

**Cultural Interpretation of Disability:  
Perspectives on Home-School Partnerships**

by

**Laurelyn Hope Morry Cantor**

A Thesis submitted to the Faculty of Graduate Studies of  
The University of Manitoba  
in partial fulfilment of the requirements of the degree of

**Doctor of Philosophy**

Department of Educational Administration, Foundations and Psychology  
Faculty of Education  
University of Manitoba  
Winnipeg, Manitoba, Canada

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## ABSTRACT

Developing collaborative partnerships with new Canadian families of children with disabilities requires that educators understand the cultural foundation of their professional practice. To address this need, I interviewed five new Canadian families of children with disabilities, regarding their perspectives on the process contributing to effective family-professional partnerships. The intent was to listen to the families' real-life stories. In addition, three focus groups were conducted with educators and administrators to document the perspectives of school professionals regarding positive partnerships.

The interviews and focus group results were interpreted from the point of view of existing literature about partnerships between families and school professionals. Recommended practices were identified and provided a framework of principles for professional behavior and attitudes essential for positive partnerships with families. The recommended practices were organized into four broad themes: (a) communication, (b) cultural reciprocity, (c) professional knowledge and practice, and (d) advocacy. In general, the interviews suggested that educators can develop culturally reciprocal partnerships with the families by helping new Canadian families of children with disabilities acquire "cultural capital." While more exploration of families'

perspectives is still needed, the outcomes of this study can serve as dialogue between educators and new Canadian families, a measure that will enhance the quality of home-school partnerships.



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Lastly, I wish to express my love and appreciation to my family and special friends for their never-ending support.

## DEDICATION

This dissertation is dedicated to:

my parents, Manuel and Freda Morry. Without their love and support all the years I was growing up, I would not have come this far. They instilled in me the importance of education, cultural reciprocity, and the perseverance to see all projects through to the end!

my children, Daniel, Jared, and Evan, who have been sources of great pride and inspiration, and

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## CHAPTER I

### RATIONALE FOR STUDY

The mandate in special education requires educators to involve parents of students with disabilities in the educational decision-making process (Manitoba Education, Citizenship and Youth, 2006). However, there is a gap between recommended practice and reality in providing positive home-school partnerships (Blue-Banning, Summers, Frankland, Nelson & Beegle, 2004; Kalyanpur, Harry, & Skrtic, 2000; Lynch & Hanson, 1997; Turnbull & Turnbull, 2000). One reason for the gap between recommended practice and the implementation of those practices may be the lack of understanding by educators of the “meaning” of home-school partnerships. The purpose of this study was to explore the question: What are the recommended practices associated with successful partnerships from the perspective of new Canadian families of children with disabilities and educators?

Banks (1997) has stated that cultural identity is dynamic, and that no two families share the same values or levels of acculturation. Along the same line, educators possess values, attitudes, knowledge of resources and recommended practices, previous experiences, and training and skills, which they bring to their professional role (Bruder, Harbin, Whitbread, Conn-Powers, Roberts, Dunst, Van Buren, Mazzearella, and Gabbard 2005). Developing culturally reciprocal relationships with families, involves “an understanding of each family’s

uniqueness and the recognition that the relationship is an outcome of the interaction of all the variables of cultural identity of both the family and the professional” (Kalyanpur & Harry, 2004; p. 532).

Any terminology intending to describe a group that has been marginalized is controversial, which is as true for people with disabilities as for ethnic groups (Harry & Klingner, 2006). Aware of the sensitivity of this process, I wrestled to reach a decision on appropriate terminology to use in this research study. After considering as alternatives “culturally and linguistically diverse”, “minorities”, “immigrants”, and “refugees”, I decided on two references, “new Canadians” and “newcomers”. The focus of this study is the experience of new Canadians in negotiating the special education system in Canadian schools

In this chapter, I outline the concept of home-school partnerships. Then, I introduce the notion of disability as a socially constructed concept, and present definitions of culture and ethnicity. Next I introduce theoretical frameworks that concern home-school partnerships and cultural awareness. This leads to the question that I developed about recommended practices associated with successful partnerships from the perspective of new Canadian families of children with disabilities and educators.

### *Disability as a Socially Constructed Concept*

Kalyanpur and Harry (1999) observe that the conditions included in the term disability vary in different contexts and that diagnosis of specific disabilities is subjective and culturally derived, as are the findings about the severity, impact and response to those conditions. The most substantial change in the

understanding of disability is not in the realm of clinical services but in the research literature that finds that while disability is universal, there is distinct variation in how cultures interpret disability (Groce, 1999).

Families of children with disabilities from diverse cultural and linguistic backgrounds may have perspectives towards the etiology and treatment of disabilities that differ from the North American biomedical model. For instance, the same problem may not be perceived as a disability in different societies (Kalyanpur & Harry, 1999). Family members' beliefs about the cause of their child's disability influence their expectations about their child's behaviour, their goals for their child, and their involvement in special education services. Traditional cultural patterns have been described for particular groups, such as the belief that conditions such as epilepsy are reflections of spiritual phenomena within the individual (Fadiman, 1997).

### *Concepts of Culture and Ethnicity*

Culture is a complex construct that is often used interchangeably with race or ethnicity. It is important to first define culture and point out its relationships to these related concepts. Carter and Qureshi (1995) define culture as "a learned system of meaning and behaviour that is passed from one generation to the next" (p. 241). According to Sodowsky, Kwan & Pannu (1995) in every culture there is a "set of people who have common and shared values; customs, habits and rituals; systems of labeling, explanations, and evaluations; social rules of behaviour; perceptions regarding human nature, natural phenomena, interpersonal relationships, time, and activity; symbols, art, and artifacts; and

historical developments” (p. 132). Based on this definition, culture comprises an identifiable pattern of behaviour exhibited by people in response to diverse phenomena in their environment, and the meanings they attach to that encounter. Because a culture is learned, it varies over time. However, culture has certain constant features, including language, which characterizes it from other cultures.

Culture, as defined by Misra (1994) is the “collective beliefs and knowledge that govern social behaviour. Culture includes the language of the people, their standards and perceptions, the ways in which they display anger or joy, and the gestures they use during a conversation.” Banks and McGee Banks (2003) suggest a more fluid and less discrete way of thinking about cultural identification applicable to multicultural societies such as Canada, in which there is a “shared core culture as well as many subcultures” (p. 7). This concept offers a complex image of macro and micro levels of culture with the macroculture being an overarching framework that includes many microcultural groups. Consequently, the cultural identity of an individual may indicate features of the macroculture as well as his or her microculture. Banks and McGee Banks (2003) see the essence of a culture not in its artifacts, food or clothing, but how the members of the group interpret, use, and perceive them. According to the authors, it is the attitudes, values, and beliefs that distinguish one group from another.

Ethnicity is used to describe a group defined by a common nationality, culture or language. Ethnicity itself does not constitute culture. However, it may



be that associative ethnic interactions contribute to the transmission of culture (Betancourt & Lopez, 1993). Wright (1983) in explaining the difference among these terms, states that, "Ethnic groups will be so defined if they share a common sociohistory, have a sense of identity of themselves as a group, and have common geographical, religious, racial and cultural roots. The central core of each ethnic group, welding it together with the thread of belief, styles of being, and adapting, is culture" (p. 5).

Despite the realization that there are multiple cultures for ethnic and racial groups, the perception remains that there is a universal culture. Culture specific information does not apply to all individuals within a racial or ethnic group category. By making assumptions, inaccurate conclusions can lead to stereotyping and misinterpreted findings. Even though many researchers acknowledge the limitations of cultural characterization, they still proceed to make them. The dilemma lies in the question posed by Tatum (1997): "How can I make the experiences of my Latino, Asian, and Native students visible without tokenizing them?" (p. 132). She concludes that "a sincere, though imperfect attempt to interrupt the oppression of others is usually better than no attempt at all" (pp. 132-133).

### Theoretical Models

A strong theoretical basis for promoting home-school partnerships is derived from two theories: the family systems theory (Turnbull & Turnbull, 1990), and Bronfenbrenner's (1979) ecological theory. The family systems theory focuses on understanding related aspects of the family in order to meet the

needs of both the family and the individuals within it (Turnbull & Turnbull, 2001). A primary feature of the ecological theory is its distinctions among environmental influences that are organized hierarchically — micro, meso, exo, and macro (Bronfenbrenner, 1979). The ecological perspective views the child as part of a family which is connected to community resources ,to extended family, to a social support network, and to ethnic, cultural, and religious factors. The ecological model explains development as a joint function of environmental influences and child characteristics.

In addition, I have considered two theoretical frameworks that examine cultural influences. Bourdieu (1986) referred to “cultural capital” as resources and information which contributes to a person’s symbolic and material wealth, status, and power. Acquiring cultural capital about the special education system, would “empower parents to become effective partners in the educational decision-making process for their child” (Kalyanpur & Harry, 2004, p. 532). The sociocultural theory, drawing mainly on the insights of Vygotsky, defines and supports a pedagogy for conceptualizing cultural differences, and the possibilities for creating partnerships between families of children with disabilities from diverse backgrounds and school professionals (Lim & Renshaw, 2001). These theoretical frameworks will be interpreted more thoroughly in chapter two.

### Significance of the Study

My interest in family-professional partnerships began when I was a special education resource teacher in inner city schools. An important element of the philosophy I took to the schools I worked in, was a strong belief that

communication with the families of children with disabilities was extremely important. However, quite often I realized that not only were there barriers and missed opportunities to communication by the family, but also by the educators and administrators.

This study is an extension of my Master's Thesis "Establishing Partnerships with Families of Children with Disabilities from Culturally and Linguistically Diverse Backgrounds", completed in 2003. In the qualitative study, I conducted interviews with six families of children with disabilities from culturally and linguistically diverse backgrounds, concerning their child's education, including the expectations with respect to the roles of both home and school. Factors were identified which affected their participation in their children's education. In the present study, I compared the perspectives of both families and school professionals regarding effective partnerships.

Research and legislation from the United States dominates the review of the literature concerning partnerships between families and school professionals. The concept of collaborative partnerships between parents and schools in the design and implementation of special educator programs is one of six principles of the Individuals with Disabilities Act (IDEA) (Turnbull & Turnbull, 2000). This research was designed to examine recommended practice in Manitoba legislation: *Appropriate Educational Programming in Manitoba: Standards for Student Services* and the recent Bill 13 legislation focus on the right of all students to "appropriate educational programming" (Manitoba Education, Citizenship and Youth, 2006, p. 5).

### Purpose of the Study

Given these interests and concerns, both personal and professional, in this study I conducted interviews with families of children with disabilities from diverse backgrounds, as well as educators, regarding their perspectives on the process contributing to effective home-school partnerships. Two research questions guided this inquiry: What are the recommended practices associated with successful partnerships from the perspective of new Canadian families of children with disabilities and educators? How do the perspectives of families and educators compare? Implications of these findings for designing new directions for models to support more effective partnerships between families and educators are presented.

### Organization of the Study

In chapter one, I provide a rationale for the study, connecting the concepts of culture, ethnicity, and disability. A theoretical framework concerning home-school partnerships is introduced. A review of the literature is presented in chapter two, including the significance of partnerships in research and legislation. I explore theoretical models as a focus for partnerships between families of children with disabilities from diverse backgrounds and educators. The research methods are described in chapter three. In chapter four, I describe the five new Canadian families who participated in this research study. In chapter five, the results of the interviews and the focus groups are presented. Finally, in chapter six, I discuss the findings and their implications for practice and for future research.

## CHAPTER II

### LITERATURE REVIEW

A thorough, sophisticated literature review is the foundation and inspiration for substantive, constructive research (Boote & Beile, 2005). Boote and Beile (2005) emphasize that a researcher cannot perform significant research without first understanding the literature in the field, the strengths and weaknesses of existing studies, and their relevance. Shulman (1999) defines generativity as the ability to build and learn from prior research and scholarship of researchers who have preceded us.

