is 29 years old. Suzy, her youngest, is 2 years old. She has a high school education and is currently looking for part-time work. She moved to her rural community over 11 years ago to marry her husband. Cindy does not drive so she is not able to visit her family as often as she would like. Her family lives in the same community Cindy was raised in, which is over 200 kilometers away. Her husband does not have family in the community but he came to the community for work. Suzy has developmental delays that are undiagnosed.

Ally. Ally is a 37-year-old married mother of 2 children. Adam at age 4 is the oldest. Ally has some post-secondary education. She and her husband have lived in the rural community for over 12 years. Both she and her husband worked in outdoor recreational occupations that are situated in the community but Ally is currently at home full-time and her husband works in the trades. Neither she nor her husband have family in the community. Adam was prenatally diagnosed with a disability.

Tala. Tala is a 35-year-old married woman who self identifies as Pilipino. Ann, her only child, born in the Philippines, just turned four years old. Tala has some college

education and works part time at the local gas station. She came to live in her rural community 5 years ago when she married her husband who grew up in the community. He works in highway maintenance. Ann has no diagnosis but is significantly, globally delayed.

Betty. Betty has two teenage children, and she and her partner have 2 children together, Kelly who is 2 years old, and an infant daughter. Betty is 41 years old. She has heavy duty mechanical training and is currently at home full time with her family while her partner works full time in the same field. They live in the house Betty grew up in, across the street from aunts and uncles. Kelly was born 6 weeks premature and developed cancer at 10 months. The treatments for cancer have resulted in developmental delays as well as other physical complications.

Confidentiality, Privacy, and Ethics Approval

The study was approved by the UBC Behavioral Research Ethics Board. Significant attempts were made to maintain confidentiality and privacy throughout the research project. Due to the nature of research in small communities the identity of the participating parents was not disclosed to anyone except the research assistant that attended the first interview. The role of the research assistant was to assist with data collection and provide child minding support if needed. The participants were identified by pseudonyms in the field notes of the observations, in the transcriptions of the interviews and subsequent write-up. Identifying information about the community location was also changed. A list of participant names and contact information was kept separate from the interview transcripts. All study documents including the observations records, artifacts, and permanent products, reflective journal and transcripts from the

interviews were kept in a locked filing cabinet at University of British Columbia. All computer files were password protected.

Data Collection

The data were collected through semi-structured interviews that were held in the homes of the parents or at another location determined by the parent. Community observations and field notes were gathered during the visits to each community. Permanent objects and artifacts were gathered from some of the parents and a reflective journal was kept by the researcher documenting her experiences, feelings, and insights into the interviews with the parents as well as her observations, experiences, and insights during the community visits.

Semi-structured interviews. The interview is a common and powerful method utilized in order to attempt to understand other people (Baumbusch & Clark, 2010, Fontana & Frey, 2000). The interviews in the present study were in-depth, semi-structured, face-to-face, audio-recorded interviews, in order to give the researcher and the parent flexibility in questions and responses. Four broad topics were explored during the interviews: 1) the community, 2) the child, 3) experiences as a parent with a child with disability or developmental delay, and 4) information and support networks. All parents participated in two face-to-face interviews that ranged from 30 minutes to 90 minutes. The first two parents interviewed were married to each other so the initial interview took place together but their second interviews took place separately. The primary purpose of the first interview was to establish a relationship between the researcher and the parent participant. The consent form (Appendix E) was reviewed and consent obtained, demographic information was gathered, and initial introductory questions were asked. A research assistant attended six of the eight initial interviews

with parental permission and assisted with data collection and provided child minding support as needed.

After each interview the researcher reviewed the audio recording and consulted with the research assistant, if she attended the interview. The review of the initial interview with the research assistant ensured that all questions had been covered. The review also helped clarify which questions required follow-up and areas to explore further in the second interview. Each parent was mailed a copy of their interview transcripts and given the opportunity to provide feedback or comment. The researcher also conducted a telephone follow-up with each family. All eight of the parents agreed that the transcripts of the interviews were accurate and agreed to allow the interviews to be used for the study. The interview guide for the parent interview is provided in (Appendix G).

Observations. Field notes were gathered from community visits, through direct observation of the family home, and within the family home by both the researcher and the research assistant. The purpose of the observations was to provide some contextual information such as descriptions of the community, road conditions and the number and location of services in the community. The observations also provided descriptors of the home environment such as the use of a wood stove or proximity to other houses or neighbours. These observations help create some sense of life in these rural and remote regions. The researcher spent two to three days in each of the communities. Community visits involved eating in local restaurants, having dinners in the community with local service providers, and spending time with local community members to help the researcher learn more about the community. Community members were informed of the reason for visiting the community and were extremely

welcoming and open with sharing their lived experience in the community with the researchers.

Permanent Products and Artifacts. While each parent was asked about sharing a special item with the researcher that reflected a story or experience of bringing their child home after their birth, only one parent shared a picture of the child and had one copy of a home visit record from the Infant Development Program. Another parent talked about a special ball that her daughter loved to play with. Another parent commented that she is a collector and has a box of everything from the first dress the child wore but she did not share any of these items with the researcher. One parent, after reading the interview transcript sent the researcher a disk with pictures and music of her child and family journey from birth to the current age of the child to provide a visual representation of the personal experience of this family.

Reflective Journal. The researcher kept a journal of her experiences conducting the study. The journal includes thoughts and documentation of decision points throughout the study. In addition, after each home visit and each community visit the researcher documented her own perceptions and reflections of the interviews and observations to provide greater context to these sources of information.

Role of the Researcher. The role of the researcher is critical in an ethnographic study. The researcher cannot isolate him or herself from the research, findings, and interpretation and reflexivity is required as this indicates that the researcher is aware that he or she is part of the social world being studied (Berg, 2009). There are some advantages of being an outsider to the cultural group being studied, since the beliefs, values, practices, and behaviors are new to the researcher and he or she might be more objective (Richards & Morse, 2007).

The role as a researcher was more of a learning experience than anticipated. Having lived and worked in a rural and remote northern community for the past 15 years, the researcher considers herself a rural person, and has very strong social and emotional ties to rural community living. The researcher also has 12 years experience working for the Infant Development Program. This previous work history gave the researcher credibility and immediate access to the Executive Directors in the initial recruitment phase as well as an immediate connection with the consultants when they were recruiting participants.

It was challenging at times for the researcher to maintain an objective stance as a researcher with such a strong history as an infant consultant. There was concern on behalf of the researcher that at times conversations moved to problem-solving strategies and engagement more appropriate for an infant consultant conversation rather than just listening to the parent responses. As awareness of this surfaced, the researcher met with the research supervisor, and discussed these concerns. The supervisor reviewed the audio recordings of the interviews and gave suggestions on wording questions in order to maintain a more objective approach to questions while still maintaining a friendly, trust-building interaction.

The researcher was very rigorous about maintaining participant confidentiality. Even though all these parents gave verbal consent to have their initial IDP referral forms shared, the researcher did not contact the program or consultant to obtain this referral form as it would have identified the parents participating in the study to the local infant development program.

By virtue of participating in these interviews, the parent and researcher were creating shared meaning and developing understanding. The researcher believes that

how the questions were approached was reflective of a strong belief system regarding disability. The questions were approached as openly and positively as possible so parents could create their own story. The researcher was aware that there was potential to be leading in some of the follow up questions and it was a challenge to maintain focus on the questions at times as the stories were very personal and engaging. Discussion of any sensitive topic has the potential to trigger emotional responses and that can be an element of social construction; that by virtue of the researcher and the parent having this conversation, there was a risk of stirring issues up for the parent emotionally but also giving them an opportunity to articulate their story, their experiences in an accepting way. Perhaps this provided a way to process or make new meaning from this experience.

Data Analysis

The data analysis is based on the analytic process suggested by Berg (2009) and is detailed through a description of each step in the process.

Step one. Data were collected and made into text. After each interview the recording was transcribed by the researcher.

Step two. Initial text was read using open coding. The first interview was read several times to be very familiar with the content. Hand written notes were made by the researcher within the text that identified initial thoughts, feelings, and connections for the participant and the researcher. The interview was analyzed at the sentence level of the interview. Berg describes the use of content analysis as “a passport to listening to the words of the text and understanding better the perspectives of the producers of these words.” (2009, p. 343). Codes were identified in the first interview as the thoughts, impressions, feelings, and comments started to repeat themselves for the

parent, the codes were inductively and analytically developed. The same process was applied to each of the interviews.

Step three. Codes were transformed into sub-themes. The open coding provided the researcher with a systematic way of looking at categorical labels. Berg uses the terms “categorical labels” as well as themes, topics, and issues in his writing. To use language that is more familiar within qualitative research and a term that is more accessible, the categorical labels in this document will be referred to as themes (e.g., travel or discussion of rural versus remote). Peer debriefing with the research assistant was utilized to check the interpretations of the data and check for researcher bias. Ongoing meetings with the research assistant were used to verify the accuracy or inter-reader reliability of the identification of themes. This was repeated with each interview and field notes.

Step four. Subthemes were grouped into broad themes. The sub themes from each interview were then grouped under broader themes based on the key elements of the research question which served as the basis of interpretation of the data. The key elements of the research question involved geographic location, community, parenting experiences and that the parent was involved in the Infant Development program due to having a child with a diagnosed disability or developmental delay. These themes were then analyzed in comparison to established research.

Table 2: Classification of Broad Themes and Subthemes from the Analysis

Broad Themes and Subthemes

Theme 1: Community Experiences

Rural versus remote

Community lifestyle

Value of Interpersonal relationships

Theme 2: Parenting Experiences

Delivery

Delay or Disability

Intense Emotions

The Unknown

Construction of Disability

Theme 3: Family experiences

Travel: considerations and issues

Family separation

Financial Burden

Service Providers

A process of change

Triangulation and Validity of the Study

Triangulation of data is a primary strategy to ensure the validity and trustworthiness of a qualitative study (Creswell, 2009; Mathison, 1988). Several sources of data were used to create the consistency of themes that emerged in this study. Data were collected using interviews, field notes, participant artifacts, permanent products, as well as a journal completed by the researcher. Field notes were collected by both the researcher and a research assistant.

The research assistant checked the transcriptions of the interviews she attended to make sure they did not contain any obvious mistakes. Parents also provided member checks as they reviewed the transcribed interviews.

