

A NARRATIVE STUDY OF THE EXPERIENCES OF IMMIGRANT PARENTS IN
CARING FOR THEIR CHILD WITH AUTISM

by

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Abstract

This study explored the experiences of immigrant parents caring for their child with autism. It has been suggested that families living with a child with autism are more likely to experience higher levels of stress compared to families who have typical children. Increased stress is also evident in immigrant families as they are exposed to new beliefs, values, and world views. Literature suggests that the experience of immigrant families and autism has not been explored. Hence, an exploratory investigation was conducted to investigate questions pertaining to these parents' experiences, and to generate questions for further research. A narrative paradigm was employed and focused on the experiences of three pairs of immigrant parents caring for a child with autism. The participants interviewed shared their experiences from their countries of origin; their current situations in Vancouver, B.C.; and their speculations and insights about the future. The narrative interviews were audio-taped, transcribed, and analyzed to develop a rich description of the participants' experiences. A systems - ecological approach was used to examine the topics in terms of relationships and subsequently applied to Christa Hoffman-Riem's conceptualization of "emotional normalization" (Hoffman-Riem, 1980).

Each of the experiences described in this study was unique and reflected the experiences of the primary participants from their own perspectives. Parents were primarily concerned about their child with autism as compared to the stresses related to immigration. From these experiences, common issues emerged in areas such as behaviour; social support; communication; family functioning styles and family related concerns; general stress; self-care; religion and spirituality; integration; finances; child

care; formal and informal support systems; parent advocacy; education and related services; independence and future concerns.

Table of Contents

Abstract.....	ii
Table of Contents.....	iv
Acknowledgements.....	viii
Chapter I. Introduction.....	1
Previous Investigations.....	3
Rationale for the study.....	4
Definition of Terms.....	6
Research Approach.....	6
Overview of the Thesis.....	7
Chapter II. Literature Review.....	9
Experiences of Parents of a Child with a Disability.....	9
Experiences of Immigrants.....	10
Personal Resources.....	11
Parents' Use of Personal Resources in Caring for a Child with a Disability.....	11
Immigrant Families' Use of Personal Resources.....	11
Social Support.....	12
Social Support and Parents Caring for a Child with A Disability.....	12
Informal Social Support.....	13
Formal Support Systems in British Columbia.....	14
Respite Care.....	15
Behaviorial Support.....	16
Self-Help Support Groups.....	16
Educational Supports.....	17
Social Support and Immigrant Families.....	20
Family Functioning.....	21

Family Functioning and Parents Caring for a Child with a Disability.....	21
Commitment.....	22
Flexibility.....	22
Optimism.....	22
Family Functioning and the Influence of Immigration.....	22
Systems-Ecological Perspective.....	24
Families as Systems.....	24
Emotional Normalization.....	25
Summary of the Literature Review.....	25
 Chapter III. Methodology.....	27
Basic Assumptions.....	27
Rationale.....	28
Relationships.....	29
Personal Background.....	32
Selection of the participants.....	33
In - Depth Interview.....	34
Analysis.....	36
Trustworthiness of the Study.....	38
 Chapter IV. Case Portraits.....	42
Portrait of a Korean Family.....	42
Portrait of a Philippino Family.....	49
Portrait of an English Family.....	55
 Chapter V. Discussion.....	66
The Interviews.....	66
The Relationships.....	68
Intra-familial Strengths.....	70

Family Identity	71
Commitment	71
Appreciation	71
Allocation of Time	72
Sense of Purpose	73
Congruence	74
Information Sharing	75
Communication	75
Rules and Value Systems	76
Coping / Resource Mobilization	77
Coping Strategies	77
Problem Solving Abilities	77
Optimism	78
Flexibility and Adaptability	79
Balance	81
Extra-familial relationships	81
The Education System	81
The Ministry for Children and Families	85
Autism Society of British Columbia	87
Finances	88
Informal Support System	88
Intra-, Inter-, and Extra-Familial Emotions	88
Sadness	89
Frustration	89
Guilt and Self-Blame	90
Anxiety	90
Fear	91
Embarrassment	91
Courage	92
Parents as Agents	93

Searching for Normality	94
Emotional Normalization	95
Practical Implications	97
Implications for Future Research	102
Summary	105
References	107
Appendix A - Bronfenbrenner's Ecological Model	117
Appendix B - Letter of Consent	118
Appendix C - Letter of Information	120

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Chapter I

Introduction

Autism is a developmental disability characterized by qualitative impairments in social interaction and communication, and a markedly restricted repertoire of activities and interests (Fong & Wilgosh, 1992). In many ways, the characteristics of autism are similar to the experiences of immigrant families caring for a child with autism, which is the focus of this thesis. The feeling of isolation is being all by oneself even though there are people around. The 'self' depends on the sense of place an individual has, not only physically, but also socially in terms of mutual obligations, commitments, and relationships (Ellis, 1994). Being burdened with linguistic handicaps, behavioral abnormalities and problems relating to others, a child with autism depends on his/her family to help plug him/her in. Families, more than any other entity, play an integral role in the development of their children (McDonald, Couchonnal, & Early, 1996). In fact, children with disabilities are more likely to be cared for by their families than any other social organization (McDonald et al., 1996). Generally, the family attempts to accommodate the developmental needs of its members and adapt to the demands of major events and changed social circumstances (McDonald et al., 1996).

Bronfenbrenner (1979) designed an ecological model which proposed that the individual and the family are affected by their immediate social and physical environment as well as by the interrelationship among the various settings of their immediate environment. They are further influenced by more remote social settings, such as economic and political processes, which, in turn, are influenced by cultural attitudes and ideologies (Strier, 1996). Bronfenbrenner's model is a useful approach to understand

immigrant parents caring for their children with autism. To illustrate, immigration often involves major changes in the physical, cultural, and social settings in which families function and develop (Strier, 1996). Consequently, the family is often confronted with unfamiliar challenges as members attempt to build new relationships. Having a child with autism combined with a lack of interaction with a foreign community may enhance feelings of isolation (Mesibov & Schopler, 1984; Strier, 1996). It has been said that culture is communication; and language, both verbal and nonverbal, is the primary mediator of our interactions with others. Language is more than words; it is a way of thinking and viewing the world (Hanson, 1992). For many immigrant families caring for a child with autism, messages cannot be adequately communicated, and thus the establishment of relationships is difficult. Consequently, feelings of frustration and isolation might prevail. Different patterns of interaction are required and each have a set of rules and norms. In a new culture with a new communication style, the establishment of new relationships take time.

Traditionally, the white middle class norm has informed our professional understanding of families living with autism (Hanson, 1990; Strier, 1996; Weick & Saleebey, 1995). As immigrants constitute a large percentage of the population, it is crucial that professionals value and recognize how culture influences family behavior. Moreover, in order to be an effective helper, an understanding of the different cultural perspectives that exist in issues surrounding child rearing, disabilities, change and intervention, treatment, family and family roles, and communication is essential (Hanson, 1990).

Previous Investigations

The body of literature on the effects of a disability on families present an “overwhelming and confusing body of knowledge characterized by competing hypotheses, conflicting findings, and tentative conclusions” (Jensen, 1992). Generally speaking, however, the current view in the literature on families of children with autism and other special needs is that these families are more likely to experience significantly higher levels of stress compared to families who have typical children (Beavers, Hampson, Hulgus, & Beavers, 1986; Donenberg & Baker, 1993; Factor, Perry, & Freeman, 1990; Fong & Wilgosh, 1992; Gallagher, Beckman, & Cross, 1983; Halroyd & McArthur, 1983; Hanson & Hanline, 1990; McDonald et al., 1996; Potaszniak & Nelson, 1984; Rousey, Best & Blacher, 1992; Wikler, 1981). It is important to note however that in facilitating change and maintaining continuity, many families have shown an ability to adapt to a variety of stressful events (Hanson, 1990). On the other hand, this stress may lead to family dysfunction requiring societal intervention (DeMyer, 1979; Fong & Wilgosh, 1992; Wikler, 1981). Research on families of special needs children has repeatedly indicated that the increased stress can result in social isolation (Cook, 1963; Cummings, Bailey, & Rie, 1966; Davis & MacKay, 1973; Erickson, 1968; Farber, 1975; McAllister, Butler, & Lei, 1973), and there are increased indicators of stress in the parents (Fong & Wilgosh, 1992; Bosch, 1996; Cummings et al., 1966; Cook, 1963; Erickson, 1968; Gallagher et al., 1983; McDonald et al., 1996).

Increased stress is also evident in families who are forced to live in a new culture as they are bombarded by unfamiliar beliefs, values, self-views, and world views. These families are confronted by new cultural norms and are forced to learn new ways of

thinking and behaving as different child rearing practices and ideologies held by the socializing agents of the host culture are dominant (Strier, 1996). On a basic level, the relations between immigrant parents and their children are vulnerable to the risks of immigration (Strier, 1996). Culture change also poses obstacles such as language difficulties, loss of friends and family, and the need to learn appropriate new social skills. Consequently, many families often experience psychological stress and isolation (Cross, 1995; Strier, 1996).

A literature review reveals that the subject, 'immigrant families and autism' has not been explored, and thus is the impetus for this study. Some parents come to Canada for their children's welfare only to find themselves isolated (Hee Nah, 1993). Indeed, the purpose of this exploratory study is to provide a foundation for subsequent research, generate hypotheses, and perhaps enrich future policies and programs.

Rationale for the Study

"Culture is the widening of the mind and of the spirit" (Hanson, 1990). Although it is a challenge to understand the many different customs, beliefs, and practices in our pluralistic society, it is essential for professionals who work with immigrant families caring for a child with autism to understand each family's value and belief system and attempt to eliminate their own inherent biases. The opportunity is for increased respect, trust, and understanding that will enable helpers and immigrant families to work together more harmoniously and effectively (Hanson, 1990; Sontag & Schacht, 1993). To empower an immigrant family, helpers must first honour the immigrants' home cultures and respect their knowledge and understanding, be sensitive to their decisions and choices, and be prepared to use the family's own expertise (Cochran, 1992; Hanson,

1990; Hirayama & Cetingok, 1988; Sontag & Schacht, 1993; Turnbull & Turnbull, 1994; Weick & Saleeby, 1995). "Empowering relationships develop over time and it takes time for participants to recognize the value that the relationship holds. Empowering relationships involve feelings of connectedness that are developed in situations of equality, caring and mutual purpose and intention"(Connelly & Clandinin, 1990). In a narrative interview, we can connect with these families and understand an immigrant family's personal dimension.

Over the past decade, professionals have been encouraged to collaborate with families of persons with special needs and mental illness, as families of children with disabilities are valuable resources for professionals who wish to help them (Collins & Collins, 1990; DeChillo, 1993; Grunebaum, 1986; Hatfield & Lefley, 1987; Lazar, 1988). Moreover, the empowerment of immigrant families, a goal of social work, relies on effective collaboration between immigrant families and helping professionals (Gold & Bogo, 1992; Hirayama & Cetingok, 1988; Strier, 1996). A review of previous research suggests that there is a lack of information pertaining to immigrant parents caring for their child with autism. It was hoped that my research would provide insight into the functioning of these immigrant families. It endeavored to highlight the concerns as well as the positive elements in their day-to-day experiences in caring for their child with autism. The purpose of this study was to understand the experiences of immigrant parents in caring for their child with autism. Parental strengths, ecological context of families, and instrumental needs including child care, financial, informational, and emotional parental needs were hoped to be highlighted.

Definition of Terms

This study explores the experiences of immigrant parents in caring for their child with autism. For the purpose of my thesis an 'immigrant' is defined as one who comes as a permanent resident to Canada. 'Autism' refers to a condition present from childhood characterized by complete self-absorption and a reduced ability to respond to or communicate with the outside world (Hart, 1993). Moreover, it is a severe, life-long, developmental disability, which affects an individual's behavior, communication skills, cognitive abilities, and social relationships (Fong & Wilgosh, 1992). It is identified by the presence of a set of behavioral symptoms that include the failure to develop normal social relationships; abnormalities in speech, language, and communication; abnormal relationships to objects, events and sensations; and a pattern of developmental delays or differences (Fong & Wilgosh, 1992). It is interesting to note that autism has been documented to be more stressful for families than other childhood disorders such as mental retardation or chronic physical illness (Bristol, 1984; Cummings et al., 1966; Fong & Wilgosh, 1992, & Holroyd & McArthur, 1976). 'Caring' refers to the ability to support and nurture one's children.

Research Approach

A narrative approach was employed for this research as this methodology is considered to be ideal in highlighting the living elements of relationships and the psychological processes (Jensen, 1992). Three immigrant couples from different countries were selected on an opportunistic basis, and were independently interviewed. In all cases, participants were parents caring for one or two primary aged (5-8 years) children with autism. Case portraits were developed which provided a collection of

perceptions from the participants used in the analysis. This method is an effective way to draw out valuable detailed information. According to Strickland (1994), participants are in the best position to make observations about “what one thinks one did in what settings in what ways for what felt reasons” (Strickland, 1994). In the analysis, a systems-ecological model was used to review the themes in terms of intra-, inter-, and extra-familial relationships. As parents caring for a child with autism attempt to achieve normality in relation to families living with typical children, Christa Hoffman-Riem’s conceptualization of emotional normalization is useful in that it helps describe the family’s quest to overcome the unordinary circumstances in caring for a child with autism (Hoffman-Riem, 1980).

Overview of the Thesis

This paper is organized into five chapters. Chapter 1 overviews the ecological context of immigrant families in caring for their child with autism. Previous investigations pertaining to autism and immigrants are discussed. It also includes the rationale for the study, definition of terms, and the research approach. Chapter 2, through an examination of the literature on autism and immigrants, discusses the information in two strands, immigrants and autism. The literature is reviewed within categories including personal resources, social support, and family functioning styles. Chapter 3 explains the methodology used. My personal perspective, design, procedures, selection of the participants, in-depth interview, analysis, the systems-ecological perspective, results, and strengths and limitations are discussed as well. Three case portraits of families from Korea, the Philippines, and England are included in Chapter 4. Chapter 5 includes the discussion of the findings. Themes are sorted into intra-familial and extra-familial

relationships. Intra-familial relationships include family identity, information sharing, and coping/resource mobilization. Extra-familial relationships include education, Ministry for Children and Families, finances, and informal support systems. As well, intra-, inter-, and extra-familial emotions are discussed. deCharm's concept of agency is useful in describing these parents (deCharms, 1976). Finally, Christa Hoffman-Riem's conceptualization of emotional normalization is discussed. This paper concludes with a discussion of practical and future implications.

Chapter II

Literature Review

An abundance of literature exists on families living with children with autism and/or other disabilities (Beavers et al., 1986; Beckman et al., 1983; Bosch, 1996; Bristol & Schopler, 1984; Cutler & Kozoff, 1987; DeMyer, 1979; Donenberg & Baker, 1993; Fong & Wilgosh, 1992; Hanson & Hanline, 1990; Sherman & Coccozza, 1984). As well, much has been written pertaining to immigrant families; however, there is no literature available which combines 'immigrant families living with a child with autism'. Current and relevant information on each of these topics is reviewed in this section.

Experiences of Parents of a Child with Disabilities

The literature is consistent in identifying numerous stresses presented in families of persons with developmental disabilities (Beavers et al., 1986; Beckman, et al., 1983; Bosch, 1996; Donenberg & Baker, 1993; Fong & Wilgosh, 1992; Hanson & Hanline, 1990; Sherman & Coccozza, 1984). Stress in families of children with autism has been documented as well (Breslau & Davis, 1986; Bristol & Schopler, 1984; Cutler & Kozoff, 1987; DeMyer, 1979; Fong & Wilgosh, 1992; Schopler & Mesibov, 1984). Parenting a child with autism likely produces stresses for the family because of the magnitude, intensity, duration, and unpredictability of the situation (Fong & Wilgosh, 1992). For example, parental stress is often attributed to the child's poor communication skills and the child's inability to understand developmental tasks. As well, infants with inconsistent temperaments or less social responsiveness may contribute to higher levels of stress in the parents (Bosch, 1996). Studies have drawn attention to a multitude of issues experienced by individuals with disabilities and their families pertaining to family resources, social

support, and family functioning. The demands of caring for a child with special needs may be discrepant with the family's financial, social, or physical resources, thus contributing to stress. Most literature suggests that living with autism on a daily basis can leave parents exhausted, pessimistic, and at risk for burnout (Factor, Perry, & Freeman, 1990; Schopler & Mesibov, 1984; Sullivan, 1979). Generally, families of children with autism report feelings of stress on each parent individually, the marriage, and other siblings (Fong & Wilgosh, 1992). Because the child with autism appears physically normal and often extraordinarily attractive, whether or not the child has autism is ambiguous. Mothers often feel responsible for their child's atypical behavior until proven otherwise. Often these feelings of guilt and inadequacy are reinforced by professionals who imply either that there is no problem or that the problem is one of parental mismanagement. Indeed, the ambiguity of the child's autism can significantly increase the risk of family crisis (Schopler & Mesibov, 1984).

Experiences of Immigrants

The adaptation experiences of immigrants vary according to their place of origin, occupation and education, traditional values, and socialization (Hee Nah, 1993; Kessler-Harris & Yans-McLaughlin, 1979). The literature has stressed some common aspects of experience among the immigrants, specifically in language (Portes & Rumbaut, 1990), employment (Portes & Rumbaut, 1990), adjustment stress (Hee Nah, 1993), and interpersonal conflict (Hee Nah, 1993). Indeed, immigrants are subject to stress that natives seldom experience (Cross, 1995).