The literature review sets the comprehensive context of the study, clearly defining the scope of the research and situating the existing literature in a scholarly and historical context (Boote & Beile, 2005). By not only reporting the results of the existing literature, but also critically examining the research methods used, the researcher is able to determine what still needs to be learned and accomplished in a way that allows for a new perspective. A good literature review is the basis of both theoretical and methodological insight (Boote & Beile, 2005).

Based on this premise, the review of the literature includes four main areas. Both families and educators bring to an interaction a set of beliefs and attitudes within their own ecological realm that affects how they understand the concerns that they encounter, which dictates the solutions they arrive at. I begin

with the historical background of partnerships, and continue with an examination of the different theoretical perspectives, including ecological, sociocultural, family systems, and cultural capital that have influenced home-school partnerships. Drawing on perspectives, theories, and research methodology from other fields of study is integral to understanding home-school connections. Although the ecological, sociocultural, and family systems theories provide a framework for home-school partnerships, using cultural capital theory has the potential to increase the knowledge base that allows us to consider issues that would impose successful partnerships for new Canadian families with children with disabilities. Next, I synthesize and critically analyze prior research in the area of home-school partnerships. I focus on barriers to participation, and suggest the need to incorporate approaches that allow educators to recognize the cultural foundations of their practice towards more effective partnerships with families. I discuss Manitoba's recently mandated legislation to provide "appropriate programming and services " (Manitoba Education, Citizenship and Youth, 2006), that meet the individual needs of every student in the most inclusive environment. I examine the guidelines and policies concerning parental involvement and effective partnerships. From a practical perspective, the population of Canada is becoming increasingly diverse, which, in turn, results in classrooms becoming increasingly diverse. The final section of the literature review discusses Canadian trends in immigration, and entrance procedures for individuals with disabilities.

## The Framework for Partnerships

### *Evolution of Partnership Models*

Historical accounts of families of children with disabilities are important to better understand the need for family-school partnerships. Proponents of the eugenics movement (1880-1930) viewed parents as the underlying genetic cause of their child's physical, emotional, or intellectual disability (Turnbull & Turnbull, 1990). Beginning in the 1930s, parents began to organize local parent support groups which, in turn, generated national organizations. From the 1950s to the 1970s the medical model supported an authoritative role for professionals discouraging initiative on the part of parents and creating a culture of dependence (Fine & Gardner, 1994). Parents were expected to accept and implement the treatment programs prescribed by professionals.

The *psychotherapy model* most prevalent in the 1950s and 1960s, assumed parental pathology in the discovery of their child's "deficits" (Turnbull, Turbiville, & Turnbull, 2000). This model focused on helping the parent through the "grief cycle" to emerge as accepting of their child's disabilities and if necessary, placing him or her outside the home (Wolfensberger, 1967). The professional was the primary decision-maker in this model, with control over diagnosing treatment, and decisions about best outcomes for the child and family (Skrtic, 1995). This "power-over" approach was especially problematic for families from culturally and linguistically diverse backgrounds (Turnbull & Turnbull, 2002).

The *parent training/involvement model* from the 1960s to the 1970s was based on an assumption that the family environment was partially the cause of the child's disabilities. Parents were provided with training to improve their child's learning environment (Turnbull et al, 2000). The focus remained on the professional as the primary decision-maker.

The *family-centered model* introduced in the 1980s, was more of a "power-with" relationship, in which families and professionals shared power (Turnbull & Turnbull, 2002). Family choice was honoured, and family strengths were recognized in developing and implementing early intervention (Turnbull et al, 2000).

The *collective empowerment* model expands the concepts of family centered programs to expand the capacity of families, professionals, and the broader community to access resources and make choices. Power is redefined as access to resources rather than control; it is conceptualized as capacity building for all participants (Turnbull et al, 2000).

#### *Home-School Collaboration*

Home-School collaboration is very important as a means of improving education for all students. Friend and Cook (1996) define interpersonal collaboration as "a style for direct interaction between at least two coequal parties voluntarily engaged in shared decision making as they work toward a common goal" (p. 6).

Turnbull and Turnbull (2001) refer to collaboration as "the dynamic process of families and professionals equally sharing their resources in order to



make decisions jointly” (p. 13). Thousand, Villa, Paolucci-Whitcomb, and Nevin (1996) discuss collaboration as an essential element in the successful development of partnerships between schools and parents, enabling schools to meet diverse student needs through shared expertise, such as: (a) shared ownership of problem definitions and solutions, (b) shared knowledge and expertise, and (c) increased cohesiveness and willingness to work together on future projects. Parents should be included in decisions affecting their children both on ethical and professional grounds, and because family members provide valuable information regarding a student’s language skills, behaviours at home, and school background (Gersten, Brengelman & Jimenez, 1994).

#### Theoretical Perspectives of Home-School Partnerships

Early theories of learning charted new unexplored territory. They provided experimental paradigms for research and introduced basic constructs that could be studied scientifically (Gredler, 2005). As the 21<sup>st</sup> century unfolds, Canada’s changing population challenges both educators and the workplace. Each of the four theories that are discussed, the cultural capital theory (Bourdieu, 1986), the sociocultural theory (Vygotsky, 1987), the family systems theory (Turnbull & Turnbull, 1990), and the ecological theory (Bronfenbrenner, 1979) address particular issues relevant to home-school partnerships.

#### *Cultural Capital*

Consideration of cultural capital is an important component of a holistic theoretical framework from which to examine home-school partnerships, particularly for new Canadian families of children with disabilities. Based largely

on the work of French sociologist, Pierre Bourdieu, (1930-2002) educational researchers have examined the unequal distribution of power and status among various populations as it relates to acquiring education (Harker, Mahar & Wilkes, 1990). Bourdieu (1986) focused on class based structures and inequity, and identified three types of capital, known as human, cultural, and social, which contribute to a person's abilities to acquire symbolic and material wealth, status, and power in society (Trainor, 2008).

Human capital is easily understood, however, cultural and social capital need clarification. Cultural capital, according to Bourdieu (1986), consists of a style of interaction, including the knowledge and skills that are the products of an individual's position in society that inform the way a person thinks and acts. Bourdieu (1986) states that cultural capital is initially passed down by the family. Families whose home and community environments reflect mainstream culture acquire social networks that implicitly transmit knowledge of patterns, and norms, providing them the skills to function well within the school environment. In analyzing the experiences of working-class and immigrant families in French schools, Bourdieu used this concept to explain how the social structures of a host society tend to sustain themselves (Weine, Ware & Klebic, 2004). Bourdieu (1998) claimed that cultural capital is portioned out through "information capital", for example, some newcomer families know more than others about how the education system works. Application of the definition to parent advocacy in special education is presented in the following example: A parent who attends the IEP meeting for her child has specific questions and requests regarding the

educational program of her child. She understands her role in the IEP meeting and communicates her ability and intent to collaborate with the school professionals (Trainor, 2008).

Bourdieu (1986) defined social capital as resources, both tangible and symbolic, that come from a person's connectedness to society through social networks. According to Bourdieu, (1986) social capital is a personal asset that provides tangible advantages to those individuals, families or groups that are better connected. Following upon the work of Bourdieu, other proponents of social capital (Coleman, 1988). Fukuyama (1999), and Putman (2000) have defined social capital as social networks of trust, reciprocity and cooperation. Coleman's (1988) research on "social capital", the norms and relationships that enhance the likelihood of success, examined parental commitment to the success of children and youth in school. Within the family, he saw social capital as bonds between parents and their children, demonstrated in part through involvement with their children's efforts at school. To expand on the previous example, before attending the IEP meeting, the parent joins a support group and connects with other families who have knowledge and experience about special education processes. She receives social and emotional support, as well as information that influences her involvement in the IEP meeting. Newcomer families may not be aware of these avenues for participation in their child's education.

Bourdieu (1974) maintained that capital resources operated concurrently, resulting in social reproduction. This means that people who have acquired

different forms of human, social, and cultural capital are able to gain access to further resources, whereas those who do not, struggle to gain access to resources. The concepts of *field* and *habitus*, also developed by Bourdieu, help explain the function of capital (Harken et al., 1990). Field is the contextual environment in which people exist and carry on with their daily lives (Webb, Schirato, & Danaher, 2002). Referencing the example the field would refer to the interactions between the family and the educators.

Habitus, or “a system of cognitive and motivating structures” (Bourdieu, 1990, p. 53) refers to the rules and structures under which people perform daily living activities. Through day-to-day interaction, people acquire information about their habitus, allowing them to function within a society without questioning why it is they act a certain way, or assign value to one object, action or interaction more than another (Bourdieu, 1986). Concerning IEP meetings, there are explicit rules and guidelines, including who is involved, where it takes place, what topics are discussed, as well as protocol for communication and interaction.

Family involvement in both general and special education varies, according to the types of both social and cultural capital resources, valued and used by families (Lareau & Horvat, 1999). Horvat, Weininger, & Lareau (2003) found that families advocated for their children to obtain effective teachers, address behavioral disputes, and receive equitable special education services.

Although special education legislative initiatives have done much to create opportunities for equity, very often these structures do not achieve this goal (Trainor, 2008). These opportunities depend upon parental involvement, without

which these opportunities are reduced. Yet, families who have not acquired cultural capital may hesitate to become involved (Harry, 1992), and educators may marginalize families input (Harry & Klingner, 2006). They may also lack the linguistic ability to become involved, and are more likely to work long hours making it difficult to attend.

Bourdieu's theoretical position of cultural capital is useful in understanding inequity in relationships between families and educators. According to Bourdieu (1986), school is the major site where cultural capital is acquired, and how the social status quo is maintained. Relationships between families and educators are viewed as ones in which the preferences, attitudes, and behaviours of the dominant class are most highly valued (Lareau, Horvat, 1999; Valenzuela, 1999; Stanton-Salazar, 2001). Those in power, control the form of culture that is acceptable and dominant within the school system (Bourdieu, 1986). Educators and administrators are already overburdened with many responsibilities and therefore, taking the time to have cultural connectedness with students and their families is challenging. It is not that the school system wants to perpetuate these power differentials, it is just that the reality of over-stretched and under-staffed education requires great effort to provide for cultural differences. This places newcomer families, especially those who are economically and socially disadvantaged as former refugees, at a significant disadvantage. It is much easier for schools to ignore the needs of these students since the students and their families lack the power to appeal.

A major question is to determine whether new Canadian families of children with disabilities feel co-equal with school professionals. Parents may want a more active role, yet may defer educational decisions to professionals who are perceived to be the experts in the education of children with disabilities (Kalyanpur & Harry, 1999; Parette & Petch-Hogan, 2000). Kalyanpur and Harry (1999) have indicated that the prevailing model of professionalism is a barrier that significantly impedes collaboration: "The perception that a professional is a person of high standing and a figure of authority makes it difficult for parents to participate in education decision making" (p. 29).

Fine and Gardner (1994) also mention the concept of "co-equal status" in regards to collaboration. Fine and Gardner (1994) allege that it is impossible to ignore the specialized training of professionals but it is equally important to acknowledge "...the beliefs and perception of parents by professionals, and an appreciation of the parents' insights, ideas and experiences" (p. 299). Skrtic (1995) differentiates between "the professions" and other social groups: "Society gives professionals greater autonomy than it does other social groups on the assumption that their knowledge is valid and useful and that they will use it on behalf of their clients and the public good" (p. 7).

Bowers (1984) refers to cultural capital as the knowledge and skills with which we find our way in society as competent adults. By acquiring cultural capital relating to the special education system, families become empowered to become effective partners in the educational decision-making process for their child. The acquisition of cultural capital is challenging for families who have

recently immigrated to Canada, partly because they have little knowledge of the educational system, of the practices valued by teachers and schools, and of their rights with respect to educational issues (Rueda, Monzo, & Arzubiana, 2003). Kalyanpur and Harry (2004) contend that school professionals, as members of the special education system, "have the responsibility to share with parents the "cultural capital:" or the knowledge that will help them to negotiate their way through this system" (p. 531).