The research assistant also provided member checks and inter-coder reliability. The researcher met with fellow graduate students and the research assistant on an ongoing basis and discussion and reflection was provided for the entire study, consistently checking and re-checking the accuracy of the data, the coding, the

themes, and the findings. Meetings were also held with the academic supervisor as well as members of the thesis committee. Presentations were made to the research team of the *Including All Children and Families- Expanding Partnerships* on a regular basis as one of the studies under this project.

Chapter Four: Findings

Overview

The purpose of this study was to gain greater understanding and describe the experience of raising a child with a disability or developmental delay when the family lives in a rural or remote community from the perspective of the parent. The intent of this study was also to bring the voice of the parents into the literature. Three broad themes (Community Experiences, Parent Experiences, Family Experiences) emerged from the interviews. These themes served as the foundation to the study resulting in responding to answering the research question: “*What are the parenting experiences of parents living in rural and remote British Columbia who are receiving services from the IDP of BC because they have an infant or child under the age of three with a diagnosed disability or identified developmental delay?*” Within each of the three broad themes, subthemes were also identified. The findings in this chapter are summarized by the themes and subthemes that emerged in exploring the research question.

Theme 1: The Community Experience

This broad theme situates the participants within the context of where they live their lives. Questions of how participants identify their community, including whether it is rural or remote were explored. The theme also included what they liked or disliked about living where they live; and how they describe their lifestyle in community were also discussed. The value the parents put on relationships, knowing who people are in their community, and being known by the professionals was also evident within this theme.

Rural versus remote. The definition of rural or remote was looked at extensively prior to this study. While important in terms of defining the area for the

purpose of the research, most of the parents did not use the term rural or remote but rather referred to their community as “small town”. “Because it’s just how we live. We have to drive three hours to do a lot, I wouldn’t say off the grid but it’s not congested. I always say small town.” (Ally).

The parents were divided on whether they referred to their community as rural or remote. Five of the eight parents defined their community as rural and not remote because of their access to amenities and businesses such as Tim Horton’s or Canadian Tire. Don suggested that remote was “a community that you have to fly in to.” One parent would only use the term “small town” and the two parents who referred to their community as remote discussed this in terms of the lack of amenities and services. By the Metropolitan Influenced Zone (MIZ) definition, all the communities where the families in this study lived are defined as remote. No one commutes to a larger urban center on a regular basis.

Situating oneself within the community was important. A key element to establishing a relationship with the families was a discussion of how the long the trip was to get to their community, the road conditions, what route was taken, and had the researcher ever been to the community before. The discussion of rural versus remote with the family provided the context for further conversations about what made these communities significant for them.

Community lifestyle. The lifestyle of the rural community was described by many parents in terms of their proximity to work or other services. Nancy liked the fact that she is two minutes away from everything, such as the grocery store or the doctor’s office. Don noted that the proximity allowed increased time with his family and that living in a rural community allowed him to share his value of outdoor experiences such

as hiking, skiing, and horses with his daughter. Outdoor, family-based experiences were also descriptors used by Wilma as her family packs up and camps by the lake every weekend in the summer. Betty camps with her family on a nearby isolated island and has a camping site all year.

Sally noted that her community is a good place to raise a family, and that it is cheaper to live there so one parent can stay home. She reported that there are good programs such as a French immersion school with no waitlists and good daycare. Sally commented that people also choose to live in her rural community because of the active outdoor lifestyle and healthy eating. Nancy and Don also commented that they were much more aware of what they were eating and access to the outdoors that allowed for an active lifestyle was important. Ally and her husband moved to the community for the active outdoor lifestyle and are active in the community. She remarked that she loves it, that she never needs to take her car out of the driveway, and that she walks everywhere.

While most of the parents indicated a strong value of access to outdoor opportunities, for one parent, living in her small community did not meet her lifestyle preferences.

Here is really, really quiet...I'm stuck home. I don't really like living here, it's such a small town, I don't like it. If I lived in the city I would go to the mall with my friend. Here there is no where to go, you just go get grocery and then come home. (Tala)

Interpersonal relationships. A consistent theme that was discussed by all the parents was the importance of interpersonal relationships. All the parents discussed how long they had been in the community, what brought them to the community and

their proximity to their family. Further, they discussed the importance of having close relationships with people, feeling that people know who you are and care about you. This extends notably to the importance of having a 'relationship' with the professionals that were involved in their lives. The value of the social cohesion of these rural communities was expressed in many ways.

The parents had lived in their respective communities between 5 to 12 years. One mother grew up in the community, left for a few years for work and then returned 11 years ago to be near her parents, siblings, and extended family. Two of the husbands of the mothers grew up in the community so they had extended family in the same community but not their own family. Two parents had family close by and this was one of the reasons for choosing the community.

Parents commented that they valued being known and knowing others. Ally stated that what most people don't like about a small town, "everyone knows your business," is exactly what she likes about it. She knows all her neighbors on her street. Betty described her community as "safe" and she liked the fact that if she broke down on the side of the highway she would know who was going to drive by depending on the time of day. Wilma and Ally commented that they like it that they see the public health nurse in the grocery store and she reminds them it is time for immunizations. Parents discussed how they liked seeing the "professionals" on the ski hill or in the grocery store and this made the professional seem more human. This created a sense of security or safety in the service providers.

Like when you are from a small town, like our doctors are... they deliver all your kids, you establish more of a relationship there than in the city because you get to see them

in the grocery store, on the ski hill, maybe their kids at school if they have kids.. they are just other people in the community, they are not really like “I’m the doctor”. (Sally)

Wilma’s Christian faith plays a large part in her life. Her children attend a Christian school and she and her immediate and extended family attend church on a regular basis. Their church is an integral part of her social network. Wilma described her role in her community as being more visible in the community,

They know who you are, you have a higher responsibility to show yourselves, to be more open, able to listen and talk to other people because you have a higher accountability, right? Not only to the Lord but to yourself. (Wilma)

This social cohesion created a sense of safety or security for Wilma as she stated that being known in the community, she believes that she would not have gotten the types of services (Infant Development Program) if she was in an urban center.

The community experience is an important place to start. The parents discussed the importance of relationships in their community. The concept of community cohesion, that everyone is taking care of one another, family, friends and service providers. While relationships are important, so is the opportunity to participate in the outdoor lifestyle that is commonly valued within these communities. The exploration of the parent’s definition of their community as rural or remote provided insight into their concept of community.

Theme 2: Parenting Experiences

In the theme “parenting experiences”, it was clear that parents felt the need to share their powerful experiences of either the diagnosis of their child’s disability, the birth of their child, their journey to finding a diagnosis or ongoing struggle with obtaining

some diagnostic information. As these parents all had young children, the question was posed, “Tell me about how your child came into your life”. Each response provided a rich description not only about the arrival or birth of their child, but also the journey of detecting the delay or disability and the emotional intensity of this experience. Five subthemes, delivery, disability versus delay, intense emotions, the unknown, and construction of disability emerged during the analysis the theme “parenting experiences.”

Delivery. It was surprising to the researcher that none of these parents gave birth in their home community, although they were living there at the time. Ally and Sally delivered in a specialty children’s hospital because of an earlier pre-natal diagnosis. Betty started labor prematurely which required delivery in another community and when further complications arose, the infant, Kelly, was flown to a large urban medical facility. Tala had chosen to have a home birth in her home country and while she had no indication of complications during her pregnancy, upon delivery, she and the infant, Ann, transferred to two different hospitals with increasing intensity of medical intervention. Wilma and Nancy delivered their babies in neighboring communities because there were no deliveries in their local hospital. Cindy delivered in another community because of medical complications with a prior pregnancy and delivering in her home community was not an option.

Delay versus disability. The determination of a child having a disability or a developmental delay was a life- changing event in a parent’s life. When the disability or delay was detected and how it was detected created a unique journey for each parent. Of the 7 children in this study, 2 children received a diagnosis of chromosomal abnormalities prior to birth and have identified diagnoses. One child, Ann, was born

with birth defects and has significant global delays but there were no prenatal concerns. The remaining 4 children, infants Erica, Beth, Suzy, and Kelly also had no prenatal concerns. The identification of the delay was a very different process for each parent ranging from “having to fight everyday” for information or a diagnosis to a parent who initially thought early intervention was a “waste of time”. The identification of delay for each of these four children took a significantly different path.

Erica was described as an infant who was *failing to thrive*, not putting on weight, and was becoming more and more lethargic. Her mother, Nancy “just knew something was wrong”. Nancy felt like she had to fight to get people to listen to her, but was dismissed as just a “neurotic mother”. This increased her feelings of isolation from her friends, family and community. After much advocacy on Nancy’s part, Erica was seen at BC Children’s Hospital and at the age of two received a diagnosis of developmental delay due to a genetic micro-deletion. However the diagnosis did not come with any developmental prognosis. Nancy describes it as one of the worst years of her life.

I had a horrible year, that was one of the worst years of my life, yeah I thought I couldn’t parent because there was like too much stress. You know, from the get go, though with her, I have had to fight for every doctor, every diagnosis...cause no one thought that anything was wrong..... so I feel like it has been a fight, everyday. (Nancy)

While Nancy describes her husband as her biggest supporter during this time, Don mentioned that he did not recognize or realize the severity of Erica’s delays initially either.

Suzy was also described as failure to thrive as an infant. Cindy noticed Suzy was throwing up a lot, losing weight, was lethargic and sleeping all the time. Cindy

consulted her community support systems at the Native Friendship Center and they drove her to appointments. Suzy was delayed in her motor skills and Cindy was very anxious about learning the cause of Suzy's delay. Cindy finds it challenging in the community to explain to others why her daughter is not walking.