Personal Resources

Parents' Use of Personal Resources in Caring for a Child with a Disability

For families living with autism, the lack of resources can often be a source of stress. The economic burden of caring for a developmentally disabled child is undoubtedly much more demanding for lower class families (Sherman & Coccozza, 1984). Understandably, financial needs can be a source of stress for parents of children with developmental delays. Expenses can include hospitalization fees, specialized equipment, therapeutic and behavioural services, medications, and dietary supplements (Bosch, 1996). It has been reported that families who keep a child with special needs at home are more likely to show downward social mobility than those who utilize external assistance (Sherman & Coccozza, 1984). Secondly, many parents never get a break from their child as it is often extremely difficult to obtain suitable child care arrangements (Fong & Wilgosh, 1992; Wikler, 1981). Young children with unusual care giving requirements may demand specific amounts of time and energy from their parents which can contribute to parental fatigue (Bosch, 1996). Finally, some parents feel that their greatest need is informational resources, and they do not have access to enough information for various reasons. Parents reported that they are in constant search for information about services currently available and those which might be needed in the future (Bosch, 1996).

Immigrant Families' Use of Personal Resources

An immigrant family may also lack some personal resources (Hirayama & Cetingok, 1988). As immigrants are transplanted into an unfamiliar culture, many experience a sense of powerlessness (Hirayama & Cetingok, 1988). One factor which contributes to this sense of powerlessness is the lack of money. Economic survival is the

foremost concern for most immigrants (Hee Nah, 1988). It has been noted that professional immigrants often begin at the lowest level in their occupational field, regardless of their premigration experience credentials, and they often face underemployment (Hee Nah, 1988). Certainly, the data pertaining to resources with families living with children with special needs and immigrant families is pertinent; however information on resources for immigrant families living with a child with autism has yet to be researched.

Social Support

Social Support and Parents Caring for a Child with a Disability

Another important area which appears to influence the coping ability of parents with a child with special needs is social support (Bristol, 1984; Holroyd, 1974). Satisfaction with social support is often more important than the social support actually received. Satisfaction has been linked to feelings of maternal competence, the maternal ability to balance multiple roles, and instrumental support from informal networks (Bosch, 1996; Bristol, 1984; Fong & Wilgosh, 1992). Some researchers have also found that mothers of children with autism who experience the least stress receive the greatest support, particularly from their spouses and relatives (Fong & Wilgosh, 1992). Stress occurs when parents perceive that they lack the resources to act on certain situations (Bristol & Schopler, 1983). Support from spouses may be especially crucial (Belsky, 1984; Bristol & Schopler, 1983; Friedrich, Wilturner, & Cohen, 1985). Marital satisfaction may be difficult to attain. That is, fathers and mothers perceive and cope with their children with special needs in different ways (Rousey et al., 1992). To illustrate, some authors assert that mothers often blame themselves for their child's disorder and

suffer from more psychiatric problems such as reactive depression involving increased physical and psychological tension (Fong & Wilgosh, 1992; Mesibov & Schopler, 1984; Rousey et al., 1992). Parents may experience a grieving period in response to this unexpected life event; however the grieving is not resolved in a single phase, but may occur at various stages throughout the family life cycle (Bosch, 1996). In fact, community workers can “overestimate” the impact of the initial crisis and underestimate that of later grief episodes even though they are aware of the chronic nature of parental stress (Bosch, 1996). Few investigators have looked at fathers; however, it has been noted that fathers withdraw from family interactions altogether (Mesibov & Schopler, 1984), or that, sometimes, fathers report a reaction to the mother’s depression and preoccupations with the child’s autism (Fong & Wilgosh, 1992). The different responses can negatively influence the marital relationship (Weick & Saleebey, 1995). Nonetheless, mothers’ reports of marital satisfaction are highly correlated with her coping behaviors (Wikler, 1981).

Informal Social Support

Informal support systems have been found to be negatively correlated with the amount of stress perceived by parents of infants with developmental delays. Informal support systems such as friendships, in spite of their importance, may be difficult to establish. Research suggests that parents of children with special needs often experience stigmatized social interactions. They face hostile stares, judgmental comments, murmurs of pity, and intrusive requests for personal information (Wikler, 1981). Although parents report that they do learn to cope with the stigmatized interactions successfully, the growing discrepancy between the child’s size and mental functioning tends to increase

the number of stressful encounters (Wikler, 1981). Research suggests that the richest sources of information are other parents of children with autism, but these relationships pose problems due to the variability in autistic tendencies (Wikler, 1981). Research on the utilization of social services has indicated that ethnicity, income, geographic location, and disability status place an individual at risk for under utilization of services (Sontag & Schacht, 1993).

Formal Support Systems in British Columbia

Support from helping professionals can alleviate some stress (Bristol, 1984) and formal support services can foster the development of coping strategies; however, an effective formal support network can be hard to find (Farran, Metzger, & Sparling, 1986). Some parents go to specialists for advice and information, and they find that the advice offered is inadequate for handling the daily practical tasks of rearing a child with autism (Wikler, 1981). In fact, some parents start to resent professionals over time, and contend that they are more harmful than helpful (Mesibov & Schopler, 1984). One author stated that "too often, family therapists...have worked in ways that implicitly blamed the family" (Grunebaum, 1986). Working with professionals can intimidate some parents and can cause uneasy feelings (Bosch, 1996). Moreover, it has been documented that professionals harbor negative attitudes towards families of persons with special needs and have augmented the stress and guilt that families have already experienced (Appleton, 1974; Hatfield, 1978; Lamb & Oliphant, 1978). They often feel that the service delivery systems are 'unresponsive, fragmented, and dehumanizing' (McCallion & Toseland, 1993). Some parents report their help as having exclusionary and blaming attitudes (McDonald et al., 1996). It is known that early intervention for children with autism is

essential in order to reduce the long term impairments associated with autism in terms of both cost and the impact on the family and community. Without early diagnosis and intensive early intervention, the severe mental and social disabilities will continue. Consequently, treatment throughout their lives will be costly (British Columbia Council on Autism, 1998). More specifically, the current long waiting lists for services in B.C., and the decrease in services discourages opportunities for early intervention. Time is critical as a two or three year old will respond much more quickly to treatment than a five year old (B.C. Council on Autism, 1998).

Respite Care. Respite care has been consistently noted as one of the support services families need to help them cope (Apolloni & Triest, 1983; Bristol & Schopler, 1983; Salisbury & Intagliata, 1986). Generally, parents evaluate respite care very positively and suggest that it has improved their quality of life (Apolloni & Triest, 1983; Cohen & Wils, 1985; Factor et al., 1990). Recent studies have indicated that respite care leads to a decrease in negative maternal attitudes towards the child with disabilities and increased positive family interaction in families living with children with special needs (Wikler, 1981). It is important to note that users of respite care tended to be parents of children who were lower functioning and had more behavior problems. Non-users tended to report higher levels of perceived social support (Fong & Wilgosh, 1992). In B.C., the Ministry for Children and Families has implemented strategies which focuses on providing support that allows a family to “retain its dignity” with the assistance of respite services (B.C. Council on Autism, 1998). Recently, funding has not been able to keep up with the numbers of children diagnosed, and consequently, services are often not

implemented until the family is in crisis and the child's difficult behaviors are safety concerns (B.C. Council on Autism, 1998).

Behavioral Support. Three programs provided for families living with a child with autism include the Laurel Group, Communication Behavior Instruction (C.B.I.), and the Provincial Resource Program, formerly called Gateway. These programs are subsidized by the Ministry for Children and Families in B.C. Many families in B.C. have found that these programs have been useful in the implementation of behaviour modification programs in their homes. One behaviour modification program that parents find helpful is the Applied Behavior Analysis approach (A.B.A.), also referred to as the 'Lovaas' type of behavior analysis. The aim of this method is to simplify what a child with autism has to learn into its smallest components and then help the child put those skills together into a more meaningful activity (Pugh, 1998). A.B.A. has shown to be effective in modifying severe behaviour disorders among children with autism (B.C. Council on Autism, 1998). In fact, numerous families in B.C. are having to pay for programs as many therapies that families find useful are not covered by a Medical Services Plan (B.C. Council on Autism, 1998).

Self-Help support groups. Another source of support for family members living with someone with special needs is a self-help support group. Self-help groups for families of persons with autism have been found to provide a setting for the sharing of common problems and coping strategies for its members (Potaszniak & Nelson, 1984). As well, when input from professionals is available and consistent, families report being better equipped to cope with the situation (Test & Stein, 1980; Weick & Saleebey, 1995). Some of the benefits of being a part of a self - help group include an increased level of

awareness; understanding that there are others like oneself, peer acceptance without stress; increased tolerance of others; and an opportunity to share concerns and interests with others. One group created by individuals with autism is the ANCA Development Club for people who have autism. Through structured interactions, autistic persons are able to learn about autism and how it affects them directly. C.A.N.A.D.A., or the Canadian Autistic National Association for Determined Adults, is another support group for people with Asperger's Syndrome and Autism. The Autism Society of B.C., through the Autism Support Network (A.S.N.) has established an Autism support network across the province. This network consists of individual parents, foster parents, and professionals. They have worked together to create Parent Support Groups throughout the province who are interested in autism. The network connects individuals and groups in B.C. with information and provides conferences. As well, these groups provide family support such as crisis counselling and referral information, life services planning, advocacy, parent training, liaisons with professionals, resource agencies, and government agencies, community education, and a resource library. In addition, a volunteer buddy program and an integrated summer program are useful programs for families living with autism.

Educational supports. The education system has the potential to help a family living with a child with autism. Currently, the Vancouver school system labels the child with autism, and the child gets categorized and treated accordingly (Jones, 1995). For example, a vast number of immigrant children with autism in the Vancouver School District learn in segregated settings for students with emotional disturbance or behaviour disorders, and the "identification-labeling-treatment process" occurs within this

framework (Fine & Carlson, 1992). Too often, students with autism who speak English as a second language in these programs fall increasingly behind while missing instruction in regular classes. "In some cases, what they miss is more important than what they get" (Willis, 1993).

Research consistently finds that when families are involved in the educational process, children do better in school (Carlson, 1996). Active parental involvement is related to numerous positive educational outcomes for schools, parents, and students (Carlson, 1996). Despite evidence supporting the critical link between the family and school, as well as the considerable overlap of home and school socialization roles, genuine collaboration between these social systems is infrequent (Carlson, 1996).

Moreover, research has consistently found that teachers tend to blame parents when children are experiencing difficulty in school. Thus, parent - school collaboration most often occurs within the context of crisis, tension, frustration, and defensiveness rather than within the context of a mutually supportive and respectful relationship. Teachers are not provided the training to establish strong working relationships with parents; thus, they remain reactive to crises (Carlson, 1996). The incompatibility between school culture and solution - oriented family/school meetings suggests that a considerable amount of inservice teacher training may be necessary to shift teachers' attitudes from attention and documentation of a child's problems to a focus on strengths and possibilities (Carlson, 1996).

Literature suggests that many parents and teachers of children with autism support the mainstreaming philosophy in B.C. (B.C. Council on Autism, 1998). Parents strongly approve of the inclusion philosophy now endorsed by the B.C. Ministry of Education,

Skills and Training, but they worry about the dwindling of resources and trained personnel - both of which are in short supply in B.C.'s schools because of monetary limitations (B.C. Council on Autism, 1998).

In some cases, children with severe forms of autism are denied an appropriate education because the system does not provide more specific programs designed to assist them to acquire skills which would encourage their participation in the regular classroom environment (B.C. Council on Autism, 1998). Sometimes they are given medical exclusions and suspended for an indefinite period of time. Consequently, the responsibility often lies with the family in helping them to prepare them for life in the community. At present, the Ministry for Children and Families does not provide services during school hours for families living with children with autism (B.C. Council on Autism, 1998).

Special Education Technology (SET-B.C.) is a Provincial Resource Program established to assist school districts to educate students whose access to the curriculum is restricted primarily due to physical disabilities, visual impairments, and autism. This program is useful for families caring for a child with autism in that its main focus is the student, and the team meets with the school district teams to develop specific strategies. A look at the social support systems utilized by parents caring for a child with autism reveals the importance of both formal and informal support systems. Informal systems include friends and family. Formal systems include respite, self-help groups, and educational services.

Social Support and Immigrant Families

Research on immigrant families reveals that language barriers; unfamiliarity with the local customs, rules, and norms; subtle discrimination and prejudice against them; and the loss of social support networks, status roots, and the “connectedness” that are found in their native environment enhance feelings of isolation (Hirayama & Cetingok, 1988).

Until these families develop a new support system with various formal organizations such as schools, health care facilities, and the Ministry for Children and Families, they must adjust to the psychological and social stress alone. They are forced to learn a new set of behaviors and customs in order to establish new relationships. Although most immigrant families develop new support systems within or outside of their ethnic communities through personal relationships, voluntary associations, religious organizations, or other informal networks, some families fail to build relationships outside (Hirayama & Cetingok, 1988). It has been reported that cultural differences between families and the formal support system may affect service delivery. That is, cultural values may inhibit some families from discussing their personal lives and pressing issues with unfamiliar people. Hirayama & Cetingok claim that empowering immigrant families involves helping them cope effectively with their new environments by helping them develop and accept new roles and behaviors. As well, the helper must respect ethnic characteristics such as family loyalty, integration, cohesion, and mutual assistance (Hirayama & Cetingok, 1988). Some families may have family values that inhibit their reliance on outside help from the family (Bosch, 1996).

Except for immigrants from English-speaking countries, the first problem an immigrant encounters is learning a new language (Hee Nah, 1993). Occupation

determines the level of language skills that will be required (Hee Nah, 1993). Many immigrants get stuck in low level, unskilled jobs and thus attain a minimum level of language skills (Hee Nah, 1993).

Numerous immigrant families do not have extended family networks and neighbours on whom they can depend (Hirayama & Cetingok, 1988). When these are absent and when other supports are nonexistent, the family is forced to rely on its own inner resources. In such cases, the family is subjected to extreme stress (Hirayama & Cetingok, 1988). Moreover, many immigrants do not have the knowledge or information about where to seek help and many lack knowledge about civil, political, and legal systems. This can enhance feelings of alienation (Hirayama & Cetingok, 1988). The two factors which predict adjustment in many studies are relationships with others from one's home country and friendships with host country nationals (Cross, 1995; Furnham, 1988). In essence, satisfaction with one's social support network has been found to be inversely related to the experience of problems in living for a variety of populations (Turner, Frankel, & Levin, 1983).

Family Functioning

Family Functioning and Parents Caring for a Child with a Disability

Family functioning is the third area which has received significant attention in the literature. A multitude of theories have struggled to explain why families confronted by similarly stressful situations, respond in different ways. Interpersonal, intrapersonal, and ecological variables have all been suggested as important factors in these differential responses (Gill & Harris, 1991). Family functioning includes a family's attitude, level of commitment, flexibility, and optimism.

Commitment. To begin, many theorists have argued that the relationship dimension of family functioning, which has also been referred to as integration (Potasnick & Nelson, 1984) or cohesion (Olson, Russell, & Sprenkle, 1983), is an important stress-meeting resource (Potasnick & Nelson, 1984). That is, the degree to which family members are mutually supportive of one another and open in expressing their feelings is critical.

Flexibility. Another important dimension is the family's ability to be flexible and adaptable in times of stress (Potasnick & Nelson, 1984). Its ability to change its structure, share tasks and responsibilities, and have flexible roles to meet the changing demands within the environment are critical (Potasnick & Nelson, 1984). Often, internal conflict is evident within families of children with special needs which may cause problems for other siblings. The presence of a child with special needs may cause problems for the other siblings. That is, the child with disabilities may dominate the family's resources or another sibling may be expected to take on a mothering/support role against his/her will (McCallion & Toseland, 1993).

Optimism. Similarly, families who have positive attitudes and are able to find satisfaction in other areas of life, cope more easily with the stresses of a child with special needs than do families who do not use these strategies (Sherman & Coccozza, 1984; Bristol & Schopler, 1983)

Family Functioning and the Influence of Immigration

Many researchers have probed the processes of immigrant family functioning and cross-cultural adjustment (de Anda, 1984; Cross, 1995; Hee Nah, 1993; Hirayama & Cetingok, 1988). Factors such as age, marital status, and experience in other cultures

often predict adjustment. (Cross, 1995; Furnham & Bochner, 1986; Searle & Ward, 1990; Ward & Kennedy, 1992). It has been noted that immigrant families with an interdependent self-construal are more apt to pursue a sense of belonging with others (Cross, 1995). Thus, the individual's thoughts, feelings, and behaviors are largely a function of his or her relationships with others and group memberships (Cross, 1995). In contrast, individuals with an independent self-construal separate themselves from relationships or group memberships (Cross, 1995). It is interesting to note that East Asians encourage self-reliance so that they will not be a burden on the group (Cross, 1995; Lo, 1998). Many immigrants report that intimate relationships are difficult and thus derive minimal support from them (Hee Nah, 1993). At present, there is a gap in the literature about immigrant families' functioning style and how they cope with the stresses of a child with autism.

To conclude the literature review, it is important to note that other literature suggests that many families cope effectively and positively with the additional demands experienced in parenting a child with a disability (Krauss, 1993). Moreover, some research suggests that families of children with disabilities exhibit variability comparable to the general population in terms of parenting stress, family functioning, and marital satisfaction (Krauss, 1993). In fact, some authors claim that the stress of parenting a child with a disability brings some families closer together, and the rate of divorce in families of children with special needs does not differ significantly from families of typical children (Davis & MacKay, 1973; Wikler, 1981). Also, it has been documented that many immigrants thrive in a foreign community where they develop new support systems within or outside their ethnic communities through personal relationships,

voluntary associations, religious organizations, and other informal networks (Hirayama & Cetingok, 1988).