In a qualitative study, Lareau and Horvat (1999) found that African American families of high socioeconomic backgrounds used social and cultural capital in ways that differed from African American parents from low socioeconomic backgrounds. They found that families whose expectations and patterns of behavior matched well with the school's expectations and culture, experienced less conflict than did families whose actions and expressions contradicted "a narrow band of acceptable behaviours" (p. 42). The value of capital is determined mostly by community members who have the power to make such evaluations. Bourdieu (1986) argues that these decisions are made by the decision-makers to cling to their hierarchy of professional expertise.

In Valenzuela's (1999) study of U.S. – Mexican youth living in Houston, Texas, generational status, relationships among peers, and immigration issues were variables in the educational experiences of the participants. Teachers and administrators were interviewed about the academic achievement and postsecondary options available to students. It was determined that educators very often make assumptions about the students based on how well they

assimilate into the dominant culture (Valenzuela, 1999). In addition, these assumptions often inhibit culturally and linguistically diverse students' understanding of self, futures planning, and goal attainment.

Stanton-Salazar (2001) also explored the concepts of social capital and social integration as they relate to the educational attainment of U.S.-Mexican youth living in California. Limited resources available to the participants affected their ability to make the most of their public school experience. Both social capital and cultural capital, including community involvement, links to resources, and references to postsecondary education and career opportunities may escape the group of families from diverse cultural and linguistic backgrounds (Stanton-Salazar, 2001).

Trainor (2008) examined the cultural and social capital that parents use while advocating for their children with disabilities. Five focus groups and twenty-seven in-depth interviews of participants from a range of socio-economic, disability, and racial or ethnic backgrounds revealed important aspects of advocacy and access to information (i.e., cultural capital) and relationships and connections between people (i.e., social capital) (Trainor, 2008). Both intercultural and intracultural differences existed among parents. The data also illustrate the use of capital during advocacy for individuals and advocacy for systemic change. Implications for the practice of education, based on Trainor's (2008) findings, include increasing educator's attitudes and skills about collaboration across groups of families with diverse backgrounds.



*Sociocultural Theory*

Vygotsky, (1987) widely recognized as the founder of sociocultural theory, conducted research on the relationship of culture and learning in the early 1900s under cultural circumstances very different from those of today (Mahn, 1999). Sociocultural theory supports a pedagogy for valuing difference and creating inclusive communities useful to framing the cross-cultural interactions between professionals and families of children with disabilities (Lim & Renshaw, 2001).

Sociocultural theory views learning as situated within interrelated historical, cultural, institutional and communicative processes (Lim & Renshaw, 2001; Mahn, 1999). The notion of learning extends beyond the individual to the individual in interaction with others within communities of practice. Through this interaction individuals gain sociocultural knowledge and practices, such as ways of speaking and behaving, conventions for representing ideas, communicating, and values and beliefs (Lim & Renshaw, 2001). For Vygotsky, the key sociocultural concept of acquiring cultural tools is the *zone of proximal development (ZPD)* which highlights the way individuals with greater cultural capital can scaffold the participation of novice participants in social and cultural activities.

Fitzgerald and Goncu (1993) applied Vygotsky's theory of the zone of proximal development to the area of family-professional partnerships. They suggest that parents and professionals explain to each other the skills that each considers necessary to create culturally inclusive partnerships. Research studies on the perspectives of parents of children with disabilities from ethnic groups

such as African-Americans (Harry, Allen, & McLaughlin, 1995; Kalyanpur & Rao, 1991), Latino-Americans (Harry, 1992), and Native Americans (Sontag & Schacht, 1994) have revealed cultural dissonance as a barrier to parent-professional collaboration. These studies illustrate the importance of understanding the perspectives of, and interactions between, culturally diverse families and professionals. The research procedures used in these studies included ethnography, interviewing, life histories and case studies. This research explores the perspectives of the participants by examining their locally situated “funds of knowledge” (Moll & Greenberg, 1992, p. 320) and providing them a voice.

The metaphor of *scaffolding*, is extremely relevant to the process of building cultural reciprocity between culturally diverse families and professionals. Scaffolding refers to the “forms of assistance that enables an individual to learn and acquire new knowledge, skills, and tools that are initially beyond the learner’s capacity” (Lim & Renshaw, 2001, p. 17). Scaffolding activities for building home-school partnerships include opportunities and assistance to express and compare values and ideas with others; acknowledge multiple representations of concepts, and agree to advance to effective courses of action (Lim & Renshaw, 2001).

Besides enabling a voice for newcomers, sociocultural theory encourages the creation of culturally inclusive communities. Kalyanpur and Harry (1997) emphasize the importance of “a posture of cultural reciprocity” in which professionals “engage in explicit discussion with families regarding differential

cultural values and practices...respect the new body of knowledge that emerges from these discussions, and make allowances for differences in perspective when responding to the family's need" (p. 25). These researchers assert that collaboration between parents and educators requires that professionals first develop an awareness of their own cultural and ethical values, and recognize the assumptions and taken-for-granted beliefs imbedded in their professional practice, a process that facilitates the empowerment of professionals (Kalyanpur & Harry, 1997). Next, by communicating this knowledge when interacting with the families towards a shared understanding, the empowerment of families is facilitated. Cultural reciprocity occurs through scaffolding the participation of each other to appropriate cultural tools and capital.

### *Family Systems Theory*

Family systems theory provides a framework for understanding what a family is and how it functions. Turnbull and Turnbull (1990) merged family systems with disabilities. By shifting to a family focus, the student is no longer viewed in isolation, but within the context of his or her own family. Turnbull and Turnbull (1990) proposed a family systems framework to organize four major perspectives which include: 1) family characteristics, which focus on the descriptive elements of the family that shape each family's individuality, 2) family interactions, which focuses on the relationships that occur among family members, 3) family functions, which refers to the tasks family members perform to meet individual and collective needs such as economic or educational needs,

and 4) the family life cycle, which represents the sequences of changes that affect families over time.

Family systems theory makes three assumptions relevant to partnerships with families: 1) the input/output configuration of systems, 2) the concepts of wholeness and subsystems, and 3) the role of boundaries in defining systems (Turnbull, Turnbull, Erwin & Soodak, 2006). A family's characteristics are the inputs into family interactions. The output of these interactions is related to family functions and how family members interact with each other and with others outside the family.

Family systems theory must be understood as a whole and not by its parts. The family consists of subsystems (marital, parental, sibling, and extended), and the child with a disability can impact each of these subsystems. Professionals should focus on the reciprocity within the family (Turnbull et al., 2006).

The third assumption of family systems theory is that subsystems are separated by boundaries that define the interactions family members have with each other, and with others outside the family. Families vary in the degree to which their boundaries are open or closed to educators. This will affect how much the family will collaborate with educators (Turnbull et al., 2006). In some families, extended family members take on parental roles because the boundary between the two subsystems is open. Grandparents may meet resistance when they make suggestions to their grandchildren's teachers (Cantor, 2003).

*Ecological Theory*

Bronfenbrenner's (1979) ecological model views the child as part of a family, and encourages exploration of the family's connectedness to community resources, the involvement of extended family, the nature of the social support network and the meaning of ethnic, cultural and religious factors.

Bronfenbrenner's ecological model supports the understanding of development as a joint function of environmental influences and child characteristics.

Bronfenbrenner (1979) defines the ecology of human development as "...the scientific study of the progressive, mutual accommodation between an active, growing human being and the changing properties of the immediate settings in which the developing person lives, as this process is affected by relations between these settings, and by the larger contexts in which the settings are embedded" (p. 21). Bronfenbrenner focuses on three features of this definition: 1) the ecological model views the developing person as influencing and contributing to his environment; 2) development is not conceptualized as unidirectional rather it is reciprocal, requiring interactions between the child and the environment, and; 3) there are multiple environments that impact the child, and the child impacts multiple environments (Bronfenbrenner, 1979).

A primary feature of ecological theory is hierarchical environmental systems of influence (Bronfenbrenner, 1979). Hierarchical systems of influence refer to the analysis of development within the larger ecological contexts of four

levels of systems – micro, meso, exo, and macro – rather than on one level only. Turnbull, Blue-Banning, Turbiville and Park (1999) suggest how the ecological perspective can enhance the overall quality of life for the child and the family by encouraging families and service providers to: “1) regard the child as an authentic member of the family’s and community’s ecological environments; 2) determine what is important to the child and the family in terms of quality of life across all four systems; 3) find out what is in place that is consistent with their priorities; 4) establish what changes are necessary to create a better match between what is important and what exists in their lives, and 5) provide partnership education, supports and services to create preferred quality of life enhancements” (p. 166). An ecological perspective shifts the focus from only concentrating on the child’s developmental gain to concentrating on a transformed ecology in which children with disabilities can improve in their development as they interact within a responsive environment (Turnbull et al, 1999). The partnership team for each family may include other family members, professionals, and members of the family’s community from all four ecological levels.

One feature of the macrosystem, the fourth level in Bronfenbrenner’s (1979, 1992) taxonomy refers to the concept of a “cultural repertoire of belief systems” (Bronfenbrenner, 1992, p. 288). Bronfenbrenner’s theory suggests that the belief systems of the significant others in the child’s world (e.g., parents and teachers) create a “blueprint” (Bronfenbrenner, 1979, p. 26) for the child’s developmental competence (Sontag, 1996). Identification of macrosystems,

describe the child's place within the broader context of family, community, lifestyle, and cultural belief system becomes an important step in the development of the child. By incorporating Bronfenbrenner's ecological framework into special education research, there is the potential to generate knowledge and influence practice. The child is considered an active agent influencing the interactions in his or her microsystems (Bronfenbrenner, 1992).

Communication between families and school professionals is a major indicator for effective and successful partnerships. In my Master's thesis (Cantor, 2003) it was noted that families from non-English language backgrounds may be reluctant to interact with school personnel because they feel that they lack the necessary skills to communicate. These language differences may be even more complicated by difficulties in understanding special education terminology and practices. By creating access to cultural mediation, not only to translate from one language to another, but also to serve as a liaison between two cultures, can be an invaluable resource to support families of children with disabilities from diverse cultures.

### Research on Family-Professional Partnerships

The current literature on family and professional collaborative partnerships contains numerous references to expectations for parents with respect to home and school relationships. Epstein (1995) identifies six components in a framework for parent involvement. The six types of involvement identified by Epstein include: (a) parenting (helping families with parenting skills), (b) communicating (assuring effective communication about school programs and

students' progress), (c) volunteering (organizing volunteers and providing volunteer opportunities), (d) learning at home (involving families in working with their children at home), (e) decision making (including families in school decisions), and (f) collaborating with the community (coordinating resources and services).

Although Epstein (1995) stresses that the six types of involvement may be initiated by anyone, including schools, family members, or a community organization, some scholars have criticized her categorization as limited by its school-centered focus (Kohl, Lenguma, & McMahon, 2000).

Epstein's (1995) model of "overlapping spheres of influence" presents three overlapping circles representing family, school and community. Various factors, including time, experiences, philosophy, and practices of the family, the school and the community, determine the degree of overlaps among the circles. With families from culturally diverse backgrounds, these spheres of influence are likely to be divergent (Southwest Educational Development Laboratory, 2003). However, there are varied perspectives on how congruence, or overlap, should be defined – it may mean sameness in values, lifestyle, behaviour, etc., or it may mean mutual acceptance, understanding, and respect for differences (Southwest Educational Development Laboratory, 2003). Special education policy and literature outline additional responsibilities for parents to advocate for their child's disabilities, and to participate in decision making through development of the individualized education program (Turnbull & Turnbull, 2001).