Yeah well to me it's complicated because like I don't really know because there is no diagnosis. To me it makes it hard because people are like oh so what's wrong with her why's she not walking? I don't know I wish I could just say because she has this... but there is no reason. (Cindy)

Wilma's daughter, Beth, had mild motor delays. Wilma was reluctant to work with the Infant Development Program as she said that, "children's development does not fit into a box, I didn't think there was an issue". She did not want to "waste her time" or the consultant's time as the motor delay was not that significant to Wilma. She had an older child in the Infant Development Program so was comfortable with the consultant and had an established relationship with her. Wilma's hesitancy is evident in her description of completing the Ages and Stages Questionnaire with public health:

And they do the questionnaire and submit that was also another indicator for them that he was not developing but for me that's not a problem because he's a boy and he doesn't have to fit into this box or whatever he's just a kid and so when I did the Ages and Stages Questionnaire with Beth so then I was like oh so what if she's not standing, so it doesn't matter. So I would always answer honestly because I thought it didn't matter right but maybe if I had known that they were going to be coming in once a month..... (she trails off laughing). (Wilma)

There was great diversity in the response of parents in pursuing developmental information about their child's delay. Nancy expressed that she was "fighting everyday" to get developmental or diagnostic information. Cindy accessed general community support services and was familiar with early intervention but still wanted diagnostic information so she could explain this to others. Wilma was reluctant for services but over time saw this as a benefit to her children's development.

The experiences of parents with children with a diagnosed disability were different. Both Jack and Adam had questionable ultra-sound results during routine ultra-sound testing but living in rural communities meant trips to larger urban centers to obtain specific diagnostic information. Both parents had concerns about access to timely diagnostic information. It took eight weeks for Sally to get to BC Women's Hospital for an ultrasound and by then it was 25 weeks gestation so the decision to terminate the pregnancy was no longer a choice. Sally commented that, "While things worked out for us, but for someone else it might not work out, they might feel like their choices aren't there."

Ally had routine ultra sounds in her home community that detected a fetal abnormality. She said that the local radiologist knew something was wrong but was not able to talk about it and then it took further time to get a referral to a larger medical facility that would provide them with more comprehensive information. Prior to the birth of Adam, this family traveled extensively to determine the diagnosis, and referred to the day when they got a "final possible diagnosis" as "D-Day"

The experiences of Ally and Sally who were parents of children with diagnosed disabilities as well as Tala whose daughter Ann has significant global delays from birth, has extensive involvement with medical and developmental interventionists. While

these parents told stories of the extensive travel back and forth to obtain medical intervention, sometimes every week, they are unique in that the diagnosis of a disability allowed them access to supports and services such as the Infant Development Program and the At-Home Program which provides financial support for travel, home care needs, renovations etc. These three parents indicated that they felt very well supported in their community services. Ally and Sally shared that while the first few years were hard, their children are doing “better than ever expected”. Further, Tala celebrates every milestone that Ann achieves.

Intense emotions. Regardless of when or how the delay or disability was detected, for all these parents the emotional intensity of this life-changing experience was expressed in numerous ways. As the parents described the birth experience, bringing their child home, the constant monitoring of what their child was or was not doing and the uncertainty of what might happen next, they used words that illustrated the intensely emotional and traumatic experience this has been: horrific, sad, brutal, disbelief, surprise and nightmare.

All the parents commented on experiencing an emotional impact of varying degrees of depression and/or stress. Three parents used the term PTSD (post-traumatic stress disorder) in that they initially coped but later experienced different significant emotional reactions to their situation. Cindy noted that her depression was brought to her attention by her infant development consultant and the staff at the Native Friendship Centre and she attributes the post-partum depression to “everything that was going on, it was all just too much.” Sally described that she was a lot more emotional, having nightmares and bad dreams. She commented that she thought she was coping well until a year after Jack was born; she explained that “you sort of put

yourself in a different zone to deal with it all". Ally shared that while she believed professionals did a good job monitoring her mental health status, the experience of the father is often overlooked. Ally's husband ended up with high blood pressure and depression after Adam's third year.

He had this post-traumatic thing when everything started to go well. He was like why do I feel like this? Last winter was a nightmare for him...because everything was okay but for the first three years it was really full on. We would go, oh what are they going to tell us next? I didn't realize this but while I was pregnant he would be positive for me and then call his mom and be bawling and I had no clue (Ally).

Two parents, who have professional roles in their community, commented on the necessity of accessing support and counseling outside of their community. Nancy was uncomfortable seeking counseling from the medical professionals within her own community as she worked with them on an ongoing basis. Sally commented that in a small town everyone knows you and there are expectations of her and like any other professional if they had a problem, they need to go out of town to talk to someone.

The Unknown. All of the parents expressed that to some degree they dealt on a daily basis with unknown outcomes for their child and anxiety about the future. Betty's child, Kelly, has developmental delays due to chemotherapy to fight a brain tumor. Betty very clearly stated that she takes it one day at a time: "I can't.... I can't focus on what might happen, this is what's happening right now and it's going good so let's just leave it at that".

For parents with children with development delay the anxiety and unknown was related to developmental prognosis. Other parents expressed fears for when their child

starts school, and wondered whether funding for special services will be available. The phrase “*falling through the cracks*” was used by parents to describe missed or possible missed opportunities. Parents who had a child with a diagnosed disability referred to the sadness they felt with other parents who may fall through the cracks by not being able to obtain necessary funding. Their child may eventually fall through the cracks if the child’s development continued to progress so well that they may no longer qualify for funding or funding may not be available. For parents with a child with developmental delay the phrase “*falling through the cracks*” was in the context of the discussion of missing possible interventions at specific times; or feeling or thinking that perhaps they should have done something earlier in their child’s life that may have made a difference. Wilma used the phrase “falling through the cracks” in a discussion of how they may not have gotten the intervention services if they had lived in an urban center. The consistent use of the phrase “falling through the cracks” by these parents indicates an uncertainty that is always with them. As Nancy states of the first year, “it was good, it was bad, it was nuts.”

Construction of disability or delay. The words the parents used to describe their experiences with disability was reflective of their construction of disability. Some of the parents described their understanding of disability in the context of their current experience with adults with disability or being involved with a person with a disability as a child. Don works with men who are with community living programs and he described disability in terms of function and living independently at the age of 35 or 40. Wilma attended school with a child with a physical disability. For Ally and Sally, whose children have a diagnosed disability, they used the word disability frequently and saw

having a diagnosis of a disability as a benefit as it opened doors to access and services.

Most of the parents talked about disability in terms of what their child can or cannot do physically. Sally stated that Jack participated in everything that his brothers do, skating, hockey and golf. Ally stated that they did not ever think Adam would walk or talk or play hockey.

I think for Bill and I, even though we're super active, that's huge in our everyday life. That we have a child that was... that we were told, disabilities and that kind of stuff we definitely pushed really hard not to make it be that way. We had him in between our arms at 18 months old on skis, well really like those are like splints okay so that is what we are going to do then. So just things like that but I do see, if it had been a mental thing both Bill and I talked about that, I think that would've been harder I think severe you know total care definitely. I don't think we would've had another one, I just think it would've been way more challenging especially in a small town. Just thinking about wheelchair ramps and talking about that kind of stuff. (Ally)

Wilma differentiates physical disability versus mental disability.

If there is a physical problem or whatever you need to give them skills to deal with it. If there were mental delays it's a parent's struggle, right because the child doesn't understand or grasp but if there's physical ones then you can give them the skills to cope because mentally they can process that. (Wilma)

Parents shared their experiences of sadness when they brought their child to community events. Tala talked with sadness about Ann attending her preschool.

And the kids, they don't really play with Ann, that's really sad because in (home country) everybody plays with her. And here they don't really play with her, because they go oh, I don't really know what they think, she doesn't walk or talk she just sits and she don't really mind (Tala).

Sally described bringing Jack as an infant to her oldest sons first day of school and because of appliances to correct his open palate; people stared and did not know what to say. She thought that people were scared and this increased her feelings of isolation. As Adam had splints Ally described her sad feelings of never putting Adam in shorts for preschool.

Some of the parents speculated that their experience of parenting a child with a disability may be different in a rural community than in an urban center.

Like in the city you see lots of people with disabilities, you can say go to a group, a place with the same issues and you can all talk about it. In a smaller community there will be less people like that so there may not be regular groups or meetings. And because it is a small group, you may not all get along with the other people. (Sally)

I don't find this as a burden or inconvenient to our lives, a lot of people feel that way. Like in "S" a lot of people are like that, they come for the lifestyle... and I can't speak for everyone obviously but people are like, oh poor you, you have a child that is holding you back from doing all these fun things you could be doing. But actually I just find that he just adds another view of all the fun things we are going to do (Sally).

The parenting experience of raising a child with a disability or developmental delay is a uniquely personal experience for each of these parents. All the parents in this study shared the intensity of emotion that they experienced when they first were informed of their child's diagnosis or coming to an understanding of their child's developmental delays. They also expressed ongoing feelings of stress and living with uncertainty of what the future holds for them and their child. The timing of the identification of the disability versus the ongoing pursuit of determining a developmental delay creates different journeys for the parents in this study. The construction of disability was explored in terms of the context of their experience with people with disabilities either as a child or in their interactions with people with disability in their community. While the experience of having a child with a disability or developmental delay impacts each parent uniquely, the following theme explores the experiences that were shared by the broader family system and by all the families in the study.

Theme 3: Family Experiences

The third broad theme, family experiences, outlined the experiences shared by these parents by virtue of their unique situation of living in a rural or remote community and having a child with a disability and/or developmental delay. The challenges of travel, separation from family when taking care of children's medical needs, financial burden, experiences with service providers, and the process of change for the parent are the five subthemes that emerged within the analysis of the broad "family experiences" theme.

Travel. Living in a rural or remote community requires travelling. Tala casually describes driving three hours each way (250 kms) to go shopping for one day: "You leave at seven a.m. and arrive back home at 9 or 10 p.m." While parents were casual

and accepting of the fact that travel was required given their geographic location, travel to larger urban centers during the winter from any of these communities meant winter road conditions, with snow, ice and black ice, change of weather patterns from one community to the next, driving over high mountain passes, and the inevitable highway closures and accidents. While the acceptance of travel was just understood to be part of the rural lifestyle, these parents travel with children. All of the parents traveled back and forth to the medical facilities located in urban settings, several times during the first years of their child's life, sometimes as often as once a week. Ally describes a particularly challenging winter travel experience:

. Yeah we had avalanches for over a week, so that was one of the horrific things about not being able to get home and being stuck in a small town right. So Bill hitchhiked to Calgary because there were no buses coming or going, hitchhiked to Calgary the long way, so he did that with the truck drivers and snowplow drivers and everything else. Yeah the roads closed I think it was 45 minutes after, there was a massive slide came down after we got through. (Ally)

The reality of bringing home a medically fragile or medically involved child given the distance from the medical care in the larger urban center, was described by several of the parents. Sally and her husband brought Jack home from Vancouver which is typically a 12-hour drive but frequent stops made this a much longer journey.