Systems - Ecological Perspective

Families as Systems

A systemic framework such as the systems-ecological orientation considers the reciprocal interplay of the child with autism within each system. Thus, in order to understand the experience of immigrant parents caring for their child with autism. The microsystem, exosystem, and macrosystem within which they live will be explored.

Bronfenbrenner's systems-ecological framework is useful in developing our understanding of immigrant parents caring for their children with autism. The term 'microsystem' refers to the relationship among the parents and child with autism and the environment in an immediate setting such as their home, school, and playground. The 'mesosystem' refers to the interrelationship among the various microsystems of which the child with autism is a part. The 'exosystem' considers the specific social structures and institutions of society such as transportation, social services, education, and mass media. The 'macrosystem' refers to the overall cultural and institutional patterns of which the other systems are parts. This includes the economic, political, legal, social, and educational systems (Fine, 1994). (Refer to Appendix A) It was thought that these perspectives might be helpful in explaining parents' interactions and relationships within these systems. The themes can be found in terms of relationships that prevail in the microsystem, mesosystem, macrosystem, and exosystem in which the parents reside.

Immigrant families, like all families, are systems in themselves. Each family strives to be open, ongoing, goal-seeking, and self-regulated. 'Open' refers to the parents

styles of operating within the families and with agencies in their external environments; they have open and honest exchanges with all family members and with people outside the families. 'Ongoing' refers to the state of flux that the families are in; family processes are dynamic. 'Goal seeking' described the parents' ambitions to help their children. Finally, self - regulated' refers to the families' rules which act as gatekeepers for the flow of information that flows into and out of the family systems (Becvar & Becvar, 1996).

Emotional Normalization

Indeed, Hoffmann-Riem's conception of 'emotional normalization' seems to be applicable to an understanding of immigrant parents experiences in caring for their child with autism both inside and outside of the family unit. To illustrate, the decision to move to another country is cause for a multitude of emotions including relief and happiness and fear and loneliness. Emotional normalization is the process whereby immigrant parents work hard to build 'normal' relationships and live a normal life by attempting to minimize the difference they feel that exists between themselves and more typical families. In order to achieve emotional normalization certain conditions need to be fulfilled in areas such as social support, family functioning, and family resources. Further exploration into prevalent themes and the concept of emotional normalization in terms of relationships will be presented in Chapter five.

Summary of the Literature Review

A literature review suggests that minimal research has been done pertaining to immigrant parents in caring for a child with autism. Information pertaining to immigrant parents and autism in relation to personal resources, social support, and family functioning styles was scarce. Hence, an exploratory study which describes the

experiences of immigrant parents in caring for their child with autism was seen as being useful.

Chapter III

Methodology

This chapter details the methodology and procedures employed in conducting the study. The first section includes an explanation of the narrative paradigm and basic assumptions of this mode of inquiry. My personal perspectives and beliefs about human nature as well as a rationale for why I adopted a narrative mode of inquiry is included in section 2. The third section overviews the design of the narrative study. The fourth section focuses on the selection of the participants, the interviews and analysis process. Finally, the chapter ends with some strengths and limitations of a narrative mode of inquiry.

Basic Assumptions

The focus of narrative inquiry is to understand a person's experience of their world. Humans are storytelling organisms who, individually and socially, lead storied lives. Thus, the study of narrative is the study of the ways humans experience the world (Connelly & Clandinin, 1990). Such a narrative inquiry invites rather than discourages storytelling (Strickland, 1994), and assumes that the researcher and the co-researcher create a co-constructed narrative, which is an interpretation of the story told by the interviewee. The analysis is a continuous process whereby a series of anecdotes and developing themes lead to a richer, more condensed, and coherent story to be told (Kvale, 1996).

Mishler (1986) suggests that an inquiry requires six steps: (a) interviews, (b) repeated listening to taped interviews and reading of the transcripts, (c) discovery of trajectories in the interviewee's history, (d) development and refinement of a model (e)

selection of a narrative as a representative case, and (f) specification of episodes and the structure of the narrative for detailed analysis and a co-constructed interpretation.

Another approach which was applied in my narrative analysis is Lee Strickland's account of narrative 'lenses' (Strickland, 1994). She contends that stories can be analyzed using different narrative 'lenses' such as (a) plot structure, (b) narrative structure of episodes, and (c) characteristics of the narrator and the protagonist. To illustrate, the plot of a story evolves as events and is related to an evaluative endpoint or goal which is important to the story teller (Strickland, 1994). As well, narrative structure of episodes is a useful method of analyzing the data. These episodes might be isolated by using a scheme developed by Silliam Labov and Joshua Waletsky consisting of an abstract, orientation, complicating action, evaluations, resolution, and a coda (Strickland, 1994). The most reportable incident then is something worth telling and is generally approached through a series of complicating actions connected either causally, temporally, or both (Strickland, 1994). Finally, a look at the protagonist and the narrator is pertinent. Strickland contends that the protagonist is an actor demonstrating the narrative truth of the past. The goal in understanding the story is to analyze why the storyteller reveals a particular version at a particular time (Strickland, 1994).

Rationale

The narrative paradigm describes our very being in the world; we interact with people and build relationships on the basis of how we make sense of them. We engage in informal interviews every day, as we listen to stories with friends and try to assign meaning (Ellis, 1994). "Conversation is a basic mode of human interaction. Human beings talk with each other - they interact, pose questions, and answer questions. Through

conversations we get to know other people, get to learn about their experiences, feelings, hopes and the world they live in” (Kvale, 1996). Voice is meaning that resides in the individual and enables that individual to participate in a community; “voice suggests relationships: the individual’s relationship to the meaning of her/his experience and hence, to language and the individual’s relationship to the other, since understanding is a social process” (Connelly & Clandinin, 1990). An unstructured interview is an ideal mode of inquiry for understanding how people experience their world. I agree that “forgetting the rules in creative interviewing allows research subjects to express themselves more freely, and thus to have a greater voice both in the research process and in the research report” (Casey, 1996). The researcher who approaches the interviews with pre-structured categories, would find only that which he/she had considered. A collaborative method which places emphasis on sharing historical narratives and first personal accounts of all relationships provides a richer depiction of the truth directly with the people with whom I am interested. My aim is to get their stories in the face of the constraints of their everyday social world. Persons are interviewed in hopes that they will share some stories with me. The narrative interview provides this opportunity.

Relationships

A paradigm which places emphasis on relationships was employed to understand the lived experience of immigrant parents in caring for their child with autism. The family system is a network of relationships which are interactive and are changing over time (Fine & Carlson, 1992). Each family provides the child with basic physical needs, emotional bonds, a secure base, life experiences, a network of communication, and models of appropriate behavior and attitudes. The parents’ ability to meet these important

functions is dependent upon many relationships, including the relationship with: his/her spouse, finances, formal and informal support services, the education system, community organizations, and the Ministry for Children and Families. Parent-child interaction depends on the role demands, stresses, and supports emanating from other settings. Not surprisingly, supportive links between the family setting and the external environment play a significant role in their relationships with their children with autism. In essence, the child with autism is nested in the family system; each family system is embedded within a larger ecology of social systems, and thus is affected by changes in the community and in society (Bosch, 1996). For the purpose of this thesis, a relationship is defined as an emotional association between two people. Moreover, two individuals relating together are not independent; they mutually influence each other. 'A' and 'B' exist in the context of a relationship in which each influences the other and both are equally cause and effect of each others behavior (Becvar & Becvar, 1996). Over time, A and B establish patterns characteristic of their particular relationship. A focus on the context and the processes that give meaning to the events provide a richer picture than looking at the individuals and events in isolation. In order to get a sense of the whole, I look at how the parts relate to each other. The experiences of parents caring for their child with autism becomes a window that I can look through to understand the parents place in the larger system. The various roles, relationships, and behavior patterns that characterize the parents, specific settings, and other people within that system paint a picture of the whole. Rhodes (1970) argues that emotional disturbance is a function of the reciprocity between the individual to his or her environments (Fine, 1994). He continues, "Disturbance is constituted from a reverberating circuit between the disturbing individual

and various significant individuals within the environmental settings such as government agencies and home. It is their disturbing exchange which creates the problem” (Fine, 1994). Hence, relationships play an integral role in the well being of parents caring for their children with autism and is worthy of investigation.

A look at the relationship between the child with autism and the world is important. DeMyer states that there are four broad categories of behavior consistent with the diagnosis of autism (DeMyer, 1979). These are: difficulties with social relationships, severe deficits in language, severe deficits in communication; and other associated features such as a strong resistance to change in the environment, insistence on routine, odd movements, behavior problems, attachment to inanimate objects, very unusual responses to common stimuli in the environment, lack of imaginative play, and the presence of splinter skills. It is important to note that autism itself has different features, and all have individual variations (DeMyer, 1979). Individuals with autism range from being severely delayed to academically gifted. People with autism vary tremendously in personality, intellectual capacities, social skills, and ability to cope with the everyday demands of society (DeMyer, 1979). Jensen (1992) suggests that most children with autism have difficulty with social relationships and the use of language (Jensen 1992).

The narrative paradigm, by means of an unstructured interview, gave the participants an opportunity to express their hopes and concerns in any manner. My role as listener and researcher required me to hear and understand the unfolding story in detail, and combine my understanding with theirs. I then sought to interpret the cultural processes that underlie the content of the stories themselves, and attempted to reveal the meaning of events through the lens of my interpretation. Currently, the fundamental

processes which underlie the relationships of immigrant parents and their child with autism and the relationships between the immigrant family and the members of the community are unknown. Thus, a plurivocal mode of inquiry is recommended since it results in a broader and deeper meaning of the immigrant parents' experiences. To effectively help immigrant parents living with autism, an understanding of the way they see the world is essential. From the patterns and themes that emerged from the narrative interviews, I hoped to identify what these families view as essential to their success or failure as a family unit. A co-construction of the narrative interviews may help to envision how to be more practically helpful for immigrant parents living with autism.

Personal Background

In a qualitative inquiry, relationships depend on two factors: the quality of our interactions and the quality of our self-awareness to help modify the impact of the self on our research (Peshkin, 1992). Hence, an understanding of some factors which contributed to my interest in immigrant families living with children with autism is pertinent. To begin, I started my career as a special education teacher in an inner city zone of the Vancouver School District. I instructed a Primary Educationally Handicapped Class consisting of students with severe autism. With this role, some of my responsibilities included the implementation of academic and behavior modification programs; however, a more demanding aspect of the job required me to provide support and assistance to these families who endured significant stresses due to a lack of resources, dysfunctional family operation, and a lack of informal and formal support systems. Many parents had recently arrived to Vancouver only to find themselves isolated and lost. In many cases, I

was the only connection to the community for many of these parents. To illustrate, at the end of the school year, many parents felt abandoned. In reality, I believed they were.

In addition, I bring to this study my most recent experience. In this past year, I have become a mother myself. Consequently, I am more aware of the stresses of parenthood, and I am astounded by the intensity of the experience. I have developed an understanding and an appreciation of support systems, resources, and family functioning styles. Being a parent of a *typical* child in one's *own* country of origin is demanding and all consuming in itself. I cannot imagine the complexities involved in being a new immigrant and having to care for a child with autism in an unfamiliar country. I seek a deeper understanding of how these families cope with their day to day issues whether it be handling the behaviors of their children, education, socialization, medical care, and family functioning.

More recently, I have taken on a new role with the Vancouver School Board as a District Area Counsellor in an area where 85% of the student population is of a different cultural orientation and do not speak English at home. Because my job requires that I do a great amount of counselling, consulting, and coordinating, it is essential that I have a deeper understanding of the cultural values and ideologies which play a role in parents' child rearing practices. Hence, I bring to this study a desire to help families of diverse cultural backgrounds.

Selection of the Participants

A variety of cultural backgrounds were included in my sample of parents who belonged to the Autism Society of B.C. An advertisement in search of immigrant parents living with a child with autism was placed in the Autism B.C. Newsletter. The criterion

for selecting participants required that the parents had lived in Canada for three years or less, and had a child between the ages of four and eight years old with autism. As well, it was preferred that each family be a family with two parents. The total sample consisted of three case portraits. The names of the interested participants, in this case there were three, were submitted to me by the Autism Society of B.C. The families reside in different areas of the lower mainland - Burnaby, Pitt Meadows, and Steveston, and the home countries include the Philippines, Korea, and England.

In-Depth Interview

Each participant was interviewed in person for at least two hours and all interviews were audio taped. Participants were provided with an opportunity to present their experiences in a non-structured and spontaneous way. I asked the participants to share with me their experiences in caring for their child with autism in their country of origin and in Canada. Immigrant parents searched for memories or thoughts that they chose to talk about. In two of three cases, the couples together gave me a combined account rather than two separate accounts. The first interview involved three phases. The first established and informed the co-researchers of the nature of my research. To illustrate, I conveyed to the participants that the purpose of my study was to understand the experiences of immigrant parents in caring for a child with autism. I justified my research project by stating that by attempting to understand some of the complexities, professionals and other social services will be better equipped to design and implement services that will effectively meet the needs of immigrant families in caring for their child with autism. All the participants were comfortable with my motivation and were very willing to share their stories. I tried to keep my introductory statement as unstructured as

possible to allow the participants to direct their own exploration. I hoped that they would include such things as a description of their feelings when they first discovered that they had a child with autism and a description of events that occurred prior to their decision to immigrate to Canada. As well, I used this opportunity to convey my respectful concern to the participants to foster a relationship of empathic understanding and trust. I took this opportunity to inform them that any information resulting from this research study would be kept strictly confidential. All documents were identified only by code number and kept in a locked filing cabinet. Participants were not be identified by name in any reports of the completed study and all data records on the computer and all discs were deleted at the end of the project (approximately six months). The second-phase of the interview was used for data gathering in the form of open-ended questions. In an attempt to uncover as many stories about these immigrant parents as possible, I kept it as unstructured as possible. I asked some questions occasionally for the purpose of clarification and to acquire an increased meaning of a topic. Questions included: "Share with me some experiences in your home country which you miss today, Describe some early memories in your home land, What is provided here in Vancouver which you did not experience in your country of origin?, What does that mean for you?, Could you tell me more about that?, What is it that you are missing? What do you need that you don't have?" (Ellis, 1994). I had to take great care not to direct my participants. The interview was deliberately kept unstructured in order to produce data that might otherwise be missed; however, I as the chief researcher did have a list of aspects that I hoped would be covered. Although there were non-verbal messages throughout the interview, most data which was analyzed was in the form of language, and these verbal descriptions were

interpreted by me. The extent and duration of these in-depth interviews varied and depended on the specific circumstances of each of the participants such as the nature of the experiences, the comfort level experienced by the participants, and the ability of the participant to express their experiences whether it be due to a language barrier or a sensitive topic. Finally, in the third phase of the interview, I summarized and interpreted the general gist of the interview. The participants had the opportunity to reply by stating, "That is exactly what I was trying to say," or "That is not quite what I feel." Each interview was audio-taped and then transcribed to be studied by me. After careful analysis of the first interview, I approached the second interview with specific questions in mind to help me fill in the gaps. After I identified different categories of meaning from the first interview - such as family functioning styles, social support systems, and family resources - I developed questions to increase the accuracy and meaning of my narrative interpretation.

Analysis

The data analysis took place in three parts. To begin, I adopted an unstructured interview format that invited respondents to speak in their own voices. Secondly, each interview was audio-taped and transcribed verbatim. The next step required a clarification of the material, by noting superfluous material such as digressions and repetitions and bringing the co-researchers own understanding into light as well as my perspectives. I began by reading over the descriptions searching for themes and significant connections. Themes can be thought of as "knots in the webs of our experience, around which certain experiences are spun and thus experienced as meaningful wholes" (Van Manen, 1984). Recurring topics were categorized under three main headings entitled support systems,

family functioning styles and family resources. Under those three main headings, I categorized the information into different sub-headings which include commitment, appreciation, allocation of time, sense of purpose, congruence among family members, communication, rules and values, coping strategies, optimism, flexibility and adaptability, balance, and extra-familial relationships such as the education system, Ministry for Children and Families, and finances. As well, intra-, inter-, and extra-familial emotions such as sadness, frustration, guilt and self-blame, anxiety, fear, embarrassment, and courage were discussed. After the information was stranded into categories, I tried to make sense of all these parts by looking at the whole. Narrative inquiry is strongly influenced by a sense of the whole that plays an integral role in the construction and the reading of a narrative account (Connelly & Clandinin, 1990). In attempting to search for the deeper values that reappear in various stories, I asked questions such as: What is absent in these stories in terms of my categorized topics such as social support networks, resources, and coping styles? Did they talk primarily of the past, present, or future? Is optimism present? What significant others appear in the stories? Who are the other characters and how does the co-researcher position him/herself in relation to them? Do the parents appear to be passive or active? (Ellis, 1994) By asking myself these questions, I gained a better understanding of their worlds. I tried to search for the commonalities present in all three cases by constructing a time line which included events that all three couples went through as discussed in the interview. They include (a) the events leading up to the decision to immigrate to Canada; (b) the triumphs and tribulations that they endured during the immigration process to Canada; and (c) the ongoing development and continuation of a variety of relationships both within and

outside of the family. The result is not a chronological life history, but a general portrayal of what engages, preoccupies, motivates, pleases, interests, frightens or displeases them (Ellis, 1994). Case portraits are presented. To respect the confidentiality of the participants, all names are fictional. My explanation attempts to weave the past experiences, emotions, attitudes, and interests of the immigrant parents caring for their child with autism. It is important to note that my data interpretation is a reconstruction of what the co-researchers themselves presented as their experiences. Their voices were woven throughout. I checked back with the participants to ensure that my account was consistent with their experiences.