Although professionals support collaborative interactions with parents, research indicates that a gap exists between professionals' intentions and actual practice (McWilliam, Tocci, & Harbin, 1998; Roberts, Rule, & Innocenti, 1998). Blue-Banning, Turnbull, and Pereira (2000) conducted focus groups with parents and professionals to examine facilitative factors in the achievement of visions for Latino adolescents and young adults with disabilities. Both stakeholder groups identified the disparity of power and authority in the relationship between parents and professionals as a major challenge to successful partnerships. The essence of their comments was that parents were not seen as equal partners and that professionals maintained control.

Harry, Rueda, and Kalyanpur (1999) applied the basic concepts of sociocultural theory, and ecocultural analysis in a research study of seven culturally diverse families with children with disabilities. Their results indicate that a central problem in the development of partnerships is failure to establish collaborative, trusting, empowering relationships between families and educators that support effective service delivery. They suggest that service providers need to cultivate a habit of learning to understand and respect the beliefs of others.

Blue-Banning, Summers, Frankland, Nelson, and Beegle (2004) conducted a qualitative research study, designed to increase understanding of the indicators of professional behaviours associated with collaborative partnerships from the perspectives of parents from ethnically diverse backgrounds and professionals. The study involved families with and without children with a disability, as well as professionals and administrators. Focus

groups served as the primary data collection method, and in-depth individual interviews with families with limited English language proficiency, and professionals who provide direct services to these families were also conducted using translators. Transcripts were analyzed using the constant comparison method of identifying, coding, and iteratively revising response categories to develop a series of indicators. These indicators were organized into six hypothesized domains of interpersonal partnership: professional skills, commitment, respect, trust, communication, and equality. Within each of these domains the indicators served to define the domain, e.g., listening as an indicator of communication, reliability as an indicator of trust. The comments of the families and professionals provided a “grounded theory” foundation for the development of observable measures and self-assessment tools for professionals. My research study contributes to the existing research by offering a Canadian perspective of families from diverse cultures and professionals from Manitoba.

Summers, Hoffman, Marquis, Turnbull, Poston, and Lord Nelson (2005) developed an 18 item Family-Professional Partnership Scale which measures how satisfied families are with the practitioners serving their child. This satisfaction relates to the practitioners’ behaviours and attitudes toward their child and themselves. Indicators were constructed from qualitative research on families with children with and without disabilities of various ages and disability types and severity (see Blue-Banning et al., 2004). The survey has questions concerning the services that the child and family receives with the main service

provider who has worked the most with their child over the last six months. The eighteen items relate to the six domains: Professional Skills, Commitment, Respect, Trust, Communication, and Equality (Blue-Banning et al., 2004) and are rated on a 5-point scale from 1 (very dissatisfied) to 5 (very satisfied). The items focused on the activities, attitudes, and services of the professional caring for the child with a disability (e.g., the importance of the professional's reliability and competency to meet the child's needs, and being respectful of the child). Other items related to respectful and supportive treatment of the family as a whole (e.g., polite communication, and respect for the family's values). Future work should be conducted to examine the extent to which the items on the Family-Partnership Scale are applicable to families from culturally and linguistically diverse backgrounds.

In a qualitative study in Winnipeg, Manitoba, using ethnographic interviews, Cantor (2003) described the participation of six families of children with disabilities from culturally and linguistically diverse backgrounds, in their children's education, and identified factors which affected their participation in their children's education. By listening to the families, Cantor (2003) discovered who were the members of the family, reasons for immigrating, the language spoken at home, and how families access resources in their communities. Factors that encourage the families to participate in their children's education, as well as barriers to participation were also identified.

The findings that emerged from the data resulted in five main themes. The first theme explored the value of family from different cultural and linguistic

backgrounds. The second theme was concerned with attitudes towards disability. Factors influencing parental participation in their children's education was examined as a third theme. Parental advocacy, and the families' sources of support were the final two themes. Extended family relationships were important to all of the families. One family relied on the grandparents for daycare, homework supervision, and to attend school events. The families in this study possessed a variety of culturally-based perspectives concerning the etiology of their children's disabilities. Language barriers and feelings of cultural disrespect or disregard were the two major factors that interfered with parental participation. One family sensed that their opinions were not accorded equal status to that of the teachers. The availability of support methods helped the families with coping strategies and empowered the families to be better equipped to advocate for their children.

### Barriers to Collaboration

The principle of parent involvement is based on ideals that are highly valued in the dominant culture (Kalyanpur, Harry & Skrtic, 2000). As Skrtic (1995) alleges, the field of special education arises from the dominant positivist model of western rationalism that values objectivity and professionalism. Therefore, since professional knowledge is scientifically based, it is assumed to be objective and is given more authority than knowledge that is subjective, such as parents' perspective of their child (Kalyanpur et al., 2000).

Ware (1994) indicates that this emphasis on a hierarchy of knowledge and professional autonomy creates "contextual barriers" in traditional school

organization, such as hierarchical authority and power structures which further undermine the collaborative process. Ware (1994) maintains that the expectation of autonomy and the presumption of professional expertise lead further to professional compartmentalization than to interdisciplinary interdependence and shared responsibility with parents. While the legal mandate is based on the standard of equity, special education epistemology is based upon a standard of a hierarchy of professional knowledge (Kalyanpur et al., 2000). Professionals who have been trained to believe that their knowledge gives them authority to make decisions about a student's education, must now come to terms with the idea that parents are also experts (Kalyanpur et al., 2000).

Kalyanpur, Harry & Skrtic (2000) contend that there are two problems that exist, making collaboration between families and school professionals complex. The first is that the expectation of equity, individual rights, and freedom of choice challenges that hierarchical structure of knowledge and status which is part of the positivist paradigm of professionalism. The second problem is that the expectation of advocacy assumes that all families believe in individual rights and freedom of choice, and places families from culturally diverse backgrounds that may not share these values, at an unfair disadvantage (Kalyanpur et al., 2000).

Research studies have identified barriers to family involvement in their children's education. These barriers include contextual factors; language differences; cultural beliefs regarding the role of families in their children's education; lack of knowledge and understanding of the Canadian educational

processes; and issues of exclusion and discrimination (Southwest Educational Development Laboratory, 2003).

*Contextual factors* include family resources and logistical constraints.

Common barriers include lack of time; an inability to take time away from work to attend meetings; lack of transportation; and lack of child care (McGrath & Kuriloff, 1999; Turnbull & Turnbull, 1990).

*Language barriers* are a critical factor for many new Canadians (Cantor, 2003; Pena, 2000, Turnbull & Turnbull, 2001). Limited English language proficiency may interfere with a family's capacity to access appropriate resources (Turnbull & Turnbull, 2001). A qualitative case study by Pena (2000) in an urban Texas elementary school with a large population of Mexican American families, noted that "language was particularly influential in determining the activities in which parents chose to participate" (p. 46). She found that parents' backgrounds, including education levels and language, as well as cultural values, availability of transportation and child care, parent cliques, and attitude among school staff members "influenced the ability of parents to take advantage of the parent activities organized by the school staff" (p. 46).

*Cultural beliefs* and the families' view of disability and its causation affect parental participation (Fadiman, 1997; Harry, 2003; Pena, 2000; Smart & Smart, 1991). Each culture has its own explanation for why some individuals are born with disabilities, how these children are to be treated, and what roles and responsibilities are expected of family members, and other members of the community (Groce, 1999). These beliefs are also highly variable within cultural

groups. Several studies have examined the perceptions and beliefs that families use to understand the causes and meanings of their children's disabilities.

Cho, Senger, and Brenner (2000) compared the adaptation of Korean and Korean American parents to their children with developmental disabilities. Eighty percent of the Korean parents attributed causes of disabilities to their own mistakes relative to prenatal enrichment practices and parenting attitudes, poor "Tae Gyo." The majority of Korean-American families with children with disabilities were members of Korean ethnic churches. The religious influences seemed to mitigate the experience of poor "Tae Gyo" and they experienced a new sense of hope and support through their involvement in the church.

Similarly, Fadiman (1997) illustrates the Hmong way of life in the United States as it is perceived by western medical epistemology. The main discourse is a medical case study of Lia Lee, a Hmong baby diagnosed with severe epilepsy by her American doctors. However, the condition of epilepsy is seen more as a spiritual issue than a medical one in the Hmong culture. In the traditions of the Hmong people during an epileptic seizure, literally a "spirit catches you and you fall down." The story chronicles the conflicting interpretations of the issue and the subsequent differences of opinions regarding the treatment of the problem by the family and health care providers. Fadiman's argument is that a better understanding of the Hmong culture might have enabled the Western doctors to overcome the family's resistance to science and help them adopt a more reciprocal attitude. Fadiman herself questions her

ineptitude as a cross-cultural interviewer, reminding us of how complex communications can be when different cultures are represented.

According to Serpell, Margia and Harvey (1993), some tribal societies in the central region of Africa attribute disability to magical or religious explanations. However, the authors indicate that individual differences are widely tolerated and the causation does not affect how the family regards the child with a disability.

*Families lack of understanding* about the policies, practices and expectations of American schools were described as a barrier to involvement by newcomer families (Harry, 1992). In a study of low income Puerto Rican American families, Harry (1992) noted that parents from culturally diverse backgrounds may possess cultural perspectives and expectations with respect to education that restrict their ability to collaborate with educators, and negotiate their way within the special education system. Parents who are not well informed about special education assistance requests, assessment, intervention, and follow-up procedures may not understand their rights, responsibilities and options regarding their child's education.

*Families lack of knowledge* about the subject matter their children were learning was cited as a barrier to families help with homework (Pena, 2000). Families' past negative experiences, and fears of bureaucratic intervention may also challenge family-participation (Thorp, 1997; Parette & Petch-Hogan, 2000).

*Issues of exclusion and discrimination* were also noted as a barrier to partnership (Cantor, 2003). Cantor (2003) reported that educators need to attend to family structures that do not reflect Canadian norms. They need to



"expand the parent-school partnership to a family-school partnership that allows for participation of grandparents, aunts, uncles, elders, and advocates, at the discretion of the parent" (Cantor, 2003, p. 74).

#### Research into Practice: Implications for Building Partnerships

*Preservice preparation for educators.* In order to become professionals, preservice teachers are required to complete a formal program of training that includes instruction in the theoretical and applied knowledge of the field, as well as practical experience in schools (Kalyanpur, Harry & Skrtic, 2000). They are inducted into the professional field of special education, in which knowledge, practices and discourses are explicitly taught. Harry (1996) proposes that even though macroculture provides the framework in which special education professional knowledge is based, various microcultures to which the researcher belongs may or may not coincide with the values of special education. Microcultures are a set of characteristics such as race, ethnicity, religion, social class, and gender under an overarching macroculture (Banks, 2003). When students have demonstrated that they have realized the "profession's knowledge, skills norms and values" they are certified as professionally competent (Skrtic, 1995, p. 11).

However, Skrtic (1995) indicates that professional induction is designed to create professionals with a deep commitment to a particular knowledge tradition (p. 40). As a result, professionals are operating within a cultural context often without an awareness of its imbedded values, or the factors that might impede

collaboration with families from culturally diverse backgrounds (Kalyanpur, Harry & Skrtic, 2000).

Recognizing the limitations of the prevailing model of professional education, several researchers (Blue-Banning et al., 2004; Cantor, 2003; Kalyanpur & Harry, 1999; Kalyanpur, Harry, & Skrtic, 2000; Parette & Hagan, 2000; Sileo & Prater, 1998; and Summers et al., 2005) have stressed the need for professional education to incorporate more training for professionals on developing collaborative relationships with families.

*Educator attitudes and beliefs that facilitate connection.* Kalyanpur and Harry (1999) suggested that educators adopt a “posture of cultural reciprocity” in which educators engage in discussions with families regarding cultural values and practices, acknowledging differences, and developing a reflective practice that will lead to effective parent-professional partnerships. For professionals the first step toward cultural reciprocity is building self-awareness and developing a sense of one’s own cultural identity (Kalyanpur & Harry, 1999). Gay and Kirkland (2003) contend that developing personal and professional consciousness about racial, cultural, and ethnic diversity combined with self-reflection should be major components of both preservice teacher education and in-service staff development. By developing our cultural awareness and enabling families to acquire “cultural capital” (Bowers, 1994), we can develop culturally reciprocal interactions with the families we work with.