It was crazy, if I had not had my husband to hold him, to be right there because you know he was still just 5 pounds and he had appliances in his mouth and stuff, so we had to check and make sure he didn't choke and stuff. (Sally).

Ally described the trips back and forth to the hospital where Adam was not able to sit for more than an hour, so during the three-hour drive they had to stop every hour to stretch him. They were going back and forth to the hospital once a week.

The travel factor was also a major consideration and stressor when making decisions about care for their child. Tala reported that one time after Ann was discharged from the hospital they drove three hours home only to have to turn around a few hours later as Ann developed a very high fever so they again drove the three hours back to the hospital. Ally commented that she always had to factor in the drive when deciding how “sick” she would let Adam get. It all became very burdensome. Sally’s story of making the decision of when to return home after her son Jack’s surgery illustrates the dilemma often faced by these parents.

I am considering staying a little bit longer because, you know, I am a bit nervous because he was sleeping in a little bit later and I want to see if there is any infection or anything and it would be easier to stay down here if anything comes up even though I know they can take of things there but so I just looked into it this morning to see how much it would be to change the tickets and it’s 200 bucks to change to tickets and there is only one night available here so we would have to go and stay in a hotel so its add up to maybe it’s a thousand bucks for me to go home on Monday instead of tomorrow. I just... so I don’t know what the right thing to do is cause now the money thing kind of clouds the decision... but I think we will just head home tomorrow then. (Sally)

Travel was not always negative and for some of the families the travel experience was positive because it enabled them to get out of town and spend time

with people who really understood what they were going through. Nancy and Don stayed with family during their trips to the medical center in a larger center. Someone in their extended family also had a child that required medical treatment so it was a get-away and an opportunity to just talk openly. Betty had one close person she talked to when she travelled to the medical facility with Kelly. This person also had a child with cancer and the two children had become friends and Betty felt she could talk to this parent like no other parent she knew at home. Sally also found her time away in an urban center provided her with contact with friends and family that understood her situation.

I come to the city and my friends are here. One of their kids went through cancer treatment and when we are discussing it and it's not oh no poor you and poor this it's more like so what did you do and how did you solve this problem and... completely different attitude. (Sally)

Family Separation. While the travel distances were significant, the geographic distance also created the issue of family separation. For some families it meant that the mother was in another city while the husband or spouse and possibly other children were in the hometown. Parents reported that the other spouse had only limited days to take time off work or could not leave work. The travel and accommodation costs were prohibitive for the family to be together. This also created challenges for the children remaining at home. Sally talked about her experience of being away from her husband and other young children and the profound impact that had on the children remaining at home.

You are here with your baby but I missed my other kids for three months, and you don't get to see them, and that was really hard but you just have

to do it. And to get them all here, was definitely too expensive, and my husband's job, you can't just walk away from the farm, and it was haying season. We didn't have high speed internet services and my youngest was way too young to talk on the phone...My second son, I think is still kind of recovering from that whole thing because he was just after a year old and we were just kind of bonding and then I was gone for three months. When I came back he looked at me funny for a long time and didn't trust... and he got anxious when I left. (Sally)

Betty and her child, Kelly, lived in Calgary for 10 months while Kelly received cancer treatment and her two other children were at home in the care of other family members or Jim. She described this as a very difficult time. She was not able to see her children for over three months and Betty's 14-year-old son was negatively impacted by the sudden and prolonged separation. Betty described him, upon her return, as needing to be close to her, often checking in and saying, glad you're home.

Sometimes the trips to the urban medical facility were not planned. They were emergencies and unexpected. Betty described arriving in Vancouver without her glasses or even a change of clothes. While not having her glasses would be manageable in her familiar home and community environment but when you are in a completely new situation, such as a children's hospital and trying to locate where your child is, this is a challenge. "And there it was like being dropped into a totally different environment." (Betty)

Financial burden. The financial burden was raised by all parents and it was multi-dimensional. There were significant expenses related to travel such as gas, vehicle maintenance, and good winter tires. Three parents mentioned that they

required a new vehicle due to the increased frequency of travel. When away from home there were the additional costs of staying overnight in a hotel and eating out. There were also expenses related to the additional medical or developmental items needed by the child.

There are significant medical or intervention costs related to a child with a disability or developmental delays including wheelchairs, hearing aids, orthotics, specialized clothing, specialized dietary needs, and medication. While these additional expenses are experienced by most parents who have children with disabilities or developmental delays, the unique feature for parents in rural and remote communities was accessing or resourcing these materials. Families living in rural or remote places often drove to other communities for grocery shopping because there was limited selection in the small town store, items were expensive and produce may not be fresh. When one is living on a fixed income raising a young family, all these factors must be taken into consideration. Nancy reported that due to Erica's dietary needs she got goat's milk from an urban center and it cost the family 50 dollars for four litres of milk per week. She stated, however, that when your child is failing to thrive you will pay whatever you need to pay to have their needs met. The reality of the financial burden experienced by some families is summarized by Betty:

Yep, I had to claim bankruptcy because I can't go back to work, on the first few months that we were in the hospital, when we got out her medication for that alone it was sometimes four or five hundred dollars for a few days. So that really took a beating and then him traveling to see us and you know, just everything. Then trying to keep the house going here and feeding the big kids and keeping a life here. I am sure I put a financial

stress on my brother and sister because they were feeding them and driving them and you know. (Betty)

Service providers. The experience that was common to all families that have children with disabilities or developmental delays was that they become involved with a wide range of early intervention service providers and professionals. All of the parents interviewed had a consultant with the Infant Development Program of BC. In addition, the range of service providers included: speech therapists, physiotherapists, occupational therapists, hearing and vision consultants, feeding specialists, geneticists, social workers, oncologists, and pediatricians. All the parents commented on how grateful they were to have service providers that came to their home. There was the benefit of being able to integrate therapy and services into their daily routines and some parents articulated that they saw it as beneficial because the service provider saw the child in a home or familiar environment.

One comment often made about the infant consultants was that they were “nice” people. Developing a trusting and secure relationship was significant and it was through casual and yet consistent interactions that demonstrated to the parents, that this person “cared”. Parents gave examples that this person cared: coming to the home on a regular basis, stopping in to check in on the child and family, bringing toys, and connecting parents with necessary professionals and support services. One consultant was described as particularly adept at accessing resources and obtaining financial support for the families. Ally commented that she appreciated that the helpers came to her, that she never had to call out for help. “I feel like because we are in a small town they come to us”.

The parents described their interactions with the infant development consultant in terms that were congruent with their earlier descriptions of the behaviors from “professionals” in their community that created that sense of familiarity and trust in the professional. Parents explained they valued that the infant consultant just stopped in to see how they were doing; that she called and checked in on us; that she asked others in the community about the family if they had not seen them for awhile. Betty commented, “Not being intrusive but just concerned” She reported that she valued that the consultant was looking out for the whole family not just Kelly when the consultant assisted the family in obtaining recreational activities for the teenage children.

Tala describes the level of closeness she experiences in this relationship with the infant development consultant.

If we need to ask something we always just go to [the infant consultant] cause she is an old friend of Larry’s too, they already know each other from a long time. So she saw me working at the 7-11, she told the manager, don’t be mean to her, this is my daughter... She’s like really, really nice. She thinks of me as her daughter (Tala)

The value of interpersonal relationships and social cohesion was evident in the parents’ responses. Conversely, parents described how they thought their experience with services and service providers would be different if they were living in an urban location. Cindy described her relationship with her service providers as having a ‘very personal friendship’ with all of them that she could talk to them about anything. She said they were more like friends than workers and “I think in a city, like a big city it would be like that you’d be just like another client or like “Oh, the W family”.” Betty liked that in her community Kelly was treated ‘as a person’ and she speculated that in the

city Kelly would be more like a number given that caseloads are much higher than in the rural areas. Wilma valued the personal relationships she had with her service providers and this prevented her and her children from “falling through the cracks of care”. She described her experience in an urban center in this way.

When I was in (a larger urban center) you didn't sit in the waiting room talking to other moms because you didn't know them so you didn't get in to that. Getting to know the nurse, why get to know her, next time you were going there was probably going to be someone else. (Wilma)

The value of the close personal relationship with the service provider and the need for expertise outside of their community presented a dichotomy for some parents and frustration for one. The parents recognized that local service providers did not have the expertise or specializations that the service providers in larger urban centers had and therefore they still needed to access services in larger centers. Don used the term *generalist* for his infant development consultant. While Betty appreciated her local physiotherapist, who said he was not really qualified to work with kids, but had a friendly and willing approach, Betty recognized the expertise in the larger urban medical facility where there are “neurology pediatric physiotherapists and they specialize in brain injuries and brain problems so, but it's not the same as Kelly“. Sally explained her experience with local services providers in this way.

You get people who are in those jobs who are just available but not necessarily skilled at what they are doing. There is maybe... you don't have a choice in who is doing it, you don't have a choice about the skill level, you just have to work with it. And so far it's been working good... I have had some concerns but I don't really remember who or what or what

have you but sometimes I wonder is this the right choice for him, is this the best we can do... but so far it seems like it is. (Sally)

One parent expressed frustration with the local service provision and believes that the lack of expertise may now be impacting the potential progress her child could be making:

I like those people, they are good people, but I don't think those services are, I am just actually starting to have concerns in the last 2-3 months, I don't really know the focus or their full scope is..... what's their plan?.... and, or do I need to be referred on to a bigger center. To get more for Erica cause you know, on the last assessment she was at a 7-month-old for like on the problem-solving... and uh... you know, not much was said about that or what we are going to do about that.. you know. (Nancy)

Nancy further explains,

I am feeling this tough battle because I am not feeling 100% satisfied with the services I am getting here, the Infant Development Program I am getting here, that is making me question, what is their scope... what can they do?... she has developmental needs, big time. Right... and you know, I am kind of getting exhausted trying to buy the right toys, trying to help her and teach her... because I am not the expert in that... so it's not like you are wasting your time, but you could put in a lot of time and effort and it is not the right approach... they are the specialists in infant development...you know... Every week I see she is changing a lot but there is something within her that needs to be brought out... but that is not happening in (town)" (Nancy)

Both Nancy and Don explained that they would like to be connected to a province wide resource network to obtain more information. Some parents reported that they were receiving all the information they needed through the infant consultant while some perceived this was lacking.