The most overwhelming task in the data analysis was finding the link between my 'narrative construction' and my 'narrative criticism' (Cochran, 1990). That is, having to adjudicate between the whole and each part was a difficult challenge. My initial analysis of the narrative 'whole' revealed that the experiences of immigrant parents in caring for their child with autism revolves around the emotional work invested in a wide variety of relationships. The most emotional work is invested in their child with autism, and the majority of the relationships established thereafter are based on that focal point being the primary relationship. Whether it be in their country of origin or Canada, relationships play a significant role in the lives of immigrant parents living with a child with autism.

Trustworthiness of the Study

Numerous strengths and weaknesses play a role in the trustworthiness of my study. On a positive note, the narrative mode of inquiry provides immigrant parents caring for a child with autism an opportunity to build a research relationship with me. Being that my central concept in this study revolves around 'relationships', the narrative

paradigm is an ideal mode of inquiry. Moreover, simply telling their stories may be an empowering experience (Connelly & Clandinin, 1990). In other words, the collaborative nature of the research process has the potential to give immigrant parents an opportunity to see themselves as participants in their new communities.

Another strength in a narrative study is that it offers scope for questions that are of direct significance to practice. "The principal value of narrative is that its information comes complete with evaluations, explanations, and theories and with selectivities, silences, and slippage that are intrinsic to its representations of reality." (Casey, 1996) Narrative inquiry is flexible, adaptable, and includes non-verbal behavior.

An open ended interview is a spontaneous and flexible method which allows the interviewees to search for memories and thoughts that they wish to talk about in regards to caring for their child with autism, rather than being forced to respond to rigid questions.

As well, this method provided me an opportunity to utilize many of my counselling skills as I attempted to establish a bond with the story teller. I enjoy interacting with people, and I experienced great pleasure in hearing their stories and acquiring a deeper understanding of their lived experiences. I adopted a person centered approach, and I tried to be as open, neutral, and unbiased in the interview in spite of my own inherent subjectivities. Leading questions were avoided; however, open questions such as, "How do you feel it was helpful?" and "Why do you believe life was easier in Seoul?" were asked.

The narrative paradigm steered my research and provided the foundation for my interpretations; however, I tried to use multiple sources of evidence. During the collection

and interpretation of the data, I checked my interpretations of the specific experiences with the participants ideas to validate my findings. As well, a comparison between the co-researchers, the literature, a third party, and my prior experience with families living with autism further enriched my findings. Given that different people might systemize the anecdotes in different ways, I strengthened my research by having another person review the transcripts and put the information into categories.

Verbatim accounts of conversations such as audio tapes, and direct quotes on transcripts were studied, and these materials are highly valued as data (McMillan & Schumacher, 1997). However, the presence of the audio tape also caused some anxiety as expressed by some of the co-researchers. After the first few moments however, most people visibly relaxed and seemed to forget its presence.

I agree with Howard Schuman's statement which suggests that, "too much can be inferred from answers taken at face value to questions of dubious merit... all answers depend upon the way a question is formulated. Language is not a clean logical tool like mathematics that we can use with precision... As if this complexity were not enough, our answers are also influenced by who asks the question" (Mishler, 1986). By engaging in continuous self-questioning and re-evaluation of all phases of the research process, I made an effort to acknowledge my subjectivity so that I was aware of my potential biases during my data collection and analysis. Hence, another strength which is apparent in narrative research is the personal dimension such as the notion of reflexivity. With this method, I was encouraged to place myself in my research. In other words, I was not separate from the realities of which I was investigating. In order to authenticate my

interpretation, my own presuppositions were acknowledged. That is, myself and my emotions were implicated in this research (Connelly & Clandinin, 1990).

Being that a basic tenet for qualitative research is that the researcher is the major research instrument (Connelly & Clandinin, 1990), it was important to note my particular orientation in this study in order to understand how I arrived at the interpretation of the stories.

Due to cultural barriers and a general unfamiliarity with an unknown researcher, some of the parent volunteers might not have felt at ease to disclose personal anecdotes. In fact, one parent exclaimed, "Maybe I am intimidated because I am talking to a native Canadian like you." Consequently, I question the depth of each account.

In addition, in a limited time span, perhaps families were more willing to discuss areas in which they were coping well rather than their areas of grave concern. Moreover, a narrative study that entailed thirty interviews over a longer duration might have a different tone. In brief, another research study may not reveal the same results. However, it is important to note that a limited number of interviews with three immigrant families marks a beginning in the exploration of immigrant parents caring for their child with autism. Peshkin states:

When I disclose what I have seen, my results invite other researchers to look where I did and see what I saw. My ideas are candidates for others to entertain, not necessarily as truth, let alone Truth, but as positions about the nature and meaning of a phenomenon that may fit their sensibility and shape their sensibility and shape their thinking about their own inquiries (Peshkin, 1985; p. 280).

My research has laid the groundwork for future inquiry.

Chapter IV

Case Portraits

Portrait of a Korean family

Mr. and Mrs. K care for one seven year old boy, Tomas, with autism. They arrived to Canada five months ago from Seoul, Korea. A two hour interview with this friendly and cooperative family helped me acquire a richer understanding of their experiences in caring for their child with autism in Korea and in Canada. An initial interview with Mr. and Mrs. K revealed a family who is adjusting extraordinarily well to their new home here in Canada in spite of the recent significant changes in their lives.

Tomas is an attractive, healthy, and loving boy who has autism. They described Tomas as being “high functioning - academically able - who experiences social difficulties.” Consequently, he can be hyperactive, impulsive, distractible, and has a short attention span. He enjoys the company of his parents and has trouble adjusting to new situations. In the academic domain, they describe their son as doing quite well, and this is the reason why education is so important to them.

It appeared that life in Korea was challenging for various reasons. Primarily, due to the nature of the society, Mr. K felt like it was not the conducive environment to raise their son for several reasons. To begin, he described the city as being a “crowded city and the competition is very hard and I lived that kind of life. I think that for the smart child...for smart people, it is okay.” He continued to describe his son as having a little problem, and the Korean school system would not sufficiently meet his academic needs. He perceived the education system as being one that served the typical child, but was very unaccommodating for the child with special needs. In terms of special education, he

described the special education program in Korea as one that focuses on the affluent and gifted students, and hence was not suitable for his son. Mrs. K explained, "When we were in Seoul, there are so many kindergartens preschools there but no kindergarten wanted to enter Tomas. I had to go to another area. I had to drive thirty minutes every morning there and back." Mrs. K described the circumstances of her best friend in Seoul who has a child with autism, and has to stay in school all day with her autistic son. She explained, "There is a lot of sacrifice." Mrs. K explained, "A few years ago, the Ministry of Health in Korea did not even know the meaning of autism." Mr. K continued, "As parents of a child with autism, even the government does not have any knowledge, so how can we as parents educate them? Their understanding of autism and insecurities are not even known!" On a positive note, they expressed appreciation for the Lovaas program that was offered in Seoul for children and families living with autism. "My son owes a lot to the treatment in Seoul. In three months, he learned to speak and he could be better, but I could not find that here in Vancouver, and that is my disappointment." They explained that they moved to Canada primarily in search for a better education and a better life.

The Korean culture also played a role in their decision to move to Canada. He proclaimed, "So in terms of culture and infrastructure, it is very hard for us to live there." He continued, "Well, you know Confucianism, well they are conservative, and they are a little bit closed minded for special needs. That was very hard for us."

They described the sacrifices he made in terms of his career in order to be a better father. To illustrate, Mr. K expressed some regret in his statement, "I was very happy in Seoul because I was promised management there, but I wanted to take care of my family,

so I moved here. I am very happy now as I have the time to support my family right now.”

Furthermore, Mr. K described his life in Seoul has having no time to be with his wife and child. He described his working situation, “I used to work for a big company. I would work all day and come back at 11:00 at night. This is very common in Korea. I wanted to help my son and my wife, but I could not because I was so busy... working so hard. For my son he needs his mother but he needs his father as well. I could not do that in my mother country. Our son is our major priority.”

They expressed the importance of having a strong social support system in Korea such as family. Their parents, grandparents, and aunts would help them raise their son, and this seemed to lift some of the burdens involved in raising a child with autism. Family based childcare provided them with the luxury of spending some time together. As well, it seems that this informal support system made up the foundation of their social life.

The K's are recent immigrants to Vancouver, Canada, and arrived in Canada in the past year. Since they arrived in Canada, they have enjoyed their time here. They like the nature here and they reiterated the fact that “Canada keeps its children safe.” Presently, the family lives in a small town house that they recently purchased. Mr. K recently landed a job here to help make ends meet; however, it will not suffice for the long term. He described himself as being overqualified for the job in spite of having had to write some recent tests. At present, like in Korea, Mrs. K stays home with their son and is the primary care giver in the home. Mr. K works part time out of his home in a business related organization. They both seemed pleased about the increase in time which

Mr. K can spend with the family with his present employment. They are presently living on prior savings from their home country. Due to the daily demands such as feeding, bathing, disciplining, toileting, and disrupted sleeping patterns, both Mr. and Mrs. K feel overwhelmed sometimes. In fact, they opted not to have more children due to the pressing demands of Tomas on them. They simply do not have the energy or the resources.

Their decision to move to Canada was for educational reasons only. Their son simply was not getting the education that they deemed acceptable for him. "We are very motivated to educate him because he is high functioning. He is the highest in his math class. He does not speak well, but he does understand well. We are motivated. Even though he has a problem in social interaction." Generally, they have been very impressed with the school system here in that Tomas was granted a special education assistant in his home school and was integrated into a regular classroom immediately. "I can say, my son is autistic, and the school system is willing to help...most teachers support the child with special care." Mr. K explained, "When I decided to immigrate here, I was very worried, and I was worried about how my son would be in this society. After I arrived here, I was pleased." He explained that his meetings with the Autism Society of B.C. gave him very good information. As well, he had the opportunity to meet his son's principal, school teacher, and behavioral consultant. "I am very happy and comfortable because my son is adjusting quite well." However, they expressed some concern around the nature of the program, "They are not aggressive and proactive in treating them" (children with special needs). He is in search for a system which offers a specific program for his son and suggested that he cannot find one here in Vancouver. He explained that the official system in Vancouver have kind and supportive workers, but they do not know exactly

how to help. He continued, "What I mean is my son is high functioning...so if I offer him a good suitable education, he might be able to study at a university and he will have a suitable job which is my objective for my son, but in B.C. they think more about taking care of the child and that is no good. In Korea, they do not take care of the child, but they find something that heals them."

At present, Mr. K's biggest worry is around finances. Being that he is the 'bread winner' he feels a lot of stress, and he is very concerned about the money he is forced to spend on the Lovaas Program due to the fact that there is no assistance provided. "We spend about \$20,000 per year which is very very big money for us. We have to pay for the flight fare and accommodation for the American assistance. I could earn enough money in Korea but here it is different. I cannot have the job here. The language and I don't have any relationships here. I don't have any background here. Sometimes I don't live well. I can't sleep because I can't make money for the extra \$20,000 in this society because our background is different. I have to invest 1-2 -3 -10 years to make contacts. I have sleepless nights. I know that Canadians already spend a lot of money to give children like Tomas a full time teaching aid; we have many things but these are things that take care of the child. It should be more aggressive and proactive to heal the child with autism. I don't see that kind of public policy here in this province." He expressed some urgency. "If they cannot provide on time education, I mean who will take care of him? I mean, Mother and Father will die some day, right, so uuuhhh we have limited time maybe ten years. Without education, he will waste his life. So the time is now. We need money now. In ten years, we won't need any money. I won't need any financial

support at all. The time is now.” Mr. K made it very clear that he worries a lot about his financial resources.

They talked about the importance of establishing some friends here in Vancouver. For example, they described their place of residence as being a conducive place for meeting Canadians. As well, Mr. K stated, “I am trying to have Canadian friends, as this is better for me because I will live in Canada. I play golf with Canadians. Sometimes I go by myself and meet Canadian friends. If I don’t do that, I will hang around with only Koreans.”

It appeared that going out into the public was very difficult for various reasons. To begin, they shared their feelings of embarrassment and frustration. Mrs. K shared a story that seems to occur often in her life. “Especially in a public place... He does not want to line up in a shopping mall. He shouts sometimes and has screaming fits and tantrums. Everybody looks at us and wonders why my child does that. Sometimes I explain, but most of the time, I don’t. I say, I don’t know. A child with autism looks like a normal child so it is not easy.” She felt like people were questioning her child rearing practices by subtle acts of staring or avoidance, and claimed that she had little control over the situation.

They expressed a need for more time for themselves. In response to my question, “How would your life be if you did not have a child with autism?” They responded, “It would be like parents with normal kids. I could do something for myself. Now, I have a child with autism, I can’t do anything I want to do. The only time I have is in the fitness club. A little time I can forget about my son, but then I go back home and the hard time begins. You know what I mean?” Mr. K further explained, “Even when we have the time,

and Tomas is at school, we worry. I can't relax. I give them my cell phone number in case there is an emergency. Isn't it hell. It is hell!" They worried that the school would call them. Specifically, they worried that they would be contacted by the school for behavior problems. As well, they reported that they spent very little time away from their child with autism. Consequently, they did not have time to pursue a lot of their own interests and they had very little time with only each other. They expressed an interest in getting out and doing more activities together as a couple, but were limited due to the difficulty in finding suitable child care. They experienced anxiety in merely trying to find someone who is willing and has the skills to look after their child with autism.

"Sometimes we want to go to a dinner party, but we can't." It was clear that they had made numerous sacrifices, and this is clarified by Mr. K's statement, "Parents with autism should sacrifice their lives for their child."

Throughout the interview, many strengths were apparent. To illustrate, they described their relationship as being richer with their child with autism. "In the case of us, our relationship is enhanced. In Korea, some families are in trouble with their child with autism and some are happy. I think that we are a majority though. Many couples are happy with their child with autism. I think that we are a good couple. Our relationship has become better and better because the only person we can rely on is each other."

Portrait of a Philippino Family

Mr. and Mrs. P immigrated to Canada four months ago from the Philippines. They have three children ages six, four and ten months. The two oldest children have been diagnosed with various degrees of autism.

Mrs. P worked as an executive secretary in an international institution, Asian Development Bank. She described herself as being computer literate, and has a good understanding of various software programs. Her husband had a well paying job in Manila as he worked as a government employee.

Mrs. P described her job in the Philippines, "I had a really good job compared to other employees." She explained that her salary was very good; however she still could not afford child care. It was very clear to me that she has given up a lot, and Mrs. P feels that it is unfortunate that her government could not provide services for her children. She further explained that in the Philippines she can enroll her child in special programs, but then she had to stop because she could not afford it. She explained that children with autism are very hard to train and require special care, "They can't talk, they aren't toilet trained, no matter how hard I try to teach them, they are slow, hyperactive...all these things just eat up your time trying to take care of them."

When Mrs. P found out that her first child was autistic, she described it "Well, it is like the world fell down on me." She had a lot of hopes and dreams for her first child, "Before I had her, I was preparing already to give her a good education. I bought all these educational toys and books so you can just imagine my frustration when I found out something was wrong with her. I mean I would rather accept her as being a hare lip or polio, but now with a mental incapacity you know or mental disability because it is really

tough, because you cannot communicate and it is really frustrating. I really want to talk to her...really talk, but you can't do that, but now she has improved a lot, and she is really smart in some ways. She can do things. She can draw, she has a good vocabulary, and she can speak English now."

Before her second child was diagnosed, she had questions. They said, "Don't worry." She continued, "I was afraid that he might be autistic. I feel so stupid now when I look back. I blame myself. It pains me to realize that I waited too late for him." She admits that she had some questions when her son was three years old. During the first two years, she described her son as being fine. "I thought that he was a good boy because he did not cry often. He was different. He would just sleep through the night. He was so easy. He had eye contact, loving unlike my first. I thought that he started to speak at around eleven months. One time he pointed at an airplane, and said "airplane", and another time I thought that he said, "Momma." He was also mimicking T.V. commercials, he could follow simple instructions like throwing his diapers in the waste basket, and put on your slippers. If I was upstairs, and I yelled his name, he would come up..." She explained that her little boy is more severe than her daughter because he cannot talk at all. He can sing, and he can mimic what is on TV and radio, but he is not toilet trained. She talked about the discrepancies apparent in caring for a child with autism, "He can use a spoon, and apple, I put bits and pieces there and he can pick them up but when you make him pull his pants up, he can't do it! I just don't understand it. I would like to teach him, but I just cannot get it...it is very frustrating, and I cry a lot of buckets full."

When Mrs. P described her experience with being pregnant with her third child, she was both fearful and hopeful. "I did not want to get pregnant again...Oh, I prayed hard

and hard. I said I can accept it, but please give me a normal child with normal development.”

She described her feelings when she sees more typical families around her. “You are very lucky. When I see families around with three or four children and they are all normal...because when your child is normal, you can just talk to them straightly, but with them, I just can’t express it. You know, I want them to do things, but they just can’t do things no matter what I demonstrate it. I talk to them. My daughter...she just looks at me blankly through and through... just no contact. It makes me cry.” She later stated, “It is frustrating. I want to understand my children. I want to give them all the supports they need.” Mrs. P openly expressed her frustration in caring for her children with autism. She confessed that the endless and persistent amount of care that her children require is draining and exhausting for her.

She explained that they have made big compromises in moving to Canada. To begin, they presently live in a one bedroom apartment under crowded conditions. They hope that will eventually be able to afford better housing here in Canada. “We would like to get a house of our own one day.” She explained, “The first two weeks and even in fact now, we are both very sad and we just cry both of us.”