*Parent education.* This research also has implications for helping parents to participate as effective partners by providing parent education and awareness

training programs that would empower parents. Parent training models that are based on a group counseling and support model, as opposed to a teaching model may be more culturally relevant (Mahoney & Kaiser, 1999; Turnbull, Blue-Banning, Turbiville & Park, 1999). This model allows families to share experiences within their own cultural context. Researchers should invite school districts to nominate teams interested in implementing improved models of professional practice as they relate to the family-school partnership for children with disabilities from culturally and linguistically diverse backgrounds.

*Demonstrate active and ongoing support from school principals.* Levine and Truckett (2000) noted that support from principals made a difference in helping diverse families become more involved in their children's education. They suggest that principals can show support by communicating with families (in their native language) through school newsletters, and other written materials; meeting with families to seek their perspectives; maintaining a strong presence at parent-teacher meetings and other school-sponsored events for families; and making the implementation of family-involvement policies a priority.

*Acknowledge both commonalties and differences among students and families.* Most families, regardless of race, ethnicity, or culture care about their children's future and do whatever they can to support them (Cantor, 2003; Halle, Kurtz-Costes, & Mahoney, 1997; Harry, Kalyanpur & Day, 1999). The research studies suggest that there are more similarities than differences in families' hopes and concerns for their children. However, differences do exist in families' experiences, cultural values and practices, and world views. It is important for

educators not to simply ignore issues related to diversity, or to act as if differences do not exist (Lynch & Hanson, 1997; Tatum, 1997). In a study by Lareau and Horvat (1999), ignoring racial issues forced parents and schools farther apart. Acknowledging and valuing diversity means making room for a range of voices, perspectives, resources and styles of interacting.

*Impact of school outreach.* A number of studies stress the importance of school outreach (Blue-Banning et al., 2004; Cantor, 2003; Kalyanpur & Harry, 1999; Lynch & Hanson, 1997). Important elements for outreach include flexible scheduling to accommodate working parents; drawing on families' experiences and interests to get involved; ensuring that families and professionals can communicate in the language with which family members are most comfortable, by having a translator available for all family conferences and meetings; providing written materials in families' first language; and post welcome signs and other information in the language spoken in the community.

*Role of intermediaries in building partnerships.* An emerging concept from the literature is that of an intermediary as an alliance between families and school professionals (Cantor, 2003; Fadiman, 1997; Lynch & Hanson, 1997). Intermediaries or "cultural mediators" (Lynch & Hanson, 1997) act as a liaison with families, and will be sensitive to the family's cultural background.

### Legal Requirements for Collaboration

Special education began as a movement to protect the civil rights of children with disabilities (Turnbull & Turnbull, 2003). Ensuring that they had access to educational opportunities was the basic issue. In the United States in

1975, Congress enacted the Education for All Handicapped Children Act, now known as the Individuals with Disabilities Education Act (PL101-476) of 1990 (IDEA) with its re-authorization in 2004. This legislation mandates that children with disabilities are to be provided a "free appropriate public education" in the "least restrictive environment." The policy requires professionals to involve parents of students with disabilities in the education decision-making process by incorporating parents' knowledge of their child when deciding on the most appropriate education, and informing parents of their rights and of any changes in placement (Kalyanpur, Harry & Skrtic, 2000). This allows parents the right to go to an administrative hearing on any issue related to their child's rights (Turnbull & Turnbull, 2003). IDEA legitimizes parents and students as educational decision makers, and enables parents, students, and professionals to develop partnerships with each other (Kalyanpur et al., 2000; Turnbull, Turnbull, Erwin & Soodak, 2006).

#### *Inclusive Education in Manitoba*

Basically, Manitoba educators have adopted a philosophy of inclusion as the foundation for the service delivery of special education. The most accepted delivery model is grounded in inclusive philosophy combined with a continuum of programming and supports (Freeze, Bravi & Rampaul, 1990; Hutchinson, 2002). First choice for students with disabilities is "the right to attend the designated catchment school for their residence in a regular classroom with their peers" (Manitoba Education, Citizenship and Youth, 2006). The philosophy of inclusion in Manitoba states:

Inclusion is a way of thinking and acting that allows every individual to feel accepted, valued, and safe. An inclusive community consciously evolves to meet the changing needs of its members. Through recognition and support, an inclusive community provides meaningful involvement and equal access to the benefits of citizenship.

In Manitoba we embrace inclusion as a means of enhancing the wellbeing of every member of the community. By working together we strengthen our capacity to provide the foundations for a richer future for all of us (Manitoba Education, Training and Youth, 2001).

#### *Manitoba Initiatives*

In Manitoba government documents and directives encourage educators to establish effective and meaningful family-professional partnerships. In a recently updated document *School Partnerships: A Guide for Parents, Schools, and Communities* (Manitoba Education, Citizenship and Youth, 2005) guidelines are suggested to support partnerships in Manitoba schools. This document suggests that “school partnerships play an important role in decision making and accountability” (Manitoba Education, Citizenship and Youth, 2005, p. 3).

In another Manitoba initiative *Working Together: A Handbook for Parents of Children with Special Needs in School* (Manitoba Education, Citizenship and Youth, 2004) parents are recognized as valued partners in education, knowing best their child’s strengths, abilities, needs and challenges. This document provides valuable information to families with a child with disabilities about identification and assessment procedures, as well as planning and programming

for students with disabilities. The definitions of words that are often used as part of the language of special education are included, such as adaptation, curricular modification and individualized programming. Language influences all aspects of communicating with families, so understanding special education concepts is extremely important. The document also focuses on the area of communication, and recognizes that both parents and educators feel that ongoing communication is vital to the success of a child's education. This is a valuable source of information for both families and professionals to work collaboratively, however this document does not address barriers to communication from culturally diverse families.

#### *Manitoba Legislation*

The recent mandate in Manitoba concerning special education *Appropriate Educational Programming in Manitoba* (2006) is revolutionary, as it requires school professionals to involve students with disabilities in the education decision-making process. The consultation process defined “appropriate educational programming” as:

A collaborative school-family-community process where school communities create learning environments and provide resources and services that are responsive to the lifelong learning, social and emotional needs of all students (Manitoba Education, Citizenship and Youth, 2006, p. 1).

This document states that “parents have a right and a responsibility to be involved in their children’s education. It is the obligation of schools and parents to make the best educational interest of students the paramount consideration for

decision-making and educational programming” (Manitoba Education Citizenship and Youth, 2006, p. 4). To individualize a student’s appropriate education, educators must be committed to collaboration with the family. The document stresses that it is important that assessment results must be interpreted for parents in a way that is clearly understood based on language and literacy needs. The report also proposes that the assistance of an interpreter or translator be provided if necessary, in order to involve the parents in the planning meetings.

### Canadian Trends in Immigration

Immigration to Canada exists as a means of achieving the national objective of social, economic, and cultural development, as well as family reunification (Krahn, Derwing, & Abu-Laban, 2003). It also satisfies international obligations through the resettlement of refugees (Krahn et al., 2003).

Canada’s immigration records are available from 1860, when 6,276 newcomers arrived (Krahn et al., 2003). At that time, most immigration was from northern Europe. In the earliest days of Canadian immigration there were no restrictions on newcomers countries of origin. However, by 1885, the government established a head tax to ensure that Chinese immigration would be limited (Krahn et al., 2003).

Discriminatory policies continued to restrict immigration until 1962 when the federal government started to reform immigration law. The 1976 Immigration Act was a milestone in Canada’s response to refugees, designating “refugees”



as a class distinct from “immigrant.” The 2002 Immigration and Refugee Protection Act clarified the humanitarian goals of the program established to offer protection and durable solution to refugees in need of resettlement (Citizenship and Immigration Canada, 2004). Among the objectives of the act are “to permit Canada to peruse the maximum social, cultural and economic benefits of immigration,” and “to promote the successful integration of permanent residents into Canada, while recognizing that integration involves mutual obligations for new immigrants and Canadian society” (Immigration and Refugee Protection Act, 2001).

*Who is a refugee?*

In my study, four of the families came to Winnipeg as refugees. They came from Afghanistan, El Salvador, Sudan, and Bosnia.

The 1951 Refugee Convention and its 1967 Protocol Relating to the Status of Refugees established the legal standards for refugee protection. The United Nations High Commissioner for Refugees (UNHCR), established in 1951 is the branch of the United Nations authorized with the international protection of refugees (Cultural Orientation Resource Centre, 2008).

The term, refugee, is used to refer to someone who has fled his or her home, whether to escape war, natural disaster, economic hardship, or political persecution (Cultural Orientation Resource Centre, 2008). However, according to the 1951 Refugee Convention, the term has a precise legal definition, a refugee is someone who “owing to well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or

political opinion, is outside the country of his nationality, and is unable to or, owing to such fear, is unwilling to avail himself of the protection of that country” (UNHCR, 2007). This definition includes people who have experienced persecution because of political beliefs or religious activities or because they are members of a particular ethnic group (Cultural Orientation Resource Centre, 2008).

Refugees escape situations in their home countries and find temporary asylum in refugee camps or communities in neighboring countries (Cultural Orientation Resource Centre, 2008). The UNHCR interviews them to decide whether they should be granted refugee status, thereby qualifying for UNHCR protection.

The UNHCR also tries to find a “durable solution” for any refugee situation. There are three durable solutions: voluntary repatriation to the home country, integration into the country of asylum where social and cultural conditions are usually similar to those of the home country, and resettlement to a third country (Cultural Orientation Resource Centre, 2008). Resettlement is a very difficult decision. It means separation from friends and relatives, and it may also mean that a refugee cannot return to their home country for many years. Refugees cannot request their city or country of destination. If sponsored by government or private agencies, refugees have no choice as to where they will be relocated, or they face losing their assistance (L. Wilkinson, personal communication, May 6, 2009)

Manitoba settled 16 percent of privately sponsored refugees, and seven percent of government assisted refugees arriving in Canada (Manitoba Labour and Immigration, 2007). Winnipeg was the top destination in Manitoba, receiving 76.5 percent of all refugees to the province (Manitoba Labour and Immigration, 2007).

#### *Manitoba Provincial Nominee Program*

In 1998, Manitoba was the first province to develop a Provincial Nominee Program to attract a greater share of immigrants (Manitoba Labour and Immigration, 2008). The Manitoba Provincial Nominee Program is an immigration program established under the Canada-Manitoba Immigration Agreement which recognizes that the province has required immigration priorities, and economic, cultural and social needs (Manitoba labour and Immigration, 2008).

Manitoba recognizes the important role that ethno-cultural and regional community organizations can represent in assisting immigrants to successfully relocate. To facilitate the involvement of Manitoba community organizations in the settlement process Manitoba has created a Strategic Initiative. This allows community agencies to prescreen applicants who meet Manitoba Provincial Nominee Program eligibility criteria, and issue a Letter of Support to those applicants, indicating the community willingness to assist the applicant to establish in Manitoba (Manitoba Labour and Immigration, 2008). Nominees to the program have to meet federal requirements related to health and security.

This program comprises almost 70% of all newcomers arriving to Manitoba (Manitoba Labour and Immigration, 2008). In 2006, Manitoba attracted half of all provincial nominee immigrants to Canada (Manitoba Labour and Immigration, 2008). As of January 1, 2007, Statistics Canada estimated the population of Canada at 31,612,897 and Manitoba's population at 1,148,401 (Statistics Canada, 2007). Manitoba immigration increased by nine percent in 2007 reaching 10,955 immigrants. Table 2.1 lists the source countries of newcomers to Manitoba, either as refugee claimants, or through the provincial nominee program. For the first time ever the province of Manitoba welcomed the largest annual number of immigrants in Canada. The Manitoba population of 1,186,679 received 10,955 immigrants in 2007. Most newcomers came from the Philippines, Germany, China, and El Salvador.