A process of change. All the parents discussed how having a child with a disability or developmental delay had changed them. Most parents commented that they are now more empathetic and understanding of other parents raising children with disabilities and more compassionate of differences. “Well definitely when you have a child with disabilities it is easier to talk to other people who have children with disabilities. I think other people just don’t know how to communicate with them.” (Sally).

It made it feel a bit more isolating... but that’s character building! I don’t want to make it sound all down or something ... but you find out who your friends are, you may have less that you thought but that’s okay too.”

(Sally)

All the parents consistently indicated that this has made them more of an advocate on many levels. Nancy and Don discussed how they have had to become advocates for all of Erica’s medical information. This has translated into them supporting others to be advocates for their own medical treatments.

Ally described that she had always been fighting for causes, now she feels she “has a leg to stand on”. It gives her more credibility and she is now advocating for wheelchair accessible spaces in her community, although her son does not use a wheelchair. Sally described herself as more assertive than she was before Jack was born.

The family experiences of the parents in this study highlight some of the challenges of living in rural or remote communities. The distance from services creates significant additional costs associated with travel, obtaining materials and resources in their own community and the additional burden of separation from other family members. The relationship with the Infant Development Consultant is significant. The consultant can provide necessary support and access to necessary services but for some families their support and information needs are not being met. Many of the families value local service provision but they also recognize the expertise that service providers in an urban center provide for them. The parents in this study expressed that they felt more compassionate and understanding of other parents raising children with disabilities and it also made them stronger advocates for themselves and for their child.

Summary

The findings bring the parent voice to the lived experience of raising a child with a disability or developmental delay in rural or remote British Columbia. The importance of context, the identification of the small town as a place of close proximity to services that allows families the time to spend in outdoor recreational opportunities is articulated as is the importance of the social cohesion a small town offers these parents. The value they place on knowing who is in their community, particularly the relationship with service providers was evident.

The parent experience encompasses the unique experiences of the parents having to give birth outside of their home community, the emotionally intense experience of dealing with an immediate diagnosis of a disability or the pursuit of discovering the child has a developmental delay. The timing of this information and the journey to obtaining diagnostic or developmental information was experienced

differently by each parent. These parents lived with the unknown and this experience changes them as people.

The shared family experiences of these parents were the issues and challenges related to increased travel to larger centers for services given their geographic location. This travel created additional experiences as time away from family members during very stressful times in their young child's life, the constant consideration of do I travel these roads and this time as how sick is my child? The financial burden of the travel as well as the additional financial burden of obtaining necessary supplies and resources for their child was experienced by all the parents. The parents discussed the importance of the relationship with the local service provider, and the pivotal role of the Infant Development consultant. This experience has changed these parents in their compassion and understanding of others as well as made them stronger advocates for themselves and their child.

The next chapter will provide a discussion of the findings within the existing research and literature on parenting a child with a disability or developmental delay when living in a rural or remote community in British Columbia. It also outlines the limitations and strengths of this present study as well as explores implications for early interventionists and other professionals and possible areas for future research.

Chapter Five: Discussion

Overview

The purpose of this study was to gain deeper understanding and describe the unique experience of raising a child with a disability or developmental delay when the family lives in a rural or remote community in British Columbia, from the perspective of the parent. Eight parents participated in two face-to-face semi-structure interviews that were categorized and analyzed using a systematic approach.

In this chapter, the significant findings within each broad theme of the study are discussed in context of the previous literature in the area. Implications for early interventionists and other professionals are outlined. The study's limitations and strengths are discussed and directions for future research are explored.

Key Findings in Relation to Previous Literature

The research question guiding this research provided the framework for the emergence of the three broad themes to the research: community experiences, parent experiences, and family experiences. To better understand these themes their connections to previous literature was examined and is discussed below by major themes.

Theme 1: Community Experiences. Several significant areas emerged within the theme community experiences. The families expressed no consensus as to what is rural and what is remote. Their identification with community as being rural was closely linked to the values these parents place on active outdoor lifestyle opportunities. They also highlighted the value they placed on the relationships they have within their community.

Rural versus remote. The ongoing negotiation of what constitutes a community as being either rural or remote is evident in the literature as well as the conversation with the parents in this study. The literature defines rural and remote based on geographic descriptors such as population, density, proximity to urban settings, and access to services (Macleod, Browne, & Leipert, 1998; Statistics Canada, 2009; Thomlinson, McDonagh, Crooks, & Lees, 2004). By MIZ definition, the participants in this study all lived in remote communities based on number of people commuting to a metropolitan area. However, while there was not consensus among the parents, the parents in the present study described their communities using identifying characteristics such as geographic location and proximity to service. Over half of the parents described their community as rural while the remaining parents described their community as remote due to lack of proximity to services. While important to discuss the concept and definitions of rural or remote from a research perspective, identification of the community one lives in appeared unique to each individual participating in this study.

Small town. While the parents description or identification of their community as either rural or remote was inclusive of the factors described in the literature, most of the parents referred to their community as “small town.” This small town concept was described as close proximity to services such as doctor’s offices, grocery stores, work and/or child care. This close proximity to services provided families with more leisure time to pursue outdoor lifestyle and recreational activities which they valued. Consistent with the work of Thomlinson et al. (2004), participants defined rural as more than just a geographic location but as an integral part of their lifestyle. Also consistent with the Thomlinson et al. (2004) research was the importance of health as a balance between

the physical, mental, social, and spiritual aspects of one's life. All the parents commented on the importance of their network of family, friends or church groups as sources of support and information.

Relationships. The parents in this study liked knowing who lived in their community and being known in their community. The small town and outdoor recreational experiences also created opportunities for the parents to see service providers as active participants in the community. The parents commented that seeing the service providers on the ski hill or in the grocery store made the service providers seem more “human” and this strengthened their trust in that relationship. These proximal relationships created a sense of safety and security for the families in this study.

Richards and Morse (2006) describe culture as beliefs, behaviors, norms, attitudes, social arrangements and describable patterns in the lives of the cultural group. It could be suggested that the culture of the rural and remote communities described by the parents participating in this study included active participation in nature and connection to the environment. It would also include social arrangements and attitudes that include a strong commitment to family and community as well as collective beliefs in the value of having a close meaningful relationship with people in your life, such as service providers.

Theme 2: Parenting Experiences. The second theme that emerged was that of parent experiences. These are experiences that are specific to the parenting of a child with a disability or developmental delay. The experiences discussed were the delivery, access to timely diagnostic and developmental screening, the intense response of

parents and the impact of the timing of receiving the diagnostic information on the parenting experience and the construction of the concept of disability.

Delivery. None of the parents gave birth to their child in the community they lived in. This was surprising to the researcher because not all the children had pre-natal diagnoses that would have suggested or required specialized medical care. It raises the issue of decreasing maternal care facilities and birthing opportunities (Brown, Varcoe, & Calam, 2012) in rural and remote communities. As the parents articulated the value they placed on relationships and feeling safe with their local service providers, one would question the impact of birthing outside the community when one identifies so strongly with the security of a small community. Brown, Varcoe, & Calam (2011) explored the birth experiences of First Nations women in remote communities in British Columbia who also need to deliver outside their community and found higher levels of post-natal depression, attachment concerns and overall feelings of disempowerment for the participants in the study.

Timely screening and diagnosis. Of importance to these parents given the special needs of their children, was access to timely and reliable screening and diagnostic information, a need not met within their community. Smith, Humphreys, & Wilson (2008) also found this in their research as access to timely screening and diagnostic information was a significant concern for most of the families in rural communities. For the two parents who obtained pre-natal screening in their community, the screening was not complete and the time between getting to an urban center for comprehensive screening information created significant stress for these parents. For one parent, the weeks of delay in obtaining accurate pre-natal screening that eventually took place in the urban center, meant that this family no longer had the

option to medically terminate the pregnancy if they had wished to do so, and they believed their choice was taken away. All diagnostic information pertaining to the children in this study was obtained outside of their community.

Parental response. Consistent with the literature on parental response to the experience of having a child with a disability, the parents in this study described experiences similar to the grief and loss literature. Sen & Yurtserver's (2006) study on the emotional experience of raising a child with a disability utilizes the language similar to that in the grief and loss literature in that many parents go through phases of shock, denial, suffering and depression as initial reactions to finding out they have a child with special needs. The parents in this study described their initial experience as shock, disbelief, surprise; they felt overwhelmed and hopeless. The parental experiences of stress, depression and trauma are also consistent with much of the literature on the impact of having a child with a disability or developmental delay (Hanson & Hanline, 1990; Hastings, Kovshoff, Ward, Espinosa, Brown, & Remington, 2005; Kelso, French, & Fernandez, 2005; Pelchat, Ricard, Perreault, Saucier, Bethiaume, & Bisson, 1999; Trute & Hiebert-Murphy, 2005). Most of the research in this area is collected retrospectively on parent's appraisal of their experience. The present study was not a retrospective study. The parents in this study who had children that were close to the age of 4, expressed greater appreciation for their child, and that their child was doing better than expected. This researcher developed a heightened awareness and understanding of the emotional intensity of the experience of having a child with a disability or developmental delay. The researcher speculated that inviting the parents to discuss their experience in an open way, would allow parents to express both the "joys and sorrows" of this experience. What became evident was that the intensity of

emotions was still being experienced by many of these parents. While a number of the parents indicated that it had been cathartic for them to share their stories, this is an experience that takes time to process.

The other consistent emotional experience for the parents in this study was the “unknown”, the uncertainty of what lies ahead. For the parents in this study with a child with a diagnosed disability, there were uncertainties about accessing future funding and transitioning into future programs. For parents in this study with a child with developmental delays, there was the ongoing challenge of determining what was to come next, what information should they be seeking, where to go next. Pighini (2008) found similar experiences in her research and referred to this as the ‘cycles of disability and anticipation’. This has implications not only for the stress level for parents but also for service providers to be aware of not only addressing the present needs of the child and family but also recognizing this need for future planning and ‘anticipatory guidance’ about what the next steps might be.