Since arriving in Canada, Mr. P has taken on a new job at McDonalds as a maintenance crew. He works night shifts, and his hours are from 11:00 p.m. - 7:00 a.m. He explained, “I feel really bad. I want to be with them. When I work especially leaving them altogether at night. In the Philippines we sleep in one room.” Mrs. P interrupted, “I tell him, don’t worry about me because he is guilty because he can’t help me take care of the kids.”

Their reasons for moving to Canada were solely based on the needs of their children. "We came here because of my children. They have problems. I did some researching, and I found that Canada is a great place to raise kids and I can give them a good education. They have special programs for children like them. Although we know it will be difficult, because we love them of course, we have to do it. She expressed to me with true conviction, "My children are my priority."

Since arriving to Canada, she has met with the social worker several times. She agrees that the social worker is knowledgeable, but she has not been instrumental in getting direct service. She attributed it to the economic situation in B.C. "I think the only problem that I see is a long waiting list because the budgets are being cut now and B.C. economy is in a slump. I am hoping that things will pick up."

She talked about the importance of social support. In the Philippines, they had relatives there which meant that she had both moral support and physical help. She explained that she had family and maids to help her look after the children. She proclaimed, "We could afford maids there but here we cannot, so it is a real shock! Although we knew it would be hard before coming here, but now it is a reality. It is really very tough."

Surprisingly, Mrs. P did not get a lot of support from friends in regards to her children with autism in the Philippines. She explained, "In the Philippines, it is very different there. They would not mock me. They would just talk about it and talk about it. It's like gossip you know. Oh, poor little Mrs. P. They have two abnormal children, and I just don't want to hear that."

In spite of the difficulties that they have encountered here in Canada, she stated, "But even though we are feeling that way, I feel that these hardships will come to something really worth while. Of course we are starting our life from scratch."

She is very optimistic about getting a job, but somewhat apprehensive too. She stated, "Because when I see the newspapers, I see there are jobs that fit for me, but I need to brush up on my English. So I think that I can make good money here as long as I can find help and the time." She further stated, "I don't want to be sitting at home and taking care of them. They also have to grow up and I will be working also and put my skills to use."

Mrs. P has a lot of hope in regards to her children's future. She proclaimed, "I also pray for my children that they grow up, that they will be able to marry. I hope that they will be able to work and carry a relationship, and I know that if I die, they will be okay. I want them to be able to develop like the way we are...carry on a family, have children like us. I still want them to go through life." She continued, "If they grow up to be normal people, we would be the happiest couple on earth, and we think that is possible. Here in Canada, we can work, we are still young, all the services are here, and Canadians are very helpful, and they care about children." On the whole, in spite of the sacrifices that she has made, she is very optimistic about her decision to move to Canada. She is headstrong and determined to make it work here in Canada. She talked about her supportive relationship with her husband, "We have not given up with each other and with the children also. We have to be strong for them, we have to do our best for them." She described her relationship as being closer since they arrived in Canada. "I think that

we became closer. We understood each other. I have no time to enjoy myself and he too... I mean, it's just us here...nobody else."

She is pleased with the friends that she has made here. She meets people at the mall or at the playground. She talked about the difference in sharing information about her children with autism, "But here it is more okay. I am more open. When I meet friends I tell people up front that my children are autistic because I am hoping that they can help me get through this more quickly because they know how it goes."

When asked if she has any time for herself, she replied, "No, I can't even do my nails. The peaceful time is when I take a bath. I close the door and take a shower and relax."

In order to cope with the day-to-day demands, she derives a lot of strength and insight from reading a variety of books. "Reading helps me understand my situations. Spiritual books - they give you hope."

Portrait of an English Family

Mr. and Mrs. T care for three children, Cindy, Samantha, and Susan. They are ten, seven, and five years old consecutively. The two youngest children have autism, one with severe autism and one with high functioning autism. Cindy, their middle daughter with autism, is described as being above average. She has a high level of understanding, and her I.Q. is comparable to any child her age. Mr. T stated, "She has no mental retardation as far as we can see. She has a communication problem." Their youngest child with autism is described as being a real "ham." She is very affectionate, energetic, and verbal, but exhibits a variety of other autistic tendencies such as a resistance to change, perseveration, and communication difficulties. The family members are recent immigrants to Canada, and arrived here six months ago from England. According to Mr. T, I picked an interesting time to come and interview them. They were enduring a very grueling heat wave, and Mrs. T was taking care of her three children with minimal assistance.

It appeared that life in their home country had both positive and negative features. He spoke highly of the autism panel in England which is made up of a pediatrician, a psychologist, a psychiatrist, a speech therapist, and several other disciplines who are all involved in deciding whether a child is autistic and that review starts at about eighteen months. "Most children in our county are diagnosed with autism by two years old. So, by the time the child is thirty six months old, they are in full time education." He described the story of his two girls with autism. At twelve months old, a hearing test revealed that there was something wrong with Samantha. At eighteen months it was confirmed that

Samantha had autism. Susan, on the other hand, did not manifest the same symptoms. She had the intonation and communication skills unlike Samantha, and consequently there was a time when they thought that Susan would be okay. As time went on, they realized that something was wrong; but she did not demonstrate enough of the key indicators to warrant an official autism diagnosis. He is very impressed with the organization and early intervention programs in England. Even without an official diagnosis, they promptly got Susan into a speech therapy program two days a week and received intensive one on one help. Mr. T said that, "I am sure that she would not have done so well, if she did not have that early support."

Generally, the education system had its serious drawbacks. They decided to move to Canada for primarily educational reasons. Their decision to move to Canada was "more in keeping with what we wanted our kids to get in education. We had to make a decision." He further stated, " We have always thought that Canada was full of opportunity for us compared to being in England." When they were faced with the closure of the local school where their eldest daughter with autism was attending due to a lack of personnel who could deal with her needs, they were faced with the decision of either moving to a new country (Canada) where they had Mr. T's brother and other relations or move to a new county in England.

When they visited Canada four years ago, they were looking for a school for their oldest child, they saw three things happening. When they asked about a special school for Samantha, the principal responded, "Why?" and preceded to talk about the mainstreaming program in B.C. Mr. T further explained that, "It was a refreshing change in that the principal of the school understood the situation about autism and what was

required and how to arrange for support, and it seemed like that was exactly what we wanted. We knew that our daughter did better when she was with regular mainstream kids.” Moreover, he said, “Research is saying that children who are in a normal environment who are autistic do better.” In London, she was in a classroom with a general group of children with special needs such as Downs syndrome, autism, and various other needs...she was getting one on one support but she was not being taught how to be normal. Rather she was being taught how to be normal within the special class...”

Secondly, Canada seemed like a great choice in terms of what the Ministry had to offer. A story he shared which prompted their move to Canada was with the Ministry. He continued, “We phoned the ministry in Maple Ridge, and they said that they would phone back at 2:00 p.m., and they phoned back at ten after two, and said, “Sorry for phoning back late. Now, in England, if you got a phone call back in the same week, it was a miracle, so that was impressive!”

Finally, they were very impressed with the level of general services that they could expect such as “respite care, speech therapy, and all the rest of it.” He concluded by saying that “We were given quite an education, and we thought at the time it was going to be different than what it turned out to be.”

The education system has turned out to be very helpful in certain respects and very disappointing in others. To begin, he explained, “There is no allowance for parents to have any involvement in any of the decisions about children especially in the school system. It specifically stated with the school board that parents have no say. On page 51 of the CUPE agreement, it said that the special needs of children of children with special

needs to be taken into account prior to any decisions about changes in their environment.”

He explained on a positive note that his daughter has a full time special education assistant (S.E.A.) in the present system. He described her as being “trained, educated, a hard worker, and being the right person in the right place.” Unfortunately, that S.E.A. was bumped by another union member without consultation with anyone. He is very disgruntled about the sequence of events that followed. That S.E.A. received a form letter sent by the union to the school board stating that these people were bumped and these people were filling in. The only reason they found out was an accident due to an employee working late. He stated, “If she had not received it we, the school, the teachers, would not have found out until the first day of school and nobody would have known who this person was, and I am supposed to introduce a child with autism who cannot cope with walking down the opposite side of the street. It is not reasonable!”

In response to this unfair action, he and his wife complained about the actions taken by the school district’s manager of special needs. He explained, “That title to me sounds like someone who has some educational experience. Well, it’s not. This person is an administrator, and this person is supposed to decide who is going to work with my child.” He wrote letters complaining about the decision to remove his daughter’s S.E.A. He complained that it took one week for a response and the woman was impossible to contact. When they finally got in touch with her secretary, she informed them that this woman has nothing to do with the hiring and firing of an S.E.A. They were then told that they would have to write to the school board, the administration offices and request that the information be passed on. He complains, “We would have to do this, not them, who had been told that there is a problem coming up with two of their S.E.A.s but they were

not going to do anything about it.” Mr. T suggested, “What I want is somebody to sit down and coordinate this and organize this for you.”

The T family lives in a somewhat spacious home (relative to their home in London) in Pitt Meadows, BC. The major source of income for the family consists of Mr. T’s monthly salary. Mrs. T also works a night shift on a paper route. She works from 2:20 a.m. until 6:00 a.m. Monday through Friday. By Friday, he explained that his wife is “on her knees and she pretty well sleeps all weekend.” Although Mrs. T is a trained registered nurse, the only employment that can accommodate the heavy demands from day to day is a paper route. Mr. T stated, “But now she is delivering papers because that is all she has time or the wherewithal to do.” He is very proud of his wife’s accomplishments and explained, “She has a list of qualifications coming out of her ears as far as psychology goes. She has published half a dozen articles. She has been a co-editor of several books and she has written several chapters of books. This is what we call P.K. - Pre-Kids.”

Their three children require a significant amount of time and energy. “They are 24 hour a day children but I have to find time in-between to work, so does my wife, this house needs cleaning, there is work to be done in the house. All this is secondary to the kids.”

At present, they have had to make numerous compromises and accommodations for their two children with autism. Because their children with autism were not aware of danger, everything in their house was locked up. He described, “We double lock the front door, double lock the back door, double lock the side gate, the fence around the house is six feet high, the people next door have built a six foot gate over their driveway just so

there is an additional stop for that child not to go out on the main road.” It appears that all doors are locked including the fridge.

Mr. T exclaimed, “In the future when she is 25 years old, and I am dead, she is not a full cost to society and living in an institution. I want her to be one of the 40% of children with autism who actually get out into shared accommodation or hopefully live on their own.”

Since arriving to Canada, they have discovered that “There are similar problems here, like England, but there are bigger benefits, at least down the road. We have lost a lot that we did not think that we would have to lose. There are battles that we have had to fight that we should not have to fight. It is the responsibility of the government that they are not taking up.” Mr. T expressed various concerns in regards to wait lists, insufficient transportation means, inadequate services in terms of content and quantity, uncoordinated and inconsistent services. He exclaims, “So it has been a lot of work we should not have to do. We have had to fight and fight to get what we need. I think that we expected it to be difficult, but we did not expect that we would have to put forth so much energy to get what we needed.”

Mr. T has been impressed with the school system here in some ways, but very disappointed in other aspects. To illustrate, he disagreed with the present system whereby a child at the age of six years arrives in the classroom and has a teacher say, “there is something wrong with this child.” He contended that “It takes far too long to get a diagnosis at that point to help that child in that first year, so that child will suffer and so will the other thirty children.”

Mr. T was also very disappointed with the formal support system here. He proclaimed, "You cannot help a child with autism by sticking them in a corner. You have to work with them on a regular basis, and it is not just the child that needs the help." Without doubt, he is disgruntled with the present system, and sees room for improvement. The present support system is not meeting his needs nor his child's needs. He explained, "We have significant behavioral problems that we have to deal with as a family, and those need to be addressed as soon as possible. The Ministry said, 'Well, we don't have any resources', and that is not satisfactory, but that is the answer we are getting." He further explained, "The situation is made worse because there seems to be all these groups that seem to be providing service, but in reality they are doing a little bit rather than one group dealing with the whole thing. We would cope better if our children's needs were seen to."

He questioned the timing of his decision to move to Canada. He stated, "It's unfortunate that we came when we did. Basically what we came to is...the whole thing is changing...We don't know what we can give you, we don't know what we should be giving you."

Mr. T shared a story where he felt bitter and angry towards a local politician. He described her as being "A wonderful woman I am sure, but cannot organize a drinking session in a brewery!" Being a concerned parent who is in need of more service, he attended a Ministry presentation in February which was intended to inform people of the change in the Ministry's policies. He felt that the politician deceived the audience at the meeting, and he questioned her personal integrity, "Instead of being up front and saying, this is what we want to accomplish - Help us make it happen - She just stood up there and

said, I have nothing to defend. It's not my fault, but I am defending an empty shell. It was completely the wrong idea, and instead of getting up there and saying on April 1st, everybody will see a continuity of their positions while changing the boards, we will manage the delivery of the contracts in this way. There was no coordinated plan presented..." He continued, "You can't get up in front of people and say the same thing that you said before, and expect the audience to accept it. You have to present something that said that we have moved on, that said, we are under control."

Mr. T was very disappointed by the level and quality of service that he was receiving here in Canada. He described the present system as not being one that adequately deals with children with special needs, rather it is a self-serving one. "Children with special needs are just... the only special needs are for Aboriginals, or the poor...It just does not seem to be a general focus on children with disabilities. There is a focus on what gets the government in trouble not on what does my child need." He explained that "They are not interested in children and adults who have special needs who are not a bother to anyone else." Mr. and Mrs. T found the current system to be ludicrous. He has been seeking help since he arrived from the 'At Home' Program, and his requests for supports in the home are consistently denied due to insufficient funding within the Community Living arm of the Ministry for Children and Families. He suggested that a change in the system would be both cost effective and more humane if adequate home supports were provided for loving and caring families like themselves.

He described the responsibilities of caring for a child with autism as being immense, and the burdens are too much for a family to bear. He wished that the system was more integrated, accountable and organized. He exclaimed, "We have to anticipate

for her all the time, but no one outside of this family bothers to do it. I need someone from the Ministry to sit in this chair and tell us how this is going to be organized...I need a project organizer in the ministry to sit in my house and organize it for me.”

He expressed his frustration around a pressing concern at the moment. Mr. T is bombarded with significant behavior problems each day. He is very concerned that his oldest child with autism, who is a large girl, is going to seriously hurt the younger, and much smaller one. “We are very concerned that Samantha is going to seriously harm Susan. I have told every single person that this problem exists, and I have not had one single person call me back saying that we have put this in place to try and help. Nobody has heard us!”

Mr. T was very concerned about the money that he is forced to spend. “I spend \$170.00/ month on nappies for my seven year old, and the Ministry said this is normal! It is ridiculous that I cannot get that back in some form of credit whatever way.” Secondly, in spite of the serious safety concerns of having to walk across two very busy highways to get his children to school, he complained that he cannot afford a second car. Thirdly, he complained about how his money is spent. “I can spend \$10,000.00 and bring somebody in here to work with my child for one week. At the end of the week, the person will know something about my working with my daughter. The problem is, I will then have to spend another \$10,000.00 for another support worker next time. What I need is some way of getting regular intermittent support to deal with the specific problems that I am having with my child.”

Mr. T talked about how expensive it is and compares the system to his system at home. “In this country right now, you can be sick for free, and you have to pay to get

well. In England, before we came over here, it was free to be told you were sick and it cost the same amount no matter what the costs of the drugs, to get well. It costs 5 pounds thirty to get well. In this country, it costs whatever the drugs cost. It doesn't matter if the government gives it back to you later. It costs \$10,000.00 to get well. It is the same approach with my daughter...It is after the fact that you get your money back. Spend it up front. Well, I can't spend it up front. I don't have the flexibility to spend it up front. It is on me to sort it out."

As well, he explained, "there is no consideration in this province for Lovaas or ABA techniques. It was recently in the Sun about a woman who had to give up two Registered Retirement Savings Plans to pay for A.B.A. help for her child. That is ludicrous!"

Time is a valuable commodity in their home. On one level, he accepted the fact that there is little time for themselves. On another level, one can easily sense his frustration, disappointment, and feelings of guilt when he stated "As far as time for ourselves, we make what we can. We spend time together every morning and evening." "As a family, we don't do anything together. We can't take the kids anywhere together." "The person it really hurts is my oldest daughter who gets about one tenth of our attention. She is left out in the cold in terms of time from either of us." It is clear that there are not enough hours in the day to accommodate all the tasks and needs of everyone.

Generally speaking, he is very pleased with the quality of care provided by respite care; however, he complained that the quantity remains to be scanty. He expressed great appreciation for the respite care workers that they have coming in.

In terms of living a 'normal' life, they appear to feel trapped, frustrated, and helpless. He stated, "It has been more work to get things organized." Mr. T wished that they could go away on vacations and trips, but cannot due to the extent of organization that needs to be done and the numerous safety concerns. Sometimes he wished that he could do things with his family that other normal families do. His wife said every once in a while that "Maybe we should take them (the children) camping, because it seems like such a wonderful thing to do in the summer with kids," but it frightened both of them to think about Samantha waking up in the middle of the night in a tent." It seemed that everything is a big ordeal, unlike the experiences enjoyed by other typical families.

Chapter V

Discussion

This chapter deals with the findings of the interviews. In this analysis, when I refer to parents, I refer to the participants in my study. It is clear from the case portraits that the immigrant parents caring for their children with autism discussed a diverse set of experiences. All three families had contextual similarities in that they had recently immigrated to Canada, and in two cases, the parents were caring for two children with autism. All fathers were employed by an outside agency to provide financial support for their families, and all mothers were the primary care givers and all received help at home from their partners. In spite of these contextual similarities, the differences in terms of backgrounds, parents ability to speak English, severity of autism, manifestations of the child with autism's behavior, birth order, gender, economic circumstances, and spiritual orientations between these families should be studied in their own light.