*Canadian admission requirements for individuals with disabilities*

Canada's immigration and refugee legislation admits claimants through various avenues, the independent or economic class, refugee designation, or by the provincial nominee program (De Voretz, Pivnenko, & Beiser, 2004). To qualify for Canadian admission, refugees must meet several criteria. Convention refugees are people who leave their country because of a distinct fear that they will be persecuted due to their religious beliefs, race, nationality, political opinion or membership in a persecuted group (De Voretz et al., 2004). Canada also admits Protected Persons, or humanitarian designated classes which was introduced by the federal government in 1997 to provide for resettlement of individuals personally affected by situations including civil war and armed conflict.

Canada selects immigrants on the basis of attributes such as education, employability, and youth, all of what are considered human capital (Beiser, 2005). Assessing new arrivals for the presence of serious infectious disease, or the presence of illnesses that would impose a drain on public services is also a fundamental principle underlying the Canadian approach to immigration health (Gushulak & Williams, 2004). However, there is some allowance for “special cases,” especially among asylum seekers and war-affected.

All immigrants undergo comprehensive medical screening before entry into Canada. They are asked if they, or their dependents, have been diagnosed with mental or physical health problems, and to list them on the application form. Those applicants identified as having conditions that would render them inadmissible due to potential excessive demands on health services may have their applications delayed, or may be refused permanently (Gushulak & Williams, 2004). Diseases and health issues developing after arrival are provided for by the Canadian government. Immigrants or refugee claimants with disabilities need to have a designated representative. Children with disabilities who are accompanied by one or both parents, are considered to have a designated representative.

Table 2.1

*Source Countries of Newcomers to Manitoba*

Total Population	1,186,679
Philippines	3,279
Germany	1,382
India	1,016
China	609
El Salvador	429
Israel	326
Ethiopia	274
Korea	268
Ukraine	228
United States	210
Other Countries	2,934
Total immigrant population	10,955

Manitoba Labour and Immigration (2007). Manitoba immigration facts:  
2007 statistical report. Retrieved from [www.immigratemanitoba.com](http://www.immigratemanitoba.com)

*Conclusion*

In this literature review, I discussed four major areas which underlie home-school partnerships with new Canadian families with children with disabilities. I began with a historical account of “parent involvement”, and then examined different theoretical perspectives. Then I analyzed prior research of home-school partnerships, and discussed Manitoba’s legislation to provide “appropriate programming and services” (Manitoba Education, Citizenship and Youth, 2006) that meet the individual needs of every student in the most inclusive environment. Finally, I discussed Canadian trends in immigration.

## CHAPTER III

### RESEARCH PERSPECTIVES AND METHODS

#### Research Design

The study took place in Winnipeg, Manitoba the eighth largest city in Canada with a population of just over 700,000 people (Statistics Canada, 2007). This research was designed to explore the question: What are the specific indicators associated with collaborative partnerships from the perspectives of families and educators? To understand the meaning of home-school partnerships the stakeholders are new Canadian families with a child with a disability, classroom teachers, special education teachers, resource teachers, educational assistants, special education coordinators and administrators. It was hoped that this study would be used as a starting point for discussion and dialogue between educators and families which, in turn, would enhance the quality of home-school partnerships. The most appropriate methodology for examining the meaning of partnerships from the perspectives of families and educators was qualitative inquiry (Creswell, 2002).

#### *Qualitative Research*

Today's qualitative research creates opportunities for a more complete understanding of the experience of individuals and their families whose stories that, until recently, have been suppressed in mainstream educational research (Pugach, 2001). Research participants in a qualitative research study are



complex individuals with many unique characteristics. The variables of age, gender, socioeconomic status, employability, disability status, geographic location, language, and culture, often impact significantly on an individual's belief system.

The tradition of qualitative, naturalistic research is associated with efforts to better understand the qualities of phenomena within natural contexts (Boudah & Lenz, 2000). Personal narrative and life histories are valuable forms of qualitative research that explore the lived experiences of individuals with disabilities (Brantlinger, Jiminez, Klingner, Pugach, & Richardson, 2005). Brantlinger et al. (2005) explain how these personalized accounts provide insight into how classification and treatment are perceived by people with disabilities and their families. They contend that qualitative research contributes to the field of special education and disability studies "capturing involved people's perspectives and by adding to our understanding of discourses that shape social life in schools and society" (p. 200).

In the world of educational research it is through qualitative methodology that individuals' stories are told (Pugach, 2001). Taylor and Bogdan (1998) explain that the researcher looks at settings and participants holistically. They allege that qualitative research is concerned with how people think and act in their everyday lives. Emphasis is placed on understanding the complexity of a given situation and clarifying the theoretical framework. Bogdan and Biklen (2003) describe the data collected as a result of this qualitative process as "rich in description of people, places and conversations" (p. 2).

*Researcher as Instrument*

The inductive nature of qualitative methodology requires the researcher to approach the data from a “perspective of relative neutrality” (Harry, Sturges, & Klingner, 2005, p. 11). The main purpose is to describe and understand patterns within and across cultures, rather than to evaluate (Bogdan & Biklen, 2003). In educational research the researcher is usually very knowledgeable in the field, studying a concept in which he or she is very familiar. Preconceived beliefs and perspectives will intentionally affect the data (Harry, et al., 2005). Bogdan and Lutfiyya (1996) acknowledge that researchers do bring preconceived beliefs into the research. However, the methods that qualitative researchers use aids the process of credibility. The researcher is challenged to examine his or her personal biases, in order to realize how their assumptions, beliefs and prejudices impact relationships (Harry, 1992). In both the individual interviews and the focus groups, the researcher served several functions; moderator, listener, and observer as participant (Taylor & Bogdan, 1998), interacting in the proceedings to allow for a comfortable interpersonal climate.

Many aspects of my personal identity may have contributed to my position as both an insider and an outsider. As a European Canadian woman, I may have been considered an outsider in data collection research that involved new Canadian families. When I conducted focus group interviews with educators in schools, my identity fluctuated between being a teacher, and therefore an insider and being a stranger, consequently, and outsider.

I was raised in a middle-class Jewish family by parents who instilled in me the belief that people of all races/ethnicities are equal. They taught me to question inequitable treatment of people based on racism, classism, and sexism. My first experience living and working in a developing country was the beginning of a long journey to acknowledge and celebrate differences, and to consider the impact on my own beliefs and values. While conducting research for this study on the possible dissidence between diverse groups of people and the underlying value system embedded in the special education system, I reflected on my time as a teacher. I reexamined the values that I presumed had been shared by the families I worked with, and how this affected my efficacy as a special educator.

My experience as a special education resource teacher provided me with the experience of working with children and adolescents with many types of challenges. These experiences influenced me as I interacted with participants with respect and empathy in an effort to create a shared sense of personal credibility, and acknowledge each other as coequals. I have learned to maintain sensitivity with regards to disability labeling and avoid deficit language.

### *Ethical Issues*

As a university-based researcher, I am required to adhere to the Human Subject Ethics Protocol Submission Form when making decisions about qualitative research practice. In the realm of ethics the primary relational focus is on the interaction between researcher and participant. The term trustworthiness recognizes that participants can be vulnerable, and that researchers are responsible to promote their welfare and guard against harm (Haverkamp, 2005).

Haverkamp (2005) explains that “what makes research ‘ethical’ is not a characteristic of the design or procedures, but of our individual decisions, actions, relationships, and commitments” (p. 147).

Human subjects is the term used in most legislation to describe the individuals who participate as subjects in a research study. Use of the term “subject” emphasizes the power difference and the need to protect vulnerable people. The National Bioethics Advising Commission uses the term “participant” as a more neutral term that identifies the person as different from the researcher (NBAC, 2001).

The participation of human beings in research studies is necessary in order to achieve advances in medical and social/behavioral science. Such research is not risk-free and researchers must identify and examine the potential risks to participants, weigh them against potential benefits, and share that information with the individuals recruited to voluntarily participate in research.

Traditionally, human subjects review boards are concerned that research should benefit society at large. Newer paradigms have advocated for research designs that benefit the participants directly (Fontes, 1998). Lather’s (1991) concept of “catalytic validity” is the degree to which the research influences the participants to understand their experiences, and emphasizes benefits, including those such as empowerment, access to knowledge, and community change.

Research ethics is premised on the basis that qualitative research requires participants who are willing to share information about themselves which may be extremely personal (Haverkamp, 2005). The ethics code is designed to

protect these participants. Pseudonyms were used for the participants and people mentioned by the participants. Names of schools or other places in the communities were also altered.

I always considered what is and what is not appropriate to report about a culture based on my belief system. Some information may be given in confidence, so that even though it may be interesting or helpful for cross-cultural understanding, it should not be reported (McCurdy, Spradley, & Shandy, 2005). It is important to weigh the “ethical appropriateness” of everything that is written when it represents the lives of other people (McCurdy et al., 2005).

Informed consent is a process, not just a document. Information must be presented to enable persons to voluntarily decide whether or not to participate as a research participant. The procedures used in obtaining informed consent should be designed to give information to the prospective participants in terms that they can understand.

### Participants

As previously stated, the focus of this study is the immigrant experience in negotiating the special education system in Canadian schools. In-depth individual interviews with families who have immigrated to Canada served as the primary data collection method. In addition, focus groups with educators who support these families were also conducted.

As recommended in the literature, a process of theoretical sampling (Blaser & Strauss, 1967) was used to select the families for this study. As categories emerged from the data, I added to the sample to strengthen the

emerging concepts and theories (Taylor & Bogdan, 1998). The aim of subsequent data collection is to saturate the categories and find any disconfirming evidence that might suggest revisions in the categories identified or in interrelationships among them (Glaser, 1998). The criteria for participation for the family interviews included families who have children between the ages of 9-21 years with “exceptional learning needs” (Manitoba Education, Citizenship and Youth, 2006), and attend elementary or secondary schools in Manitoba. Manitoba Education, Citizenship and Youth (2006) offers a definition of a student with exceptional learning needs as:

“a student who requires specialized services or programming when deemed necessary by the in-school team because of exceptional learning, social/emotional, behavioural, sensory, physical, cognitive/intellectual, communication, academic or special health-care needs that affect his or her ability to meet learning outcomes” (p. 70).

Nominations of the families were selected based on the recommendations of the program directors of the disability support groups and ethno-cultural groups. Every effort was made to ensure that participants came from a range of backgrounds. In theoretical sampling, the potential of each case to aid the researcher in developing theoretical insights is important.

Focus groups served as the primary data collection method to document the perspectives of educators regarding positive partnerships. A focus group is a “carefully planned series of discussions designed to obtain perceptions on a defined area of interest in a permissive non-threatening environment” (Krueger &

Casey, 2000, p. 5). Focus groups encourage participants to share ideas and perceptions with each other, consequently generating a range of possible factors to positive partnerships.

School personnel included classroom teachers, educational assistants and paraprofessionals, special education resource teachers, and school administrators. When structuring the focus groups for educators, classroom teachers, educational assistants and special education teachers were placed in separate groups from special education resource teachers and administrators. As Krueger and Casey (2000) have emphasized if there is a power differential, some participants may be reluctant to express themselves.

### Instruments and Procedures

#### *Instruments*

Interview guides provided directions for both the individual family interviews and the educator focus groups.

*Family interview guide.* The interview questions were designed from a review of the literature regarding family – professional partnerships. Although the questions were established a priori, they were open-ended, allowing participants the opportunity to provide extensive information. See Appendix A for the interview protocol.