One mother participant in the present study described the father’s experience (her husband) with depression a few years after the birth of their child. There is very little literature on the father’s experience after the birth of a child with a disability and even less with a focus on the mental health or emotional aspect. Of the limited research, Pelchat, Ricard, Perreault, Saucier, Bethiaume, & Bisson (1999) report increased stress for fathers linked to the financial implications of caring for a child with disabilities and Hastings, Kovshoff, Ward, Espinosa, Brown, & Remington (2005) concluded that the father’s well-being is dependent on the mother’s well-being. Only one father was a participant in this study. Further exploration of the experience of

father's who are parenting a child with a disability or developmental delay would provide a valuable contribution to the field of early intervention.

Timing of diagnosis. For the parents in this study, it appeared that the timing of the diagnosis and having a child with a diagnosed disability had an impact on parents' experience. Stoneman (2007) and Wang et al. (2004) also found that parents of children with a diagnosis had lower levels of stress compared to parents of children without a diagnosis. In Stoneman's (2007) study on children with Down Syndrome, parents reported that with a specific diagnosis for their child they were able to access specific information they needed and support. One parent in the present study stated that although it was helpful to connect with parents of children with the same diagnosis, her child was doing better than other children with the same diagnosis and she experienced some guilt and feeling that she really did not fit in. Parents of the children with a developmental delay in the present study expressed that they would just like to know the diagnosis so they could explain to others, have a plan of what will happen next. Trute and Hiebert-Murphy (2002) reported that parents who received an earlier confirmed diagnosis had higher levels of satisfaction.

Construction of Disability. The parental construction of disability in this study was primarily derived from the parents' own experiences with persons who have a disability currently in their community or from their childhood experiences. The parents in the present study noted a difference between cognitive and physical disability stating that having a child who would not understand or not be able to live independently would be much worse than having a child with a motor limitation.

It was of particular interest to the researcher to ascertain if the parent's construction or meaning-making of disability would be influenced by the "culture" of

rural and remote communities, since that culture values active lifestyles and the social cohesion a small town provides. It could be suggested that due to the young age of the children in the present study, the parent's construction was not yet heavily influenced by broader systemic influences such as school or community.

Theme 3: Family experiences. The families in the present study expressed a number of experiences that are shared experiences. The increased financial burden, travel and the negative impact of prolonged periods away from home were common family experiences. The presence of the infant development consultant was also important for these families.

Financial burden. The parenting experiences described by the participants in this study are consistent with much of the literature on raising a child with a disability regarding the burden of the additional costs of raising a child with a disability (Harvey, 2002; Sen & Yurtserver, 2006; Valentine, 2001). The research did not identify previous studies on significant travel costs. The participants discussed the additional costs related to the extensive travel such as the purchase of a new and reliable vehicle as well as the additional costs of locating specialized resources and having them shipped into rural communities. This can and did create significant stressors for some of the families which potentially can have a negative impact on family function.

Travel. The travel experience of families with children with special needs has not been fully explored in the literature of health care practices in rural communities. Often the studies look at the travel considerations for practitioners but not from the parent or family perspective. The parents in this study all required frequent travel to specialized medical interventions in urban settings far from where they lived. This study highlighted the frequency of travel required, the variability in road conditions when

travelling all year and the considerations or adjustments that need to be made when traveling with a small child or medically fragile child. The necessity of travel for medical and service interventions not only creates additional stress for the family, but will also impact on what the family is able to do during their limited time at home. The extensive time travelling may leave little time for the family to implement intervention suggestions or even to have time to maintain their home environment. It could also be suggested that due to the challenges of travel, parents may access emergency services more frequently because of the wait time they need to make the decision to travel, or the child may be more ill because of the travel time involved. It is important that neither the limited follow-through with intervention suggestions or possible increased use of emergency care is seen as the parent being non-compliant or neglectful, but rather; the parent making choices about use of limited time and resources.

Periods of separation. Another experience that was unique to two parents was the prolonged separation from family, including their other children, when their infant required longer hospitalization. The implications of both birthing outside of their home community and the prolonged separation then has potential to impact on the other parent-child relationships in the family. The parents described “attachment issues” with their children who remained at home while they were in the urban center caring for the medically involved child. The financial burden of this long separation was also described and that funding, while beneficial, does not consider all the day-to-day living expenses of maintaining two households.

Relationships with service providers. A significant person for parents in this study appeared to be their infant development consultant. The infant consultant, while not always the first person who the parent had contact with, provided long-term,

consistent, and local service provision. The parents considered this an important relationship. The infant consultant in some situations was instrumental in obtaining access to funding and resources that made a significant difference in the lives of the family. Family-centered practice has long been established as a philosophical approach to the delivery of early intervention services that produces better outcomes for parents of children with disabilities (Dunst, 2002; Dunst, Trivette, & Deal, 1988; King, King, Rosenbaum, & Goffin). The literature on family-centered practices discuss the importance of empowering parents, shared decision-making, etc. Trute and Hiebert-Murphy (2007) explore this further and examined the “working alliance” as a predictor of parental satisfaction with services. The key assertion is this alliance is the belief by both the client and the professional that they care for each other and they are working towards common goals. The parents in this study described knowing their infant development consultant “cared”. They reported that the consultant frequently checked in with the family, looking at all the family’s needs not just the child on their caseload. The importance and significance of this relationship for parents who live in rural and remote communities who have children with disabilities and developmental delays is two-fold. First, the parents valued interpersonal relationships and described it as core to living in a rural community. Even the parents who were not happy with the service provided indicated that they liked the person but may not be getting what they needed. For parents who have children under the age of 3, the infant development consultant may be the only child development specialist in the community and may hold the key to successful linkages to much-needed specialized information and resources. The complexity for parents is that although they value this local service provider, they also recognize they require the specialized services offered in urban centers. Some of the

parents indicated that they did not feel comfortable with what they perceived as a general lack of caring in urban centers. However, they do value the expertise provided in these centers.

Implications for Early Interventionists, and Other Professionals.

Specialized training for service providers in rural and remote communities would benefit early interventionists and other professionals to understand the critical role that “caring relationships” play in the lives of parents utilizing early intervention services. The importance and power of such relationships was important to the parents in the study. There is a challenge for the professional to being available and present in community while still maintaining professional boundaries and clarity of roles and responsibilities. Training that includes an exploration of the importance of a working alliance and a description of the pivotal role of the early interventionist in rural communities is necessary. Information on the developmental phases parents of young children with disabilities or developmental delays go through as well as information regarding the stages of stress and coping would provide some insight to parental responses or needs for engagement or support in their child’s critical first years. The ability to listen, reflect and refer appropriately are necessary skills and can be supported by appropriate and ongoing reflective supervision. Developing a reflective practice that includes an exploration of one’s own construction of disability is critical when working with families who have children with disabilities or developmental delays. The infant development consultant plays an important role in working with parents to gain understanding and acceptance into their child’s exceptionality.

Consultants in rural and remote communities also must stay linked to local, regional, provincial, and national networks and services that provide support and

information to parents who have children with additional needs. This is critical to be able to provide parents with current and relevant information within the context of the working alliance and caring relationship.

On a larger systemic level there needs to be more work done on the emotional and social impact of closing rural hospitals and having delivery options outside of the small community. The implications for families travelling great distances to access health care points to a need to explore other methods of service delivery for vulnerable children such as mobile technology, tele-health, or Skype outreach visits from urban centers. There is a need for expanded funding for families that looks at the entire family needs if, for example, a child needs to be hospitalized outside of the community. This affects not just the infant and parent but the entire family. Funding needs to take into consideration opportunities for the entire family to be together and to provide funds that reimburse for the significant costs incurred when living away from home.

Limitations and Strengths of the Present Study

Limitations. This study is limited in that it is small sample of parents and may not be representative of all families with children with diagnosed disabilities or delays living in rural and remote communities. While every attempt was made to recruit both mothers and fathers for this study and there was a clear intention and invitation for both parents to be involved in the interviews, only one father participated in this study. The voice of fathers raising a child with a disability is not strongly represented in this study although some of the mothers specifically described experiences of the father. An original intent of the study was to include both mothers and fathers as study participants. While every attempt was made to recruit both mothers and fathers for this study only one father ultimately participated in this study. As a result perceptions of

fathers raising a child with a disability, from the fathers themselves is not well represented in this study. Although some of the mothers specifically described experiences of the father these are still a mother's perception of the father's perspective. This study does not capture experiences of parents who decided to move to urban centers to obtain services for their child. It is well documented that parents with young children are often overburdened with responsibilities and therefore the respondents who participated in this study were motivated, engaged, and parents who were, for the most part pleased with the services they are receiving.

The participant response rate for this study was low. Factors that may have contributed to this low response could be that the initial invitation to programs to participate and subsequently distribute to parents, coincided with the holiday season in December. Also recent closures to the Provincial Office for the Infant Development Program in B.C. and subsequent changes to provincial and regional communication networks impeded communication with various Infant Development programs. The researcher's previous affiliation with the Infant Development Program may have been beneficial initially for gaining access to programs and infant development consultants but it may also have inhibited parents from speaking freely about experiences with consultants.

Strengths. This study had numerous strengths. The study met its intended objective of bringing the underrepresented voice of parents in rural and remote communities into the literature. This study started an exploration of the concept of the culture of rural communities and how that might impact relationships with service providers. This study brought to life the unique experiences faced by parents in rural and remote communities such as lengthy travels in challenging conditions that create

family burdens such as financial costs and time away from family. This study also demonstrated that while each family experience is unique in rural communities, parents who are raising a child with a disability or developmental delay share many of the same emotional and life experiences as other parents raising a child with a disability or developmental delay regardless of where they live. This study is a first step in the exploration of the linking of the construction of the meaning of disability within a specific cultural group. It emphasizes the approach to research and inquiry within the disability field must come from a place of reflectivity and understanding of the historical context and the social construction of disability.

Using a qualitative method of interviewing provided a rich and in-depth perspective on the parenting experience. The research method was rigorous and well suited to the research question.

Research that Should Come Next

Research that is longitudinal with the same parents would provide a rich insight into the parenting experience over time within the rural and remote context. As these parents were in a very early stage of parenting their experiences and response would change over time as they and their child interacted and engaged with more programs and systems such as preschool and school. Exploring how the interaction between these systems might influence the parent's further construction of disability.