I was surprised to discover the common themes shared by all three families. Before an investigation into the common patterns shared by all three families are discussed, my impressions of the interviews will be informative.

The Interviews

Surprisingly, given that people tend to talk about things they miss, these parents who recently moved to Canada were willing to talk about their present and future situations more readily than their pasts. In these cases, perhaps being the problem solvers that they are, they are solution focused, and see little value in looking back.

It is interesting to note that Mr. and Mrs. T speak English as their first language. Consequently, a language barrier does not hinder their abilities to manipulate the systems

around them. Compared to the other two families, they appear to be in a stronger position to actively support their children, as their anecdotes reflect advocacy.

The primary subject matter of the interviews related to child rearing; adjustment to a new environment was secondary. The tendency to discuss autism more than immigration may have been influenced by the format of the interview. Both issues played a role in their experiences. However, the different backgrounds and immigration experiences were not predominant in their stories. The parents' time was occupied by a range of daily tasks and responsibilities necessary in raising a child with autism. Consequently, they do not have the time to dwell on immigration issues. In fact, I suspect that their story patterns would be very similar to those expressed by Canadian families.

The unstructured interviews in themselves were enlightening in that the parents disclosed a significant amount of information in a relatively short time span, and there were few probes from me. Often a single question resulted in a lengthy oration. The stories flowed freely. Feelings of frustration, sadness, anger, resentment, and fear were readily revealed in the interviews. It seemed that these parents do not get the opportunity to share their experiences in caring for their child with autism with another adult very often. Hence, they embraced this opportunity.

Interviews in their homes had distinct advantages: Parents were in their home environment, and many situations occurred within the interviews which prompted discussion about some pressing immediate issues. As well, my time spent with them gave me a first hand view of their demanding child rearing schedules.

All parents tolerated a high level of activity during our interview sessions. In the short time that I was in their homes we were constantly interrupted by each child for

various reasons. In the span of two hours, Mr. T changed his seven year old child's diaper, engaged in an argument over saying "no" to feeding his insistent five year old ice-cream for lunch, fed cheerios to his five year old in-between meals, intervened in a dispute between his eldest child and middle child with autism, and untangled from a bush a spool of dental floss which had been thrown out a window in his home. Mrs. P changed two diapers; fed her youngest child a bottle; comforted two children with temper tantrums; attempted to pacify her ten month old child with hugs; and consistently got up to her autistic boy off counters, shelves, and tables. Mrs. K and I were interrupted every few moments by her child who increased the volume on the television. As well, in order to avoid confrontation, she permitted her autistic son to eat eight popsicles on his own accord during the span of a single interview.

The Relationships

It seemed that immigrant parents caring for a child with autism were not only faced with the demands of raising a child with autism; as well, they were being influenced and shaped by a new environment and are bombarded by interrelated forces and new relationships all around them. In these open ended narrative interviews, the parents talked about their experiences. Relationships and interrelationships are difficult processes to define, describe, and understand. However, patterns, trends and tendencies provide helpful clues for understanding, supporting, and recognizing the varied experiences of immigrant parents (Jensen, 1992). Hence, in this discussion, a focus on their relationships within the family and interactions with others seems pertinent.

These accounts depicted the variations of ways of which children with autism related to the world. To illustrate, Mr. K described his child as being, "high functioning -

academically able - who experiences social difficulties". Mrs. P described one of her children, "I really want to talk to her...really talk, but you can't do that, but now she has improved a lot, and she is really smart in some ways. She can do things. She can draw, she has good vocabulary, and she can speak English now." Mr. T described one of his children, " She has an I.Q. that is comparable to any child her age. She has no mental retardation as far as we can see. She has a communication problem." These parents' descriptions of their child with autism illustrate the variations of their children's ways of relating to the world.

Not surprisingly, the case portraits suggested that the focal point of the participants was their child with autism. The primary relationship with the child with autism was different from other relationships in that autism is a life long disability. The child has impaired communication skills; impaired social relationships; and abnormalities in speech, language, and communication. Due to these factors, establishing a relationship with a child with autism often requires more energy, and it is the most powerful and enduring relationship of all.

Most of the relationships outside the family unit had some relationship to the primary relationship of the immigrant parents and their children with autism. As parents worked hard to teach their children and make them feel integrated and part of the world, the children with autism, given their condition, felt apart; they felt isolated from their families and the communities of which the families were working hard to be a part. The disengaged child with autism remained autonomous and segregated. In some ways, the segregation can be looked at as a rigid boundary that exists between the child with autism and the rest of the world. The term 'enmeshment' on the other hand, can characterize the

extreme amount of emotional closeness and demands for loyalty and closeness in these immigrant families living with autism (Becvar & Becvar, 1996). Due to the demands on them, there was a lack of personal separateness, time, and space. In many ways, the individual boundaries of the parents were blurred as many parents did not have the luxury of developing a coherent sense of self-distinctive from the all encompassing family role expectations. In order to integrate their children with autism, parents depended on their intra-familial strengths and systems outside the family for the support and nurturance they needed and desired.

The relationships that parents had with their children with autism were all encompassing. It was clear in the interviews that these parents would suffer for their children, and they wanted nothing more than for their children to lead normal and happy lives. Every family made significant compromises in the name of their children. At least one parent in each family gave up desirable employment or a promotion in their home countries; all left their friends and families in hopes of finding a more conducive environment for the development of their children. Indeed, parents have sacrificed significantly in all domains in order to fulfill their children's needs. Mr. K's statement sums it up, "Parents with autism should sacrifice their lives for their child."

Intra-Familial Strengths

Unique qualities and different combinations of intra-familial strengths were apparent in all three families. The common themes fell under four main headings - Family Identity, Information Sharing, and Coping/Resource Mobilization (Deal, Trivette & Dunst, 1988) and Extra-Familial Relationships. It is important to note that these family themes were primarily interpersonal and intra-familial in that they occurred within the

family unit. These strengths influence each relationship in some way within the family unit, and are simultaneously influenced by forces outside the family unit (Deal, Trivette & Dunst, 1988).

Family Identity

Five relevant themes were apparent in all three families in terms of Family Identity. They include commitment, appreciation, allocation of time, sense of purpose, and congruence.

Commitment. To begin, all families demonstrated commitment towards promoting the well-being and development of their child with autism. This is evidenced by their mutual decision to move to Canada in hopes of a more suitable lifestyle. In order to help their child, the parents reported that they have made numerous sacrifices and were absolutely devoted to their cause. Mr. K stated, "Parents with children with autism should sacrifice their lives for their child." Mrs. P proclaimed, "My children are my priority." Mr. T asserted, "All this is secondary to the kids." These parents are dedicated, obligated, and unselfish on their quest to help their children.

Appreciation. I noticed that all parents expressed a deep appreciation for one another and encouraged each other to do better in all areas of their lives. To illustrate, Mr. T was very proud of his wife's accomplishments "before kids." As well, on the way out, he acknowledged the beautiful hanging baskets that his wife made. Mr. K seemed proud that his wife was in good physical shape and took the time to work out. Mr. P was proud of his wife's skills in computer software, and encouraged her to enhance these skills here in Canada. As well, they gave credit when credit was due both inside and outside the family unit. These families expressed a true appreciation for those people in

the field who provided practical, long term understanding and support over the years without judgment and who had helped solve many of the challenges that they were faced with. Stories about helpful people in their countries of origin and in Canada were pertinent. Finally, they took time to appreciate the simple joys in life. To illustrate, Mrs. T loved to garden. In spite of the time constraints, she found time to cultivate her hanging baskets. Mr. and Mrs. K talked about the beauty of the mountains and the natural beauty of British Columbia. Mrs. P described the beauty of downtown Vancouver, "We saw the beautiful mountains and Canada Place."

It was interesting to note that the fathers took great care of the mothers. They held their wives in high regard and exhibited great adoration. In various ways, they all showed their love and respect. For example, in all the interviews, the Fathers mentioned how hard their wives worked, and all took appropriate actions to alleviate some demands of their overwhelming work responsibilities. That is, all the Fathers participated in daily household chores and worked irregular hours in order to accommodate their wives and families.

As well, their children with autism received utmost respect. They continuously strove to give their children the sense that they respected their individuality, and they had rights and abilities. Their stories implied that their children were always heard, appreciated, and respected. As well, their devotion was evident throughout the interviews.

Allocation of time. The allocation of time was a relevant theme in all three families. It was very clear that every child with autism requires twenty- four hours a day care. The responsibilities involved in raising a child with autism are cumbersome, and rest primarily on the family. A lot of their time appeared to be occupied by the day to day care of their child with autism which included feeding, bathing, changing diapers,

disciplining, and generally protecting them. Mrs. P explained, "They can't talk, they aren't toilet trained, no matter how hard I try to teach them, they are slow, hyperactive...all these things just eat up your time trying to take care of them." In all three cases, doors had to be locked in order to protect their children with autism from injuring themselves; constant surveillance was required at all times. There seemed to be no time to relax. Even when the children were at school, parents worried about their child. Some stated that they kept their cell phone on at all times. These parents enjoyed the time they spent together in spite of the difficulties whether it be at the playground, in the mall, or trips downtown. All parents seemed frustrated about the scarcity of time spent together as a couple. Moreover, they wished that they could do more activities as a whole family like a normal family would. The lack of family activities seemed to be a cause for disappointment and frustration for all parents. Generally speaking, all three families seemed to have more time for each other in Canada compared to their countries of origin. Some expressed that they have more time with one another here in Vancouver; however, this time is spent in the home. Due to inadequate childcare, they did not have the opportunity to go out together. None of the couples reported that they had time for each other.

Sense of purpose. The sense of purpose for all three families was a drive to make their children as normal as possible. They all exhibited an overwhelming sense of responsibility. That is, each parent demonstrated a deep caring for their child and had an expectation that their child with autism be accepted and loved as a person. Each parent sought integration into society for their children with special needs. Indeed, this sense was strong in all three families which seem to give them hope and momentum required

to get them through the trials in their journey. On another level, all parents seemed upset that there was not a clear solution to their children's condition. More than anything else, they wanted their children to reach their optimum potentials, and they hoped that their child would have rich opportunities in the future. They all expressed concern about their child's ability to relate socially to people, however, they expressed pride in their individual strengths.

Congruence. All parents demonstrated congruence regarding the importance of assigning time and energy to meet their needs. Each parent had to make compromises in order to function as a family. Both parents were in harmony and demonstrated affirmative action in trying to meet their needs. They were like-minded and they worked together. For the most part, parenting styles were similar. They mutually supported and accommodated one another in order to provide an appropriate balance of firmness and nurturance for their children with autism. Also, in every family, the mother had the major care-taking role of supervising, initiating, and organizing activities around the home. In all three homes, the fathers have adopted many child care responsibilities on top of being the sole financial providers in the family. I noticed that the parental relationship was very strong. The move to a new country seemed to have strengthened the parental subsystem and seemed to have enhanced the intensity of the relationship with one another. Mr. K's statement sums it up, " Our relationship has become better and better (here in Canada) because the only person that we can rely on is each other." It seemed that the common stress factor for both mothers and fathers of children with autism was their care giving responsibilities. Although the constant and persistent amount of care that was required when keeping a family member with autism in the home is draining and exhausting, it

seemed to keep the parental unit in synchrony. They did not have time to dwell or drift apart from each other.

Indeed, the parents were in true alliance with one another, and they needed one another. Mrs. P stated, "We have to be strong for them. We have to do our best for them...I think that we became closer (in Canada). We understood each other. I have no time to enjoy myself and he too... I mean, it's just us here...nobody else." Although compromises had to be made, they worked together as a team. During every interview, the children with autism placed many demands on the parents. Even in these stressful moments, the parents did not order, direct, argue or command. Nor did they judge, criticize, disagree, or blame. Rather, parents continued to praise, agree with, and positively evaluate their children. As well, they reassured, sympathized with, consoled and supported their children. Each family was a cohesive and headstrong team pulling together in the face of numerous obstacles.

Information Sharing

The Information Sharing category refers to two aspects of family strengths. Communication among family members in a way that emphasizes positive interactions is one important aspect. The other refers to rules and values that establish expectations about acceptable and desired behavior.

Communication. The parents seemed to have excellent communication with one another and with me. To begin, both parents were able to look at the world through their spouse's frame of reference and understand what his/her world was like. In the interview, they communicated his/her understanding to one another in a way that demonstrated an understanding of their spouse's feelings. As well, both spouses expressed deep respect for

one another. This was demonstrated in both active and passive ways in their stories and in the present during the interview. Thirdly, the couples demonstrated warmth towards one another primarily through non-verbal means such as smiles, touches, and hugs, which reflects a concern and deep respect for one another. Finally, I was very impressed with the level of genuineness in our interviews as they seemed to feel comfortable. As well, their body orientation, posture, gestures, facial expressions, voice, and their willingness to share their valuable time with me had a spontaneous and defenseless air. Although I did not probe or question, they did not withdraw, distract, or divert away from sensitive issues in their lives.

Their efforts to communicate with agencies in the community were evident in all three families also. Because they relied on the outside agencies to assist them in various ways, they all made an effort to plug themselves in. In some cases, parents have had to fight in order to get their needs met by means of letters, talking to people in charge, and informing different helping organizations of their present situations. Being that the exchange of information and effective communication skills are considered to be essential characteristics of well-functioning systems, their ability to articulate their thoughts and listen to other people's ideas was a strength evident in all of the three families.

Rules and value systems. These families appeared to have similar rules and value systems. To begin, common family values dictated that parents monitored the information they shared with me. For example, acceptance into the community was important for all three families. Consequently, the information that they chose to share with me had a polite and accepting tone in light of their drive to be accepted. Mr. K expressed worry

about the confidentiality of the study. Mr. T continuously interrupted himself and said, "There are many things that are going right too," and then continued to express his frustrations. In all three cases, the maintenance of family identities involved a process in which the system boundaries screened information coming in and out of the family systems depending on family values (Becvar & Becvar, 1996).

Coping / Resource Mobilization

The Coping / Resource Mobilization category refers to five aspects of family strengths. They include, coping strategies, problem solving abilities, optimism, flexibility, adaptability, and balance (Dunst, Trivette, & Deal, 1988).

Coping strategies. All families exhibited various coping strategies that promoted positive functioning in dealing with both the normative and non-normative life events. In some cases, they read novels, some exercised, and others vented by voicing their concerns to people in power. All parents coped in different ways with the demands of every day living.

Problem solving abilities. They all exhibited tremendous problem solving abilities portrayed by their ability to move to a new country, learn a new language, find suitable housing, seek appropriate employment, make new friends, find local schools, and plug into the social service network. Each task required organization and ambition, all qualities that each family possesses in vast quantities. As well, it was clear that these parents were the experts when it came to caring for their child. Every task was a problem, and each parent approached it with pragmatism and inspiration. They were all case managers and advocates for their children while trying to make sense of their options in their new country.

Optimism. One of the most striking features in these families living with autism was their undeniable ability to be optimistic and hopeful in the face of some adverse circumstances. They were persistent and headstrong. In spite of their childrens' learning disabilities and difficulties relating to others, all parents had great optimism for the future, and they believed that anything is in the realm of possibility. They believed in their children and all took the time to read to them, teach them new skills, and assist in their language development. They hoped that their children would lead normal lives one day. As well, some believed that they would eventually land a desirable job in the work place here in Canada; In two cases, the fathers boldly accepted the compromises they were forced to make in the employment sphere. Both accepted jobs which they believe to be overqualified for. Mr. P was an experienced government executive in the Philippines, and he took a job as a night maintenance worker at McDonalds. He was disappointed that his skills are not presently valued here in Canada, but believes that they would be one day. Mr. K accepted a sales job which he too believed he is overqualified for. Both people were willing to endure the present unfortunate circumstances with the expectation that they would land better paying jobs in the future. Nonetheless, they all experienced hope for the future and the life that they were going to build for themselves in Canada. Without doubt, optimism alone can be very empowering. I was struck by their sense of optimism and hope which was demonstrated in their stories about their mother countries and\ in Vancouver. Their optimism was present in their quest to listen to all options, try new ideas, and maintain a sense of humour throughout the interviews .

Flexibility and adaptability. All parents demonstrated extensive degrees of flexibility and adaptability in the roles necessary to procure resources to meet their needs. All three families appeared to be dealing with the challenges of caring for children with autism in realistic and productive ways. Indeed, they were faced with different obstacles daily which required them to alter the roles and rules within the family. To illustrate, spouses arranged flexible work schedules in order to provide direct caring to their children. A high amount of personal sacrifice on the part of the parents was evident in all the stories. Mr. K explained, "I was very happy in Seoul because I was promised management there, but I wanted to take care of my family, so I moved here. I am very happy now as I have the time to support my family right now." Mr. P talked about his mixed feelings in giving up some family time, "I feel really bad. I want to be with them. When I work especially leaving them altogether at night." Mr. T described his wife's expertise, "Although she is trained as a registered nurse, the only employment that can accommodate the heavy demands from day to day is a paper route. She is now delivering papers because that is all she has time or the wherewithal to do." These compromises were made in each family in the areas of career limitations and financial security.

All parents have been forced to make compromises in their social life due to the difficulty in finding suitable child care arrangements. All parents mentioned sleep deprivation in one form or another, and somehow seem to carry on with their daily tasks. In order to provide inordinate amounts of long term care-giving to their dependent child, all parents have had to make compromises in one form or another.