The individual interviews with the families were guided by a family conversation guide (Turnbull, Turnbull, Erwin, & Soodak, 2006). I tried to move away from interviewing the families and towards conversing with them instead (Turnbull, Turnbull, Erwin, & Soodak, 2006). The family members were asked to

describe the most beneficial partnership that they have had with their child's teachers, and what made the partnership work. They were also asked to contrast that with one of the least effective experiences that the parent has had with one of the school professionals who worked with their child, and what were the factors they felt led to this experience being so unsuccessful. I also inquired as to suggestions they might have for educators to avoid having unsuccessful partnerships with families (Turnbull et al., 2006). The families were also asked how their cultural values and beliefs have affected their partnerships with their child's teachers. The individual family interviews offered the opportunity for in-depth discussion about facilitators or barriers for partnerships.

*Focus group interview guide.* The focus group interview protocol is included in Appendix B. Questions were designed to elicit participant responses about their perceptions and behaviours as they pertained to partnerships with new Canadian families of children with disabilities. The focus group participants were asked to describe successful partnerships, and what made the partnerships work. They were also asked to describe examples of unsuccessful partnerships. A third key question explored how cultural values and beliefs have affected the partnerships. Throughout the interview I swayed from my protocol to probe comments from participants, and to clarify a participant response. At the end of the discussion, participants had the opportunity to summarize perspectives in response to such questions as "After thinking about the issues we talked about today, which one is of greatest concern to you?" (Krueger & Casey, 2000). To



ensure consistency across time, the same questions were asked at each focus group meeting.

### *Procedures*

*Project approval.* After approval by my Doctoral committee and the University of Manitoba Research and Ethics Committee, letters describing my study and invitation to participants, were sent to disability support groups and ethno-cultural groups in Winnipeg. See Appendix C for a copy of the letter. I followed each letter with a telephone call, and when given the opportunity, a meeting with the coordinator.

Educators, including classroom teachers, educational assistants, special education resource teachers, and school administrators were also identified through letters (Appendix C.2) to school divisions in Winnipeg, as well as to professional networks.

*Nomination and selection of participants.* I requested the assistance of the coordinators of the disability support groups and ethno-cultural groups in helping to establish a purposive selection process that was responsive to each community (Fetterman, 1998). The importance of involving community leaders in helping researchers establish trust within the community, as well as for sample recruitment, was identified by Magnana (2000).

Once potential family participants had been identified, a letter was sent to each of the families (Appendix D.1), explaining the purpose of the study, and the meaning of informed consent. Information was presented to enable persons to voluntarily decide whether or not to participate as a research participant.

Informed consent language and its documentation, such as explanation of the study's purpose, duration, procedures, alternatives, risks and benefits, was written in understandable language. The account of information was used to document the basis for consent and for the participant's future references. The date, time, and location of the focus group was also included. Family member participants received a \$20.00 gift certificate to an area store, or a cheque for \$20.00 for the interview.

Family member participants included six parents, four mothers and two fathers, two siblings, and two children with disabilities representing five families. The families who were interviewed for this study were diverse on several dimensions: (a) ethnicity, (b) country of origin, (c) first language, (d) age of their child, (e) type of disability, and (f) family structure. One of the families had two children with disabilities. Of the six children, three were boys and three were girls. The children's ages ranged from nine to eighteen years old. Three of the families were headed by two biological parents, and two families were headed by mothers only.

The families came from Afghanistan, Argentina, El Salvador, Sudan and Bosnia. There were many reasons why they emigrated. Therefore, diversity results not only from different national origins, but also from unique circumstances concerning the immigration of a family to Winnipeg.

Table 3.1 portrays the five families in this study. Pseudonyms have been assigned to the families, other participants, schools, and community agencies.

Chapter four focuses on the five families who were interviewed for this research study.

Educators, including classroom teachers, educational assistants, resource teachers and school administrators, were also identified through letters (Appendix C.2) to school divisions in Winnipeg and the surrounding area, as well as to professional networks.

Once potential participants had been identified, a letter was sent to each of the educators (Appendix D.2) explaining the purpose of the study, and the meaning of informed consent. Information was presented to enable persons to voluntarily decide whether or not to participate as a research participants. Educational assistants were given \$20.00 for their participation. Teachers and administrators were not paid for their participation. Incentives for the focus groups included serving a light snack.

The first educator focus group was held at an elementary school in a multiethnic suburban community in Winnipeg. The principal of the school invited teachers and paraprofessionals to participate in the research study. Twelve staff members agreed to participate. Of the twelve staff, there were eleven women, and one man. There were three classroom teachers, two learning support teachers, five paraprofessionals, one counselor, and one physical education teacher. The focus group took place at the school.

The second educator focus group took place at a private preschool to Grade twelve school with approximately six hundred students, in Winnipeg.

Table 3.1

## Family Member Participants in the Study

Names of family members who participated in interviews	Family Structure	First Language	Country of Origin	Name of Child	Age	Type of disability (as documented)
Laila – Mother Rushid – Son Nasria – Daughter Jamila – Daughter Samira – Interpreter	Single mother	Dari (Afghan Russian/Farsi)	Afghanistan	Rushid	15	Down Syndrome
Rafael – Father Dalia – Mother	Two-parent family	Spanish	Argentina	Elana Aaron	14 12 ½	Epilepsy/Developmental Delay Behavioral Issues (undiagnosed)
Ria – Mother	Two-parent family	Spanish	El Salvador	Marcus	16	Autism
Leben – Father	Two-parent family	Dur, Arabic	Sudan	Zara	9	Cerebral Palsy
Rayna – Mother Nadia – Daughter Aleksi – Interpreter	Single mother	Bosnian	Bosnia	Nadia	18	Diabetes

Note: Pseudonyms were assigned for children, family members, and interpreters

There were three participants. The philosophy of education at the school includes the statement about inclusive special education:

“... welcomes students with special needs. The school is physically accessible and our philosophy is inclusive. In the Early childhood program and through the elementary years, students are taught within regular classrooms, with adaptations made as necessary. In the high school, students work within the regular classroom as well as at specified programs that may include life skills or pre-vocational training. There is a full time Special Education Resource Teacher and many trained and experienced Educational Assistants who work with the teachers to support individual learning in an atmosphere of diversity, tolerance and understanding.”

The second educator focus group consisted of two educational assistants and one teacher. One educational assistant has been working with students with disabilities for ten years, the other educational assistant for about four years. The teacher has been in her present position as English as an Additional Language (EAL) teacher for ten years. She has been teaching for nineteen years.

The third educator focus group consisted of two administrators and two resource teachers from the private preschool to Grade 12 school in Winnipeg.

There were three females and one male.

The Special Needs Resource teacher has been working at the school for four years. The Principal also has been at the school for four years but worked

as both a vice-principal and principal in the public school system. The Vice-principal has taught at the school and has been in her present position for three years. The Resource Teacher has been at the school for twenty years. Table 2 represents the educator focus group participants.

The individual family interviews and the school professional focus groups were conducted from May, 2007 to March, 2008.

*Scheduling and location.* The family interviews were conducted in places chosen by the families, according to each family's preference. Two were held in their homes, one was held in my home, and one was in the school, and one in the ethno-cultural centre where the family was served. The interviews were scheduled according to the families schedules, one interview was in the morning, three were scheduled in the afternoon and one was arranged for early evening. They each lasted between one and a half to two hours.

The educator focus group meetings were scheduled in the morning or early afternoon and lasted approximately one and a half hours. A snack was provided to promote a relaxed environment and encourage interaction within the groups (Krueger & Casey, 2000).

*Interpreter preparation.* In two of the individual family interviews, I did not speak the language of the family, so an interpreter was vital in assisting with each of the interviews. Language barriers are a significant challenge for English-speaking researchers who are trying to depend on the indirect connection of translators to accurately reflect meaning. Translation is defined as the transfer of meaning from a source language to a target language (Esposito,

Table 3.2

## Educator Focus Group Participants

Focus Group 1 Teachers and Educational Assistants	Focus Group 2 Teachers and Educational Assistants	Focus Group 3 Administrators
Elementary School	Elementary & Secondary School	Elementary & Secondary School
12 school professionals - 11 women; 1 man	3 school professionals - 3 women	4 school professionals - 3 women; 1 man
3 classroom teachers 2 learning support teachers 5 educational assistants 1 counsellor 1 physical education teacher	1 classroom teacher 2 educational assistants	1 Special Needs Resource Teacher 1 Resource Teacher 1 Vice-Principal 1 Principal

2001). The translator is actually an interpreter who processes the vocabulary and grammatical structure of the words and then conceptualizes the meaning. The translation should be intelligible and comprehensive.

In qualitative research, the translator has to translate the researcher's questions into a form that is understood by the participant. The second major task is to translate the participant's communication into a form that is understood by the researcher (Esposito, 2001). Optimally during data collection the researcher is able to adjust questions and comments in response to the participant's answers. Data collection and analysis become a dynamic process.

The interpreters were arranged through the ethno-cultural support groups and the disability support group. Before meeting with each of the families, I met with the interpreters, in order that they would have a basic understanding of the nature and purpose of the interview. One of the interpreters was female and the other was male. I offered a stipend of \$40.00 in exchange for two to three hours of work.

The interpreters also facilitated effective cultural communication by assisting the researcher in knowing how to address family members, how to ask questions and how to promote family participation in problem solving. I asked the interpreters to make note of communication styles they recognized as distinctly cultural. For example, we discussed the aspect of eye contact during communication.

It was important that the interpreter was aware of professional ethics, including confidentiality. The interpreters were each presented with a letter



explaining the purpose of the study and the meaning of informed consent. They signed confidentiality agreements.

### Data Collection

In-depth individual interviews were conducted with five new Canadian families who have children with disabilities. The families have children of different ages with a range of disabilities. They have also come to live in Winnipeg through various circumstances. I encouraged participants to invite other family members who they felt could contribute important information about their experiences with special education services. Family members, including spouses and siblings accompanied participants in these interviews. Two of the interviews required interpreters to translate the interview questions and the participants' responses.

Three focus groups interviews were conducted with educators. Since focus groups tend to be more productive if participants have common experiences and characteristics in common, two groups consisted of classroom teachers and educational assistants, and one focus group consisted of resource teachers and school administrators. The educator focus groups were held at the schools.

All focus group and individual interviews were audio-taped (with the permission of the participants), and then transcribed verbatim to detect emerging themes. Field notes, such as sketches of the seating arrangement, non-verbal communication, i.e., eye contact and facial expression, gestures and body

language, were also recorded during each session to ensure accurate data collection.

All information was kept fully confidential and pseudonyms were assigned to the family members, school personnel, other participants, schools, and community agencies. All data were maintained in a secure location, and will be destroyed five years after the completion of my dissertation. Upon completion of the research study, I arranged to share a summary of the findings with the families, school professionals, disability support groups, and ethno-cultural groups, as well as a means of contacting me if they have questions or concerns.

#### *Field Notes*

I recorded field notes each time I contacted the coordinators of the disability support groups and ethno-cultural groups, family members, interpreters, and school principals. In addition, I visited the disability support groups and ethno-cultural groups, and schools to drop off information packets.

#### *Individual Family Interviews*

As qualitative inquiry focuses on participants' verbatim responses, I used an audio tape recorder to record data. I explained to the family members, both before the meeting in the form of the consent letter, and before the interview began, that I was using a tape recorder. I also took notes to supplement my transcriptions of the audio recordings. However, I focused my attention to maintaining the participation of the family members through eye contact, so therefore my notes were concise.

I made every attempt to build rapport with the participants. I was friendly and thanked them for participating in my study. I introduced myself by my first name. I was cognizant of any power differential. My main goal was to be respectful and establish equity between myself and the participants.

The individual family interview protocol is included in Appendix A. Questions were designed to elicit participant responses about their perceptions as they pertained to partnerships with educators. Throughout the interview, I deviated from my protocol to probe comments based on participant responses. I invited the family members to ask questions or make comments. To conclude, I again thanked them for their participation in my study. I gave them gift certificates, the agreed incentive for participation.