Further exploration of the construction of disability within the rural community would be beneficial. As the predominant value of rural lifestyle is an active outdoor lifestyle, how does this impact a community construction of disability for a child that is not able to participate in this active lifestyle? Does the closeness of relationships in small communities create a buffer to the stressors to families who have children with

disabilities and/or developmental delays or do these relationships create additional stressors for the family in terms of understanding of disability and differences?

Further research should include more diversity reflective of the diverse population that lives in rural and remote BC. The involvement and perspective of fathers, families from more diverse cultural, ethnic, and socio-economic backgrounds and parents with English as a second language would provide valuable insight into the realities of living with a child with a disabilities or developmental delay. Given the high percentage of First Nations families living in rural and remote British Columbia, it would also be worthwhile to replicate this study within several First Nations communities. Also with the enormous migration from rural to urban centers, families residing in rural and remote British Columbia may be a slowly diminishing population.

The researcher was intrigued by the frequent use by parents of the term, “falling through the cracks”. Although parents used this term in varying situations from accessing services to concern that they as parents were not obtaining all the information necessary for their child, the term created this sense for the researcher that these parents live with the unknown, that they are fearful of missing out on a key piece of information or support or strategy. It would be valuable to further explore the concept of “falling through the cracks” and how this not only influences the parent child interaction, but also how this ongoing questioning might be influencing parental decision-making and acceptance and understanding of the current situation. It is reminiscent of the idea of, “waiting for the other shoe to drop.” Perhaps this line of research might provide some insight into the consideration of the accumulative risk factors for the parents and family and what are some of the mediating factors for the parent’s ability to cope and adjust.

Conclusions

Each parent's experience when living in rural and remote British Columbia and raising a child with a disability or developmental delay is as unique as each community, parent, and child. While there are many challenges of geographic isolation, low number of services and resources, the strength of each community lies in the value of outdoor healthy lifestyles, the social cohesion that members feel with one another and the potential for opportunity to build more significant and closer relationships with service providers in their community.

Each parent and therefore each family bring their own stories that need to be heard and explored in order to truly understand what the experience of having this child in their life means. That we need to get to know Erica, Jack, Beth, Adam, Suzy, Ann, and Kelly regardless of their diagnosis of disability or developmental delay in order to make true meaning of the parenting experience. Each child is a child first and lives and develops within their family constellation that provides the foundations for life.

A lecturer once said, early interventionists are in the relationship with parents and families for the sprint, a short distance, and families are in it for the marathon; they are the lasting relationship. As a service provider it is important to recognize the significant contribution that can be made by linking the parents with the information, programs services and support they need at the right times. It will prepare them for the marathon.

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Appendix A: Letter to Sponsoring Agencies

(Preliminary Letter of Introduction to the Project)

On HELP Letterhead

Name

Title: Executive Director/Program Director

Mailing Address

Date

My name is Hillel Goelman and I am a Professor with the Faculty of Education at the University of British Columbia in Vancouver. I am writing this letter is to request your support for our research team to work with your agency as we conduct a research project on the experiences of parents and service providers living in rural or remote communities. This letter of support will allow our research team to complete an application to the UBC Behavioural Research Ethics Board, in order to contact parents to conduct the outlined studies. Your participation and the participation of the families, is completely voluntary. It will require a minimal time commitment and will yield, we believe, significant benefits for families, service providers and agencies. This letter will answer a number of questions you might have about this work and the attachments will give you more specific details.

Who is funding this research - and why?

The research is funded by Human Development and Resources Canada through their Social Development Partnerships Program. The goal of the program is to find ways of enhancing the inclusion and participation of families who may have been marginalized due to disability, poverty, immigration or other factors.

Who are we approaching?

This work is an extension of our recently completed study in BC's Lower Mainland with parents of children with developmental delays. In this earlier study we also obtained the support from the Executive Director of the agency overseeing the IDP program, and from the Office of the Provincial Advisor of the Infant Development Program, on the recommendation of the former ID/SCD Steering Committee, that included the Provincial Advisors for the Aboriginal Infant Development Program and, the Supported /Aboriginal Supported Child Development Program. Due to the closure of the IDP Provincial Advisors' office we are now exclusively turning to the Executive Directors of agencies which administer these programs in the Interior and Northern regions of the province. The current program will include the voices of those families and service providers living in rural and remote communities. We hope that your office will be able to help us by writing a letter of support (see below and attached template), and by helping us contact families who may be interested in participating in this research.

What are the studies that will be conducted?

We are interested in conducting two studies with the **parents** of infants and children who participate in the Infant Development Program (Attachment A). One study involves two or three individual interviews to discuss with a small number of parents their experiences of raising a child with delays or disabilities while living in a rural and remote community; the study will also include a calendar for parents to fill in how often and where they access services for their child. We learned from the previous research that these interviews provide a powerful opportunity for parents' voices to be heard - while at the same time keeping the information gathered through this research anonymous. Ms Stewart will conduct the interviews as part of her master's thesis with the Faculty of Education at UBC. Ms. Stewart also has ample experience as an IDP consultant and Regional Advisor. Another study will provide parents the opportunity to rate their experiences of family centered service delivery in early intervention; for example, what works well for them and in what ways services can improve, by filling in an anonymous questionnaire.

A similar set of studies will follow that will examine the experiences of **service providers** working with your agency and with other child development/intervention and support agencies in BC.

Will the questionnaires and interviews be confidential?

Yes, they will be anonymous and confidential. No identifying data on the parents will ever be presented verbally, in print or digitally. Parents can terminate their participation at any time without any impact on their continuing involvement in IDP or any other services they may be receiving.

What are the benefits to the participant parents and agencies by supporting this work?

The findings from this research will provide an accurate picture of the needs and experiences of families with young children with special needs in rural and remote areas of the province. The information will be of benefit for early intervention programs, health and social service agencies in terms of decision making, future planning needs, and advocating for more resources specific to the needs of rural and remote communities. Moreover, at an international level, this research will highlight the outstanding work of these agencies, as they provide services to families facing numerous barriers in BC's in rural and remote communities. Families will also be invited to access the extensive resources on our website.

What should the letter of support say?

The letter of support should include a statement indicating that your agency is in agreement with contacting families for the completion of the "Including All Children and Families: Expanding Partnerships" project. For your convenience we have also included a *sample* letter of support, but feel free to use the content and format that best suits your agency. Please ensure that the letter is submitted on your agency's letterhead and signed by the appropriate individual. The letter may be sent by email (hillel.goelman@ubc.ca), faxed (604-822-0640) or by regular mail at:

Dr Hillel Goelman/Dr Mari Pighini
Human Early Learning Partnership
The University of British Columbia
440-2206 East Mall

Vancouver, BC V6T 1Z3

I know that this is somewhat short notice, but we would kindly appreciate your prompt reply by **(Wednesday, June 30)** indicating either your support or regrets in terms of your support for these studies.

We hope that this important project is of interest for your agency and that you will consider writing a letter of support. Should you have any questions or concerns about your role in supporting the completion of these studies, please do not hesitate to contact Dr Hillel Goelman, Project Director and Principal Investigator at (XXX) XXX-XXXX and/or Dr Mari Pighini, Research Coordinator at (XXX) XXX-XXXX.

All the best,

Hillel Goelman, Ph.D.
Professor, Faculty of Education
Chair, Interdisciplinary Studies Graduate Program

Appendix B: Agency Information Letter



THE UNIVERSITY OF BRITISH COLUMBIA

Department of Educational & Counseling Psychology & Special Education
Faculty of Education
2125 Main Mall
Vancouver, B. C. Canada V6T 1Z4
Tel: (XXX) XXX-XXXX | Fax: (XXX) XXX-XXXX

Experiences of Parents in Rural and Remote British Columbia

Who Have a Child with a Disability or Developmental Delay

AGENCY INFORMATION LETTER

Dear [INSERT NAME OF AGENCY WHO RESPONDED TO INTIAL REQUEST]

Thank-you for indicating your willingness to participate in our research project: “Including All Children and Families – Expanding Partnerships” with Dr. Hillel Goelman as Principal Investigator. This is an information letter to you regarding the first study we are embarking on under the larger research project:

This study is entitled: Experiences of parents living in rural and remote British Columbia who have child with a disability or developmental delay.

This is a qualitative study as part of the completion of a Masters in Early Childhood Education for Ms. Mary Stewart. As you may recall, Mary is also a part of the research team for the Including All Children and Families project. The purpose of this study is to learn more about parents experiences of raising a child with a diagnosed disability or developmental delay when they, the family lives in a rural or remote community of British Columbia.

We have included a parent information packet that we would like you to distribute to families on your caseload for the Infant Development Program. The Parent Information Packet contains:

- A Parent Introduction Letter - This letter outlines what is involved in this research study. A copy of the parent introduction letter is attached for your information.
- A Response Card - The response card is to be mailed back to Ms. Stewart if the parent would like more information or wishes to participate in this study. A copy of the response card is attached for your information.

You indicated that you have [INSERT NUMBER] families in your infant Development Program in the letter of interest that you returned earlier.

To help get our study started we need you to please send the Parent Information Packet to the parents (families) in your program that meet the following criteria:

- **Live in rural and remote communities in the Northern and Interior regions in British Columbia.** Rural and remote is defined as a community with a population under 10,000 or with a 0 in the middle of the first three digits in the postal code;
- Have a child between the age of 6 months to 47 months (3 years 11 months);
- Current or active in the Infant Development Program;
- Child has a “developmental delay” or “diagnosed disability”;
- Family/Parents can read and speak English.

After completion of this research, a summary of the findings will be sent to your agency.

Please feel free to contact us at any time if you require further information or wish to discuss this research in any way.

Laurie Ford, PhD
 Associate Professor, Principal Investigator
 Dept of Educational & Counselling Psychology & Special Education
 University of British Columbia
 Ph: XXX-XXX-XXXX
 Email: XXXXX@XXXX

Mary Stewart
 M.A. Student
 Early Childhood Education Program
 Centre for Cross Faculty Inquiry
 University of British Columbia
 Ph: XXX-XXX-XXXX
 Email: XXXX@XXXX.XX

Appendix C: Parent Introduction letter

THE UNIVERSITY OF BRITISH COLUMBIA



Department of Educational & Counseling Psychology & Special Education

Faculty of Education

2125 Main Mall

Vancouver, B. C. Canada V6T 1Z4

Tel: (XXX) XXX-XXXX | Fax: (XXX) XXX-XXXX

Experiences Of Parents Living In Rural And Remote British Columbia Who Have A Child With A Disability Or Developmental Delay

PARENT INTRODUCTION LETTER

Dear Parent/Guardian,

We are writing to invite you to take part in a research study that we are conducting in the Northern and Interior parts of British Columbia. We sent you this letter because you and your child take part in the [INSERT NAME] Infant Development Program.