The openness and 'closedness' of each family differed to some extent to personal circumstances and the need for assistance. For example, the degree to which each system

screened out or permitted new information varied. It seemed that the families allow information and permit change as appropriate, while screening out information and avoiding changes that would threaten the survival of the family unit. For example, Mr. and Mrs. K appeared to be very inquisitive and asked me numerous questions about the Vancouver School System, and how it dealt with children with special needs. Mr. T, on the other hand, was more jaded, and was not interested in what I had to say in the least. His comment portrayed his position, "With all due respect to yourself, I understand why you are here, but you should not be. I mean to me, your brief should not be what is with the service here, but what is right with the other services in other countries that we should be applying here..." His statement implied that he is frustrated with the problem-focused and ineffective systems around him, and has no desire to hear yet another redundant opinion. Mr. and Mrs. P, being the most recent immigrants to Canada, were still in a reactive state, and were in the process of understanding the systems around them. They did not ask me many questions; however, they seemed enthusiastic and very open to more information. Due to the heavy child rearing demands placed on the parental unit and need for survival, every family system required some degree of openness in order to receive assistance from the outside. All parents, being immigrants to Canada, seemed to be very open to the ways of their new society and made efforts to be assimilated by their new society and to accommodate certain customs and rules. To illustrate, Mr. and Mrs. P questioned me about Canadian law. They proclaimed, "In the Philippines, we sleep in one room. Here, it is against the law... You have to separate the children." They were sensitive to Canadian customs, and wanted to conform in as many ways as they could. Mr. P stated, "I am trying to have Canadian friends. Sometimes I go by myself and meet

Canadian friends. If I don't do that, I will only hang around with Koreans." Mr. T's efforts to go out and make new Canadian friends demonstrated his degree of openness to the new culture in which he lives.

Balance. It was apparent that each family tried to maintain a sense of balance in their private worlds. This was achieved by the use of both intra- and extra-familial resources for meeting their needs. In order to maintain balance, a combination of their intra-familial strengths combined with extra-familial resources was critical. The recent arrival to Canada and the inevitable adjustments combined with the demands of raising a child with autism left these families in a state of flux. It was a dynamic process whereby every couple tapped their strength and courage to maintain a functional family system.

In hopes to reduce the amount of stress on the family unit, parents utilized intra-, inter-, and extra-familial resources.

Extra-Familial Relationships

Immigrant parents utilized numerous extra-familial resources and social support systems. These relationships were important to them. To enhance their emotional, physical, informational, instrumental, and material situations, the assistance provided by others was essential to maintain their health and well being, promote adaptations of life events, and foster development in an adaptive manner. Extra-familial resources included the educational system, Ministry for Children and Families, Autism Society of B.C. , finances, and an informal support network of friends.

The Education System

One public enterprise with which each family had an integral, but not necessarily good relationship, was the school system. Each family developed a relationship with the

principal, the teacher, and if necessary, the school trustees and board administrators. The relationships that parents had with teachers, special education assistants, and principals were very important to them, and were a primary element in the past, present and the future.

Their expectations of the educational system were more futuristic. In other words, how they talked about the education system in Canada was not so much in the present as much as what they hoped the system would eventually do for their child in the future. They hoped that the educational system would fix their child's condition, and teach him/her the skills necessary to lead a normal life. Each family immigrated to Canada for primarily educational purposes, it is safe to say that this relationship played a prevalent role throughout their lives for these parents. The relationship with the education system was the most encompassing relationship they had in their new communities. This was apparent by the amount of time they spent on talking about their child's education. The relationship that each parent had with the school system is often confusing and conflicting due to various reasons. All the parents have been and continue to be apprehensive about their interactions with the school. In all three cases, at some point in the past or present, when the immigrant parents and the school are required to engage with one another around their child's autism, the relationship was frequently characterized by crisis, tension, defensiveness, blame, and miscommunication (Carlson, 1992).

The trepidation with which parents approached the school does have merit, as the relationship was a temperamental one. Mr. T exclaimed, "There is no allowance for parents to have any involvement in any of the decisions about children especially in the

school system.” All education systems should provide services that are to be available in close proximity and accessible without reference to physical, psychological, social, linguistic, or other barriers; and that are comprehensive and appropriate in that they address the priorities identified by the family at a level of service sufficient to meet their needs (Carlson, 1996). In Mr. T’s case, he contended that his child’s needs are not being met. In describing the union scandal, he stated, “If she had not received it, we, the school, the teachers, would not have found out until the first day of school and nobody would have known who this person was, and I am supposed to introduce a child with autism who cannot cope with walking down the opposite side of the street. It is not reasonable!” In consideration of the fact that a child with autism does not fit the ‘academic norm’ in that they often differ in the physical, psychological, social, and linguistic domains, these criteria previously mentioned were laden with guilt, blame, frustration, anger, resentment, and sadness on behalf of the parents. Thus, persons in the education system were dealing with more than individualized educational programs. Rather, they were working with parents’ hearts and souls - their children with autism who, without doubt, were the most sensitive and central issue in their lives. In essence, this stormy relationship was a result of school issues around their children. Often these issues were viewed as signs of future difficulty for their child with autism over which they felt they had little or no control.

As well, all six parents carried with them some experiences from their previous school systems in their home countries. In describing the education system in their home country, Mrs. K explained, “a few years ago, the Ministry of Health in Korea did not even know the meaning of autism!” Mr. K continued, “As parents of a child with autism, even the government does not have any knowledge, so how can we as parents educate them?”

Their understanding of autism and insecurities are not even known!" Mr. K contrasted the education system in Canada with the system in Korea, "Here, I can say my son is autistic, and the school system is willing to help...most teachers support the child with special needs..." With high expectations and an effort to prevent similar past mistakes, they brought with them their own biases and aspirations. Mr. T proclaimed, "We have always thought that Canada was full of opportunity for us compared to being in England." Thus, their expectations may be higher and their demands and frustrations greater. This might positively or negatively influence the relationship they have with the present system.

Secondly, in order to understand the relationship that parents and schools shared, it was helpful to view them in terms of two systems such as the family and school which represent purposeful entities comprised of organized and interrelated parts (Connelly & Clandinin, 1990). Like immigrant parents, the school system is an enterprise that is clearly open to the vicissitudes of public opinion and social change. Moreover, like a family, a school has a well articulated belief systems that strongly influence its staff functioning (Carlson, 1996). Like each family, a school system has a past, present, and a future. These parents were often confused about their relationship with the school system in B.C., and due to their own pressing demands, often failed to see specific contextual dimensions such as limited financial resources, limited time schedules, curriculum objectives, and general public demands for teacher performance and accountability. Due to the fact that the school system is an open and ongoing system subject to diverse opinion and a changing social context, it is not a surprise that friction occurs

occasionally. In some cases, immigrant parents of children with autism perceived the current educational service delivery to children to be inadequate.

The Ministry for Children and Families

In theory, the Ministry for Children and Families provides these parents with financial assistance, respite care, or behavior modification programs. Such supports are essential to the survival of these families. When parents discussed the experiences in their home countries, they all talked about the important role that various agencies played in their lives. Here, in Canada, assistance from the Ministry in areas such as advocacy, coordination of resources, supply of information, and crisis intervention were very helpful. In all the interviews, it was apparent that their relationship with the Ministry had provided them with some essential services such as the sharing of resources, community services, and respite care which provides parents with a little time for themselves. All families reported that they had met with a social worker, and they were all informed of the various services that were available to them. On a positive note, families appreciated that there is a recognized need for a broad based continuum of services for families with children with autism. However, the families whom I interviewed were somewhat confused about the service delivery of the Ministry, and feelings of ambivalence were apparent. To illustrate, on the one hand, all parents expressed sincere appreciation for the presence of some of the services which the Ministry has provided such as respite care, and I sensed feelings of sincere gratitude. They appreciated the *efforts* made by the Ministry. On one level the Ministry attempts to respect the needs, wants, and desires of these immigrant families and they are doing their best to maintain the child with autism in their home environment. However, the huge number of cases and the level of intensity

of services which are provided are insufficient. Having to provide 24 hour per day care for a child who is out of control much of the time takes its toll. Many parents expressed frustration concerning their inability to find consistent and coordinated services for their families, financial assistance, behavior modification programs, and coordinated case management.

One family talked about the discrimination inherent in the relationship between themselves and the Ministry. Mr. T asserted that politicians are not attentive to the needs of autism. He suggested that the Ministry for Children and Families is currently preoccupied with child abuse, hindering the ability of social workers to effectively work with the needs of parents, like themselves, living with autism.

As well, Mr. and Mrs. K spoke for all three couples, in their frustration with the generic programs implemented by the Ministry with no specialized knowledge of autism. They complained that the current system does not address the individual needs of immigrant parents living with autism. He stated, "I know that Canadians already spend a lot of money to give children like our son a full time teaching aid; we have many things but these are things that take care of the child. It should be more aggressive and proactive to heal the child with autism."

Not one of these families has received any behavioral support for their children with autism from the Ministry. They were all disappointed by the lack of service in this area, as all understand the importance of early intervention strategies in order to provide their children with basic skills.

In contrast to the discussion around the educational system, discussion about the Ministry was focused on the present. In some ways, it can be looked at as fulfilling their basic need for survival. The Ministry provided them with the fuel to simply subsist. These parents were recent immigrants to Canada. Consequently, they were in survival mode. However, a closer look revealed families who were receiving few services in spite of the magnitudes of their work. In two of the cases, sleep deprivation was a serious concern for at least one spouse. Over time, a weak bond with outside agencies could leave these parents emotionally and physically exhausted, and at risk for a serious crisis. Parents were pleased with the quality of respite care for example; however, they all expressed a need for more of it. All families were disappointed by the level of care that they were receiving and attribute it to various things such as the restructuring of the Ministry or B.C.'s recession. All families hoped that the implementation of these services would improve in the future.

The Autism Society of B.C.

These families reported that the Autism Society of B.C. was very instrumental and facilitative. The Society served as a good networking tool and pointed families in the right direction. The Autism Society of B.C. seemed to support parents as advocates for their children; informed parents of relevant information and services; promoted community participation in attaining their objectives; and provided a network between these families and other agencies.

Finances

All the parents were concerned about their relationship with finances as autism often results in severe costs to these families. The cost of diapers, behavioral modification programs such as the Lovaas method, drug, speech, and massage therapy, and child care were some of the worries expressed by all families in their countries of origin and in Canada. In particular, the Fathers reported more stress as the sole income providers.

Informal Support System

All parents expressed a need to make friends with whom they could depend on and socialize with. They needed to feel a sense of belonging to a group in order to feel more integrated and part of the community. In Vancouver, some of their friends attended meetings and social events with these groups. Unfortunately, they expressed concern about not being able to attend because they did not have the time or child care. The need for a care giver was a critical need for all parents.

Intra-, Inter-, and Extra-Familial Emotions

In the interviews, immigrant parents described their experiences in caring for their child with autism. They shared many details, and in spite of some language difficulties in two of the cases, they painted clear and colourful pictures of their experiences. It seemed that the mothers expressed stories more on an emotive plane, whereas the fathers were more cognitive. Nonetheless, their personal experiences directed the unstructured interviews. It was implied in the interviews that many common feelings such as guilt, pain, frustration, anxiety, fear, anger, sadness and embarrassment influenced every relationship. Positive emotions such as love, devotion, and hope were also evident. This mosaic of emotions were woven throughout the interview and were not tied to specific

incidents. Rather, the emotions were woven deeply into the fabric of their existence. A look at the multitude of intra-, inter-, and extra-familial emotions which played a significant role in the dynamics of the family unit is relevant.

Sadness

All the parents reported feeling sadness at various times, some more than others. Mrs. P exclaimed, "The first two weeks, and even in fact now, we are both very sad and we just cry - both of us." Mrs. K. described her life as being "Hell", and proceeded to spell it out: "H-E-L-L !" Feelings of sadness were apparent when parents discovered that their children are autistic, their child did not meet the developmental milestone of his/her age level, attempted to teach their child a new skill, missed their friends and families, or when they engaged in a frustrating beurocratic battle.

Frustration

The one emotion that was evident in all the interviews in various degrees was frustration. Whether it be trying to teach their child with autism basic skills within the home, dealing with behavior problems, or facilitating services in the community, the frustrations were predominant. To illustrate, Mr. K expressed his frustrations in the education system here in Canada, "They are not aggressive and proactive in treating children with special needs." Moreover, he goes on to say, "They think more about taking care of the child, and that is no good." Mrs. P described her frustrations in raising a child with autism, "He can use a spoon, and apple, I put bits and pieces there and he can pick them up but when you make him pull his pants up, he can't do it! I just don't understand it. I would like to teach him, but I just cannot get it... it is very frustrating, and I cry a lot of buckets full!" Mr. T's statement summed up his numerous frustrations in regards to the

services around him, “There were battles that we have had to fight that we should not have to fight. It is the responsibility of the government that they are not taking up.” It appeared that Mr. and Mrs. T’s frustrations were more than annoyances. Rather, his frustrations have culminated into outright rage. He was angry at the systems all around him.

Guilt and Self -Blame

An abundance of literature suggests that mothers of children with autism are incapacitated by feelings of guilt and self - blame (Fong & Wilgosh, 1992; Mesibov & Schopler, 1984; Rousey, Best, & Blacher, 1992). Generally, the interviews revealed people who did not feel guilty or blame themselves. Rather, parents cared for their children deeply; had taken ownership of their condition, and were on a serious quest to make their lives as harmonious as possible. They were pragmatic, accepting, and head strong.

Anxiety

All parents reported feeling anxious about one thing or another in regards to their children or other circumstances in their lives. Mr. K reported, “When I decided to immigrate here, I was very worried, and I was worried about how my son would be in this society.” In regards to describing his present financial situation he stated, “Sometimes I don’t live well. I can’t sleep because I can’t make money for the extra \$20,000.00 in this society.” Mr. T shared his worries about his two children, “We are very concerned that Samantha is going to harm Susan. I have told every person that this problem exists, and I have not had one single person call me back saying that we have put this into place to try and help. Nobody has heard us!” It was clear that anxiety was a

common denominator in their lives, and they worked hard to alleviate their concerns about their children, financial situations, living conditions, and support systems.

Fear

It was implied that these families were driven by the fear that they would not be there for their children one day. Mrs. P explained, "If they cannot provide on time education, I mean who will take care of him? I mean, Mother and Father will die some day right, so we uuuhhh have limited time...maybe ten years." Mr. T stated, "In the future when she is 25 years old, and I am dead, she is not a full cost to society and living in an institution." Mr. K stated, "I also pray for my children that when they grow up, that they will be able to marry. I hope that they will be able to work and carry a relationship, and I know that if I die, they will be okay." All parents were future oriented; however, all worked hard to eliminate their fears about the future when they may not be here to take care of their children.

Embarrassment

Two of the three families related stories reflecting embarrassment in their countries of origin and in Canada. To illustrate, Mrs. P described her circumstances in the Philippines, "In the Philippines, it is very different there. They would not mock me. They would just talk about it and talk about it. It's like gossip you know. Oh, poor little Mrs. P. She has two abnormal children, and I just don't want to hear that." In addition, Mrs. K described her experiences in the mall, "Especially in a public place...He does not want to line up in a shopping mall. He shouts sometimes and has screaming fits and tantrums. Every body looks at us and wonders why my child does that. Sometimes I explain, but

most of the time, I don't. I say, I don't know. A child with autism looks like a normal child so it is not easy."

Courage

These parents demonstrated tremendous strength, tenacity, and courage. In the interviews, some parents shared their experiences in what it was like when they discovered that they had a child with autism. They felt shattered. Mrs. P described, "It was like the world fell down on me." Their expectations of having a normal child were dashed. The plans they had around building a life with a healthy child were ruined. Mrs. P reported, "Before I had her, I was preparing already to give her a good education. I bought all these educational toys and books, so you can just imagine my frustration when I found out that something was wrong with her." These parents have endured many obstacles in getting their childrens' needs fulfilled. Their experiences exemplified moments of turbulents, trials, and tribulations. To illustrate, they have all had to arrange for various child services outside the family unit, and all have reported the difficulties in maintaining an effective and efficient level of service in their countries of origin, and in two of the cases, here in Canada. Mr. T exclaimed, "We have had to fight and fight to get what we need. I think that we expected it to be difficult, but we did not expect that we would have to put forth so much energy to get what we needed." For each testimonial of care and assistance, these parents wrote letters, made phone calls, and engaged in numerous battles.

Parents as Agents

Immigrant parents had a distinct characteristic in that they possessed the ability to take charge in situations and make things happen. They were active agents in their lives in contrast to patients to whom things happen (deCharms, 1976). deCharms (1976) characterized agency with six major features. First, an agent experiences himself or herself as the cause of his or her decisions and actions. Agents have a personal basis for taking action. Like agents, immigrant parents had meaningful motives. They left their countries of origin, arrived to Canada, and learned new rules and customs to help their child with autism. Secondly, agents set challenging but realistic goals that are anchored in meaningful motivation. Immigrant parents did what was within their control to learn. In an attempt to make more meaning of all these emotion laden relationships, it was clear that the emotional quality of the parent - child relationship was all encompassing and forceful, and took a role of overwhelming significance in their lives. This was reflected in every narrative interview in that the majority of the relationships in these parents lives was significantly influenced and driven by their primary, all encompassing relationship they had with their child with autism. English, search for new schools, and make new friends as an initial step towards making their child feel integrated. Third, agents are active while patients are passive. Immigrant parents had direction and each action had a specific aim. Fourth, agents develop a functional perception of reality that highlight what might facilitate or hinder movement toward a goal. These parents were attentive to possible means, resources, obstacles, and their own strengths and weaknesses. They established extrafamilial relationships with the educational and social systems with the aim of helping their child. Fifth, agents feel confident, while patients lack confidence.