Purpose:

The purpose of this study is to learn more about parents' experiences of raising a child with a disability or delay when the family lives in a rural or remote part of British Columbia.

Your experiences as a parent of a child with a disability or delay are important to us. The voice of parents living in rural and remote areas is often not shared in research. We hope that the findings from this study will teach us new things to help us better serve families living in rural and remote areas.

Taking part in the study means that:

- you will take part in two or three face-to-face interviews about living in a rural and remote area when you have a child with a disability or delay. You will be interviewed will by Ms. Mary Stewart. We will do the interview in your home or other location that you and Ms. Stewart agree on.
- each interview will last about 45 minutes to one hour.
- each interview will be audio taped.
- you may also be asked to share items of special interest or meaning to you about your child such as a special picture or special toy. We will talk about these items during the visit but we will not keep them. We will not remove any items from your home.
- you will be asked to let the Infant Development Program share a copy of your child's initial referral form. This one page form will help create a picture of the services and

supports you and your child receive.

- any childcare costs that you need so you can take part in the interviews will be paid by the researcher (\$8.50 per hour up to \$40 total). While you will need to sign in return for payment for costs you do not need to provide receipts.
- your taking part is voluntary and will not affect any services you and your child may receive from your Infant Development Program. You will be free to stop at any point, even after you sign the consent form.
- If you would like, you will receive a brief summary of the results within one year of the study completion.
- we are not aware of any risks if you take part in our study.
- the things you tell us not be shared with others using your name. **No individual information will be reported and no parent or child name will be in any reports about the study.**
- the information we collect will be stored in a locked filing cabinet in Dr. Ford's office. The only people who will have access to the things you share with us are the people working on this project.
- if you do decide to take part in this study, and if you have any concerns about you and your child's rights or treatment taking part in our research, you may contact the Research Subject Information Line in the UBC Office of Research Services at the University of British Columbia, at XXX-XXX-XXXX.

What do I do if I have questions or want to take part?

If you have any questions about this research project, you may contact Dr. Ford or Ms Stewart at the phone or email below. We hope you will take part in our study. If you would like to learn more about the study and what is involved or would like to participate in this study, please send the stamped Parent Response Card back to us at UBC. We have also included a sample of the consent for your review.

We look forward to hearing from you.
All the best,

Laurie Ford, PhD
Associate Professor, Principal Investigator
Dept of Educational & Counselling Psychology
& Special Education
University of British Columbia
XXX-XXX-XXXX XXXXX@XXX

Mary Stewart
M.A. Student
Early Childhood Education Program
Centre for Cross Faculty Inquiry
University of British Columbia
XXX-XXX-XXXX XXXX@XXXX

Appendix D: Response Card



THE UNIVERSITY OF BRITISH COLUMBIA

Department of Educational & Counseling Psychology & Special Education
Faculty of Education
2125 Main Mall
Vancouver, B. C. Canada V6T 1Z4
Tel: (XXX) XXX-XXXX | Fax: (XXX) XXX-XXXX

PARENT RESPONSE CARD

Experiences Of Parents Living In Rural And Remote British Columbia With A Child With A Disability Or Developmental Delay

_____ Yes, I wish to get more information about this study

_____ Yes, I wish to participate in the research study

_____ No, I do not wish to be contacted.

Your name (please print):

Your signature:

Date:

Your Phone Number:

The Best Time To Call:

_____ Morning

_____ Afternoon

_____ Evening

Appendix E: Parental Consent



THE UNIVERSITY OF BRITISH COLUMBIA

Department of Educational & Counseling Psychology & Special Education

Faculty of Education

2125 Main Mall

Vancouver, B. C. Canada V6T 1Z4

Tel: (XXX) XXX-XXXX | Fax: (XXX) XXX-XXXX

Experiences Of Parents Living In Rural And Remote British Columbia Who Have A Child With A Disability Or Developmental Delay

PARENT CONSENT

Dear Parent/Guardian,

Thank you for you taking part in our project. This is a follow up consent to the information letter we sent earlier. Please read the following form carefully as we review it with you. Sign one copy and leave it with Ms. Stewart before we start the interview. We will give you a copy of this information for your records.

Purpose:

The purpose of this study is to learn more about parents experiences of raising a child with a disability or developmental delay when the family lives in a rural or remote community of British Columbia.

Your experiences as a parent of a child with a disability or developmental delay are important to us. The voice of parents living in rural and remote areas is often not represented in research, especially if the parent has a child with a disability or developmental delay. We hope that the findings from this study will teach us new things to help us better serve families living in rural and remote areas.

Taking part in the study means that you understand that:

- you will take part in two or three face-to-face interviews about your experience living in a rural and remote community when you have a child with a diagnosed disability or developmental delay. This interview will be conducted by Ms. Mary Stewart It will be conducted in your home or other location that you and Ms. Stewart agree on.
- each interview will last about 45 minutes to one hour.
- each interview will be audio taped.
- you may also be asked to share items of special interest or meaning to you about your child such as a special picture or special toy. We will talk about these items during the visit but we will not keep them. No materials will be taken from your home.
- you will be asked allow the Infant Development Program to share a copy of your child's

initial referral form to the Infant Development Program. This one page form will create a broader picture of the services and supports you and your child receive in your community.

- any childcare expenses that you need so you can take part in the interviews will be paid by the researcher (\$8.50 per hour up to \$40 total). While we will ask you to sign for any reimbursement, receipts are not needed.
- your taking part is voluntary and will not affect any services you and your child may receive from your Infant Development Program. You will be free to stop at any point, or not to take part at all without any consequences, even after you sign the consent form.
- if you would like we will send you a brief summary of the results within one year of completion of the study.
- we are not aware of any risks if you and your child take part in our study.
- the information you give us is confidential. **No individual information will be reported and no parent or child will be identified by name** in any reports about the study. We will do everything we can to make sure there is no personally identifying information about you or your family in any report.
- the information collected will be stored in a locked filing cabinet in Dr. Ford's office. The only people who will have access to the information you give us are the researchers working on this project.
- if you do decide to take part in this study, and if you have any concerns about you and your child's rights or treatment taking part in our research, you may contact the Research Subject Information Line in the UBC Office of Research Services at the University of British Columbia, at XXX-XXX-XXXX.
- if you have any questions about this research project, you may contact Dr. Ford or Ms Stewart at the phone or email below.

What do I do if I have questions or want to take part?

We hope you will take part in our study. If you would like to learn more about the study and what is involved or would like to participate in this study, please send the stamped Parent Response Card back to us at UBC. We look forward to hearing from you.

Sincerely,

Laurie Ford, PhD
Associate Professor, Principal Investigator
Dept of Educational & Counselling Psychology
& Special Education
University of British Columbia
XXX-XXX-XXXX XXXX@XXXX

Mary Stewart
M.A. Student
Early Childhood Education Program
Centre for Cross Faculty Inquiry
University of British Columbia
XXX-XXX-XXXX XXXXX@XXXX

**Experiences Of Parents Living In Rural And Remote British Columbia
Who Have A Child With A Disability Or Developmental Delay.**

PARENT CONSENT

I have reviewed the consent information on the previous pages with Ms Stewart and understand what is being asked if I take part in this project (please check one).

Yes No

Please check one of the following:

Yes, I would like to take part in this study.

No, I do not want to take part in this study.

Your name (please print): _____

Your signature: _____

Date: _____

We will leave you one copy for your records

THANK YOU

If you would like to receive a copy of the results when we complete the study, please give us your mailing address. We will send you a summary of the results within one year of our completing the study.

Your Name: _____

Your Mailing Address: _____

Your City and Province: _____

Your Postal Code: _____

Please return this with your consent.

Appendix F: Eligibility Criteria Checklist

Experiences of Parents in Rural and Remote British Columbia Who Have a Child with a Disability or Developmental Delay

Eligibility checklist for parents during phone contact

The following information will be gathered during the phone call to those who express interest by returning the response card. It will be completed by the researcher during the phone conversation.

Date of contact	Parent name	Location name and postal code. Must live in a rural or remote community.	Child age 6 month to 47 months.	Diagnosed disability or developmental delay Yes/no

Appendix G: Interview Guide for Parent Interviews

Experiences of parents living in rural and remote British Columbia when raising a child with a disability or developmental delay.

Interview Guide for parent interviews

Note: This will be done in a face-to-face meeting with the parents and will serve as the starting point for the interviews in the study

1. Initial meeting:

a) Initial Introduction

Introduction of self and research study.

Discuss and sign consent form

Give parents information on community support resources

b) Background questions for parents. (Demographics)

Name _____

Age of parent: _____

Marital status: _____

Is there another person in a parenting role in your household?

If Yes, who? _____

If yes, What is their Age? _____

What is your Educational Level: _____

Age of child: _____

Any other children living in the home: _____

ages of children: _____

c) Initial interview questions:

Community questions:

Tell me about how you came to live in (name of community)?

How long have you lived here?

What is important to you about living in this community?

Child questions:

Tell me the story about how (your child/name) came into your life?

Were you expecting a child with disability or developmental delays

How has having a child with (disability or developmental delay) influenced your experiences as a parent?

Can you tell me about what your typical day would look like?

Do you have a support network, such as extended family or friends you can go to for assistance if you need it?

Where do you get most of your information about your child?

Where do you get most of your support about taking care of your child?

In your opinion, how would your experience of parenting be different if you were living in another place, for example a city?

Prompts:

Can you tell me more ...?

So what you are saying is....?

What was that like for you....?

2. Potential Follow up questions for Interviews two and three

Clarification of any outstanding comments or issues that parent raised that we not fully explored.

When we were discussing ----- you mentioned -----can you tell me more about that ...?

In reference to what you mentioned last time, what you were saying is....?

When you talked about -----what was that like for you.

I would like to know more about?