These parents had an optimistic outlook and believed that they can make changes in their situations. Finally, agents assume responsibility for actions, goal attainment, and consequences while patients minimize or deny responsibility. These parents accepted blame or credit when it was due. This related to their sense of ownership.

Searching for Normality

These parents were recent immigrants to Canada, and they were amidst a process of adjustment in that they were learning new rules and regulations, customs, establishing new friends, and exploring the territory. On another level, immigrant parents were all driven towards the attainment of an ultimate goal; that is, conformity with a central norm of family life. Their need to conform with the central norm of family life was apparent throughout the interviews and depicted in the case portraits. To illustrate, they were constantly comparing their own circumstances to those of 'normal' families.

The term 'normal' is used to refer to different concepts, depending on one's frame of reference, which are strongly influenced by the subjective position of the observer and by the cultural surround (Becvar & Becvar, 1996).

Different theoretical concepts of normality are interesting to note. To begin, from a medico - psychiatric model, it is based on the criterion of absence of pathology. Persons who are asymptomatic, manifesting no disturbances are considered normal and healthy. An approach common in sociological and behavioral studies use the statistical norm, or average to identify typical patterns or traits. In humanistic theories, normality refers to 'self actualization' or potential. Finally, General System Theory suggests that normality attends to individual developmental processes over the life course in the context of transactional systems dependent on an interaction of biopsychosocial variables (Becvar &

Becvar, 1996). All of the above definitions can be used to describe these immigrant parents perceptions of normality. To illustrate, Mrs. P stated, “When I see families around with three or four children and they are all normal...it makes me cry.” In response to my question, “How would your life be if you did not have a child with autism?”, Mrs. K responded, “It would be like other parents of normal kids. I could do something for myself!” When Mr. T compares his circumstances to his neighbours, he said, “ It has been more work to get things organized.” These statements reveal how immigrant parents organized their experiences in relation to ‘normal’ families. Their ultimate goal was not unto itself; rather, it was in association with or a connection to a typical family’s way of life.

Emotional Normalization

Every narrative reflected the ultimate aim of emotional normalization. That is, they were striving for full integration, emotionally and physically, in an attempt to construct a normal life for themselves and their children. To understand how these parents evolved towards attaining emotional normalization, an examination of their lives within the context of both the family and the culture, with its inherent set of past and present intra- and inter-familial strengths, and how they changed over time was essential. Emotional normalization has occurred when both the parents and the children feel completely integrated in their embedded systems.

The attainment of emotional normalization has many layers and can be viewed in the context of embedded relationships in different places and changing over time. Caring for a child with autism is very demanding and in itself is not conducive to a normal existence. Moreover, the goal of emotional normalization could have felt distant as these

immigrant families felt like strangers in a new community. In an effort to make their surroundings more familiar, parents, together with their children, were forced to establish relationships on the outside of their microsystem, the immediate family unit.

Many interplays were at work within the family unit as intra-familial strengths such as commitment, congruence, purpose, communication, coping strategies, appreciation, and rules, values, and beliefs interacted with each other in such a way as to mobilize the family to meet its immediate needs and simply survive. Moreover, these strengths which influenced the relationships inside the family, indirectly affected the relationships established outside with the medical profession, social services, speech pathologists, behavior modification workers, respite care givers, teachers, political figures, and other support networks. All of these processes played a role in attaining integration. Thus, the various strengths within the family system influenced the relationships inside the family unit, and these relationships affect and were affected by the relationships outside. By working hard to maintain healthy relationships both inside and outside the family unit, they strive towards their goal of emotional normalization.

The constitution of the immigrant family has been discussed in terms of the emotional work invested in the parent child relationship and all those relationships surrounding it. The turning point of having a child with autism move from a noncommunicative disintegrated state into a communicative, functioning and integrated human being was what every family hoped to experience in Canada. Every couple experienced some pain and grief in their countries of origin when they found out that their child had autism. They tried to make things work in their home countries, but felt like they were missing something. They were on a quest to make their lives better, and

they made a collaborative decision to immigrate to Canada in hopes to provide their children with a normal life. Here, in Canada, they were bombarded with new systems, customs, and values, but these stresses were secondary to the stresses related to their child rearing experiences. A common thread throughout each life and in each country were the relationships that were established to alleviate stress, provide them strength, and enhance feelings of similarity. Emotional normalization can be described as a process worked at by immigrant parents in caring for their children with autism to minimize the difference between their own families and 'normal' families. For the child to develop to his/her optimal potential, the child depends on the family to initiate and sustain different relationships on the outside of their family unit in order to make things feel normal on the inside. Families have moved to Canada, and they continue to strive for integration as the attainment of emotional normalization is a life time process.

Practical Implications

To understand the experiences of immigrant parents caring for children with autism, a narrative approach was employed. It was apparent from the interviews that their experiences related to concerns around their children with autism. The issues related to being recent immigrants to Canada appeared to be secondary in this study. Some immigrant parents felt that the service delivery was disintegrated and inadequate in Canada. Others have been in Canada for a shorter time, and have not encountered as many shortcomings.

Nonetheless, an analysis of the data in terms of relationships suggests that helpers must consider an eclectic ecological solution in order to effectively help these immigrant families caring for children with autism. To maximize our intervention skills, parents

caring for their children with autism can be viewed contextually and in interaction terms. In other words, an understanding of the match between the family and the environment is critical.

Professionals must be held accountable to families and tax payers for providing support that will foster independence in immigrant families living with autism. Like their backgrounds, families living with autism vary significantly in their abilities and thus individualized supportive programs and trained assistants who have knowledge of autism and a genuine understanding of cultural diversity is essential. In essence, for children and parents living with autism to reach and maintain their optimum potential, services must be accessible, equitable, and appropriate to all families.

In an effort to improve services to these families, community based child case management programs are necessary to improve coordination among service providers and to increase families access to required services. That is, the entire community is a resource for meeting the needs of families with children with autism. Of course, families must make an effort and be open to successful integration into community based living. Ronnau (1991) suggests that the family is the primary link between the continuum of services which the child or adolescent will need. It is virtually impossible, and often counterproductive, to work with the child in isolation from the family; to help the child, you must help the family (Werrbach, 1996).

It seems that each family is confused about the roles and responsibilities of the different organizations and services in Vancouver. Whether it be in the Ministry of Health, Education, or for Children and Families, there appears to be no coordination of the various programs for children and families living with autism. The present system is

too fragmented and there is minimal accountability. In order to help an immigrant family care for their children with autism, one main center could be created for excellence in autism. Experts in autism, extensive resources, and specific behavioral programs should be systematically provided for all families living with autism.

The interviews revealed that some of these parents would benefit from having case managers. They could play in key activities such as assessing family and child strengths, coordinating service plan activities, mediating among service providers, and providing unconditional support for immigrant families and children with autism.

Secondly, parents should have access to an early intensive intervention program. After all, without early diagnosis and intensive intervention, most will remain severely mentally and socially disabled (B.C. Council on Autism, 1998). Consequently, they could be tax burdens for the rest of their lives.

Mr. T talked about the system in the U.K. whereby the diagnosis requires a team (pediatrician, psychologist, speech pathologist, and other disciplines as needed) all with skills and experience in the diagnosis of autism. By this action, parents get a thorough account of their child's disability, and recommendations are made for appropriate interventions. It is apparent that there is a team in B.C. whereby parents are referred to Sunny Hill Hospital in Vancouver; however, the waiting times for assessment range from six to twelve months (B.C. Council on Autism, 1998).

All three families discussed important therapies which were not covered by the Medical Services Plan. Mr. K, along with dozens of families in British Columbia, are funding from their own resources, the flights of American consultants to set up an in-home ABA program (B.C. Council on Autism, 1998). These include the Lovaas type

applied behaviour analysis and other programs. It is apparent that autism has significant financial implications for these families. Perhaps local politicians and administrators should modify the present policies to ensure that families living with autism are not ignored and discriminated against. Currently, children with disabilities receive services only when funding is available, and they do not have any legislated right to services (B.C. Council on Autism, 1998).

Mr. T complained loudly about the 'At Home' Program. He, along with many other parents caring for children with autism do not receive the services. In recent years, the majority of children with autism are not provided with the medical portion of the program apparently because they have no obvious physical disability. Perhaps administrators of the At-Home Program should re-consider their guidelines so that they do not discriminate against children on the autism spectrum.

Due to transportation restrictions and child care issues, families would benefit from having a choice between a autism-specific learning facility or an at home intervention program.

It has been noted that schools - more than parents- are in a position to create the conditions needed to overcome difficult relationship barriers (Carlson, 1996). Home - school collaboration mechanisms should be implemented to assure the empowerment of families living with autism.

As the various social support systems restructure their programs in the future, I hope that the needs of families living with autism must be considered. New programs which place emphasis on an integrated, pro-active approach will be very beneficial.

It was evident in my analysis of the case portraits that these families possessed numerous strengths that could be used by the helpers. Mr. T probably speaks on behalf of numerous families who are in need of more help at home. He wants to keep his children in his loving and caring home, but he requires assistance. An increasing number of parents are being forced to put their children into care at great cost to society because the Ministry for Children and Families cannot provide sufficient service to keep the child at home with the current level of subsidization. Currently, professionals in the Ministry for Children and Families are overwhelmed with other serious problems such as child abuse. The B.C. Council on Autism stated, "It is ironic that the Ministry for Children and Families must provide foster homes to children whose families are unable to cope, but they are not obligated to provide vital services for disabled children to remain in their family home" (B.C. Council on Autism, 1998).

On a positive note, an 'Autism Action Plan' has recently been developed in B.C. by the Ministry for Children and Families in conjunction with the Ministry of Education. This project is intended to include a variety of other Ministries such as Health, Human Resources, and Advanced Education as well as the Autism Society of B.C. (Garside, 1998). The aim is to develop an encompassing plan to solve the issues related to autism within a framework of services to children and youth with special needs. Important areas that are going to be incorporated into the plan include: Diagnosis and Assessment; Early Intervention Programs; School and Education; and Transition to Adulthood and Adult Services.

In essence, families such as this require a proactive, solution - oriented approach which focuses on family strengths and capabilities in a way that supports and strengthens

their family functioning styles. In contrast to treatment strategies that dwell on the problems, more attention should be directed to future possibilities (Dunst, Trivette, & Deal, 1988). To help families reduce tension, manage conflicts, and meet their demands and needs, a promotion approach is helpful. "Helping is the act of promoting and supporting family functioning in a way that enhances the acquisition of competencies that permit a greater degree of intrafamily control over subsequent activities (Dunst, Trivette, & Deal, 1988).

Implications for Future Research

Patterns of interaction over the long term could lead to valuable insights as to how these individuals have endured the obstacles over time. It would be interesting to perform this study in ten years to see if in fact these families have attained feelings of integration and emotional normalization.

In the future, more relational and explanatory research methods might be employed. However, at present, because there is minimal or no research in this area, exploratory, descriptive, and formulative approaches are appropriate. My thesis marks a beginning. An investigation into the lives of immigrant families showed that their challenges related to being parents rather than being immigrants. This might have been a result of the questions asked in the interviews. Hence, their experiences may not be dissimilar to those found in other Canadian families living with autism. Future research might be carried out in an effort to compare the experiences of a Canadian family to that of an immigrant family living with autism. Perhaps because the interviews took place within six months of the parents' arrival to Canada, they have been occupied with more pressing child care issues, and immigration issues will follow. It would be interesting to

perform another narrative study in the future under different contextual circumstances. For example, if the parents would have been in Canada for a longer period, and their perceptions might differ. As well, the systems around them such as the Ministry for Children and Families, education, and other community organizations might be subject to different influences. As a result, the content of the narratives might differ as well.

It is important to note that the families who participated in this study were able to speak English. Consequently, they might have been in a stronger position to access the services around them. On the other hand, families with limited English proficiency could be seriously disadvantaged, as cross language communication can be frustrating. A language barrier could cause a family to feel more segregated. A future research study which establishes a collaborative alliance with a family with limited English language may help caregivers understand their subjective experience and eventually encourage personal authority and autonomy among non-English speaking immigrants.

Once a rich understanding of the lives of immigrant families has been portrayed, future research might be used to elucidate the relationships between hardiness, social support, and stress symptoms apparent in immigrant families. Furthermore, longitudinal research might help to clarify the development of certain skills and social support over time. Comparisons to parents of children with other disabilities and to parents of typical children might be helpful too. Variables that relate to the severity of the child's disorder could be discussed in the future such as the amount and intensity of the maladaptive behaviors and other family variables such as marital satisfaction and internal conflict.

Indeed, by attempting to understand some of the complexities in immigrant parental coping styles, professionals and other social services will be better equipped to

design and implement services that more effectively meet the needs of immigrant families with child with autism. As we move towards the twenty first century, helping practices, theories, and policies with families of diverse backgrounds must consider diverse family coping styles; relationships between the family and the community, and the capacities of families to “sustain, survive, and thrive in a world that often does not support their well being” (Weick & Saleebey, 1995). My study, by making their voices heard, will help national and local policies develop “enabling niches” for immigrant families living with a child with autism and create environments in which these families feel more competent and comfortable (Brower, 1988; Weick & Saleebey, 1995).

Summary

The ultimate aim of my study was to understand the lives of immigrant families living with a child with autism. Families were primarily concerned about their child with autism as compared to the issues pertaining to immigration. In this narrative study, three families shared common contextual factors such as: the quality of relationships within and outside of the family, the nature of social supports, community acceptance, financial obstacles, and the availability and utilization of supportive services were revealed in the interviews. Moreover, similar psychological, social, and interpersonal characteristics of the immigrant parents, family units, and communities were highlighted.

The stories of the immigrant families living with autism in this study consisted of a set of very diverse and varied experiences and circumstances. Variables such as the degree of autism, the number of siblings, access to family resources, social support, and familial functioning styles all played a role in the telling of their stories; however, many similarities existed between the families in terms of general topics and areas of discussion. Many issues were consistent from family to family; however, their means of dealing and coping with different stressors differed. Immigrant parents caring for a child with autism discussed serious issues that were prevalent in their countries of origin and in Canada. They were woven throughout their pasts, existed in the present, and will perhaps continue in the future.

Numerous themes emerged from the narratives, and they were analyzed in terms of relationships. Bronfenbrenner's systems-ecological model looks at the family embedded as a system of nested structures. Family functioning styles such as the level of commitment, sense of purpose, communication, values, flexibility, allocation of time,

congruence, coping strategies, optimism, balance, and problem solving abilities were studied. As well, relationships with social support systems and family resources such as finances were also included in the analysis. Finally, the themes were discussed in the context of emotional normalization, a term given to a family's ultimate goal to integrate into their communities.

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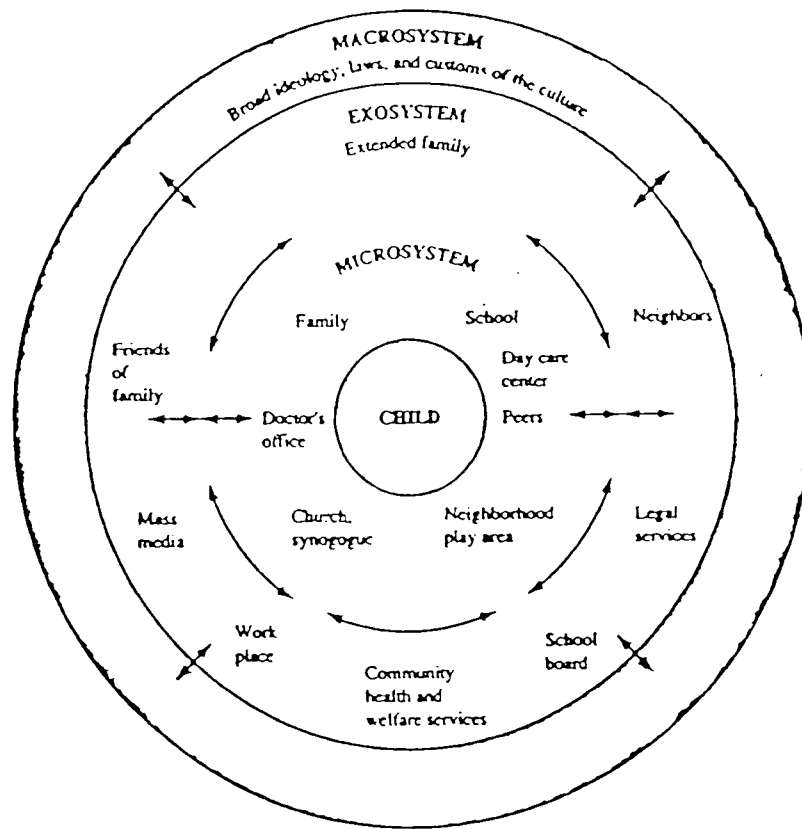
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Appendix A

Bronfenbrenner's Ecological Model (Kopp & Krakow, 1982)



Consent: I understand that my participation in this study is entirely voluntary and that I may refuse to participate or withdraw from the study at any time without jeopardy to my present lifestyle.

I have received a copy of this consent form for my own records.

Subject Signature

Date

Signature of a Witness

Date

Appendix C

Letter of Information

February 9, 1998.

Dear Parents;

The purpose of my study is to understand the experiences of immigrant parents caring for a child with autism. By attempting to understand some of the complexities, professionals and other social services will be better equipped to design and implement services that would effectively meet the needs of immigrant families with children with autism.

I intend to interview parents of children with autism who are presently permanent residents of Canada and have come from another country. Participants would be required to share their experiences in an interview (approximately one hour) which will be audio taped and subsequently transcribed. Participants will remain anonymous.

Thank you for your consideration.

Sincerely,

Glenda Wallace