After two of the interviews, I debriefed with the interpreter. This process consisted of reviewing any notes taken during the interview and discussing the interview questions and participant responses.

### *Educator Focus Groups*

Each of the educator focus groups was held at the educators' schools. The focus groups began with an overview of the study. As with the family members, I explained that I was using an audio tape recorder to record the participant responses. The importance of maintaining confidentiality was also discussed.

Interview questions were designed to elicit educators' perceptions about partnerships with new Canadian families of children with disabilities. For example, the question "How can teachers ensure that families receive effective,

understandable, and respectful consideration that is compatible with these beliefs, practices, and preferred language?" prompted discussion about communication between families and educators. The questions were designed to be open-ended in order to allow participants to speak extensively about their experiences.

#### *Member Check*

A summary of the emergent themes and interpretations was sent to each participant at the conclusion of the focus groups and interviews, along with a self-addressed stamped envelope. The cover letter requested input as to a) whether the summary was an accurate interpretation of this perspective, and the group they represented, and b) whether they had any additional comments. I had no response to this letter.

#### *Data Analysis*

The main objective for including diverse participants was to ensure the responses of family members and educators represented a wide range of possible viewpoints. The variations and commonalties are presented in the results. Respective comments by family members and educators were also compared in the course of my analysis.

The audiotaped interviews of the families and educators were transcribed verbatim. Immersion in the data took place during data gathering and transcription of interviews. It continued with repeated readings of transcripts, listening to tapes, and reviewing of field notes.

The narrative data from the five family interviews and three educator focus groups were analyzed using two levels of qualitative methods, postdiscussion reflection (Taylor & Bogdan, 1998), and the constant comparative approach by Glaser and Strauss (1967).

#### *Immediate Postdiscussion Reflection*

At the end of each focus group session and individual interview, the field notes were reviewed, and main themes were documented. The overall tone and climate of the discussions, and any representative quotations from participants were also noted (Taylor & Bogdan, 1998). In addition to listening to what participants said during interviews, I also recorded their participation styles, including their willingness or reluctance to discuss their feelings, as well as nonverbal communication during the interviews.

Researcher reflexivity, or self-reflection, provides an opportunity for the researcher to understand how his or her own experiences and understanding of the world, affect the research process (Morrow, 2005). I kept an ongoing self-reflective journal of my experiences, reactions, and assumptions or biases during the research investigations.

#### *Constant Comparative Approach*

I analyzed the data using the constant comparative approach by Glaser and Strauss (1967), an inductive approach in which observations, comments, and quotes are coded according to the types of information revealed. Strauss and Corbin (1998) referred to the first step in this process as "open coding".

After rereading the interviews, I coded the data for underlying patterns and themes, using colour coding to help me sort and organize the data. I constantly compared them with one another to decide which codes belonged together.

The second step was to group the distinct codes according to conceptual categories that reflect commonalties among codes (Strauss & Corbin 1998). Strauss and Corbin (1998) refer to this as “axial coding” which reflects the idea of clustering the codes around specific “axes” or points of intersection. I used a sorting approach, described by Taylor and Bogdan (1998), which involved cutting up an extra set of transcripts and placing data relating to each coding category in separate file folders. On each response I recorded the particular source, respondent, and data collection episode. The codes were then compared to each other to derive a set of thematic categories that classified the data.

The third analytic level according to Strauss and Corbin (1998) is referred to as “selective coding.” At this point I treated the various code clusters critically, deciding how they related to each other and what stories they told. The codes were compared to each other to derive a set of thematic categories that classified the data. Interpretations of these categories were examined for theoretical explanations, as well as any unexpected emergent themes. Through this type of analysis, the findings were firmly “grounded” in the data, as opposed to predetermined assumptions I could have brought to the research study (Taylor & Bogdan, 1998).

*Category Reduction*

After I had confirmed the codes, I wrote the individual definition of each code, along with the code name, on index cards. The codes were compared with each other and subsequently categorized with similar codes. The final data reduction process involved organizing categories into larger themes of partnership. The individual categories were conceptualized as sub-themes or recommended practices for the broad theme in which they were included. The sub-themes or recommended practices were analyzed to make them as objective or as measurable as possible.

*Verification*

Although not as indicative to interpretive research, researchers using qualitative studies also need to ensure that the empirical data are credible and trustworthy. Trustworthiness is essential to conducting qualitative research that will be applicable or transferable (Brantlinger et al., 2005). Trustworthiness may be defined as the extent to which the researcher and practitioner can trust the findings of research, and is built on the quality and descriptiveness of the methodology and analysis (Carmine, 1997).

Morrow (2005) cites trustworthiness as a core criteria for quality or rigor in qualitative research. Qualitative research is not done for purposes of generalizability, but rather to produce evidence based on exploring specific contexts and particular individuals (Brantlinger et al., 2005). Brantlinger et al. (2005) claim that there is an expectation that reviewers will recognize similarities to their situation and judge the relevance of the information to their own

circumstances, referred to as particularizability. A failure of trustworthiness may be detrimental to the readers, who may base decisions on flawed information.

The way in which cultural validity (Quintana, Troyano, & Taylor, 2001) is achieved through research designs has major implications for the dissemination and utilization of the resulting research outcomes. They note that cultural validity “specifically addresses the cultural aspects of research” (p. 617). In determining appropriate “user groups”, it is important not to assume that all findings are generalizable to all groups. The characteristics of the original sample should be greatly regarded when considering outcomes (NCDDR, 2001).

Harry, Rueda, and Kalyanpur (1999) suggest that professionals adopt “a posture of cultural reciprocity,” in which professionals engage in explicit discussions with families regarding differential cultural values and practices. This will bring to the interactions an open mind, the ability to be reflective in their practice, and to listen to the other perspective. This approach requires that the reflective posture be internalized and incorporated into all professional practice, and that professionals look beyond cultural differences to the values underlying these differences.

Denzin and Lincoln (2000) refer to this shift as the “crisis of representation” and is concerned with questions about whose reality is represented in the research. This crisis has led to a greater understanding of the complexities of fairly representing the experiences of the participants, rather than researchers, as the authorities on the participants’ lives (Morrow, 2005).



Numerous strategies were implemented throughout this research study to ensure that the empirical data were credible and trustworthy, including a) multiple informants, b) multiple data sources, c) member checks at the end of each focus group, d) verbatim transcripts, and e) coding checks.

### Conclusions

Individual interviews with five new Canadian families of children with disabilities, and three educator focus groups served as the primary data collection method to acquire an understanding of successful partnerships. The study was conducted in Winnipeg, Manitoba.

I took steps to follow rigorous qualitative methods and strengthen the trustworthiness of the data. I felt that the data represented a wide range of possible viewpoints. The primary value of this qualitative study was to explore what the term partnership between families and educators indicated.

In the next chapter, the stories of the five families that were interviewed in my study are presented.

## CHAPTER IV

### FAMILY STORIES

In this chapter I present the real-life stories of five families who have children with disabilities, who have come to Winnipeg from various countries and through complex circumstances. They have children of various ages, with a range of disabilities. The family members tell the stories themselves. I have made every effort to maintain their voices, their manner of expression, and to distinguish the findings from my interpretation.

Each family story was organized to provide descriptive information on the family structure, and the type or types of disabilities of the children. An overview of recent historical and political events of each country of origin has been presented. The historical orientation does not provide a myriad of detail about many of the historical events and the people who are important to the history of each country, but enough is included to understand events that have shaped the lives of the families.

The circumstances of immigration for each family have also been presented. Their reasons for emigrating are discussed. Four of the families came to Winnipeg as refugees. Their stories reveal the difficulties and hardships that they had to endure. One of the families came to Winnipeg through the Provincial Nominee Program.

Finally, the family's belief system will affect their perspective towards disability. Considerable variations exist within and between cultural groups regarding health beliefs and practices. Each family has its own distinct beliefs regarding health, illness, and disability (Bennett, Zhang, & Tarnow, 2001). Generalizations about families should not be based on ethnicity, socio-economic status, religion, education, or geographical location (Bennett, Zhang, & Tarnow, 2001). Lowenthal (1996) points out that the way in which families perceive and interpret disability is of great importance because their perspective toward their child with a disability may be affected.

### The Families

To adopt a family member's perspective means trying to put yourself in the shoes of another person and to view the world as seen by that person (Overton, 2005). It means recognizing that person's complex history of experiences, and understanding their family values, their cultural values, and their individual beliefs. Pseudonyms have been assigned to all family members, other participants, schools, and community agencies to ensure confidentiality.

### *Laila's Story*

Laila and her family are originally from Afghanistan. However, as Laila explained to Samira, the interpreter, "Because of the war in Afghanistan, they moved to Pakistan, from Pakistan to Iran, and then finally they ended up in Canada." Laila applied to the United Nations High Commission for Refugees (UNHCR) and was approved for resettlement as a refugee. At the time of this interview, Laila had lived in Winnipeg for nine months with three of her four

daughters and two sons. Her fourth daughter is married and remained in Iran.

Laila's children range in age from fifteen to twenty-five years old.

Prior to the interview, I met with Samira, to discuss my research, the Family Conversation Guide, and the Letter of Consent. The family speaks Dari, the name given to the various dialects of Afghan Russian/Farsi. When Samira and I arrived at the family's home, one of the daughters, Nasria, greeted us at the door. She kissed Samira on the cheeks three times, and seemed very pleased to see us. We went upstairs to the living room, where Laila was sitting on the sofa with her son Rushid, and another daughter, Jamila.

Rushid was born in Pakistan in October, 1992. He has Down syndrome. During the interview he was in the room, and watched an East Indian movie with English subtitles.

Down syndrome is probably the most familiar of all the genetic disorders that can result in intellectual disabilities (Friend, 2008). This syndrome occurs in both sexes and across racial/ethnic groups. Individuals are most often born with forty-six chromosomes, twenty-three contributed each by one's mother and father. In individuals with Down syndrome, an extra chromosome exists in the twenty-first chromosome pairs, also referred to as Trisomy 21. It is still unknown why this extra chromosome occurs, but it is this genetic factor that causes children with Down syndrome to have easily identifiable characteristics (Friend, 2008). Though all children with Down syndrome have some degree of intellectual disability, other factors, such as environment, have a considerable impact on their learning potential (BC Ministry of Education, 2006).

### *Historical Orientation*

During the interview I realized how little I knew about the political and historical events in Afghanistan. Samira had informed me that Laila's husband had been killed. Aware that this was a very sensitive subject, I did not question either Laila nor Samira regarding this. To learn more about Afghanistan's historical and political background I conducted research via the internet and library. One novel that I read by Khaled Hosseini, *The Kite Runner*, brought me closer to understanding what Laila and her family had endured.

Afghanistan is located in Central Asia, and is made up of thirty-four provinces. The country's capital is Kabul. Afghanistan is bordered on the west by Iran, and the east and south by Pakistan. Its northern neighbors are Turkmenistan, Uzbekistan, and Tajikistan. China lies to the northeast (Robson & Lipson, 2002). See map 1.

From 1933 – 1973 Afghanistan was a monarchy, commanded by the ruler, Zahir Shah. The Soviets became Afghanistan's major aid and trade partner, but shared that rank with the United States (Robson & Lipson, 2002). Afghanistan benefited from the competition; both the Soviets and Americans funded roads and hydroelectric dam systems. In 1973 the former Prime Minister of Afghanistan, Mohammed Daoud Khan, seized power. Then, in 1978 he was overthrown by the People's Democratic Party of Afghanistan (PDPA).

The PDPA established many political and social reforms in Afghanistan, including eradicating religious and traditional customs. Friction rose between the PDPA and groups of Afghans who opposed these changes, and in 1979 Soviet

troops invaded Afghanistan. Millions of Afghan civilians fled into Pakistan and Iran to escape the destructive Soviet military (Robson & Lipson, 2002). After ten years the Soviet troops finally withdrew, and the mujahedin (warriors in a holy war) converted Afghanistan to an Islamic State.

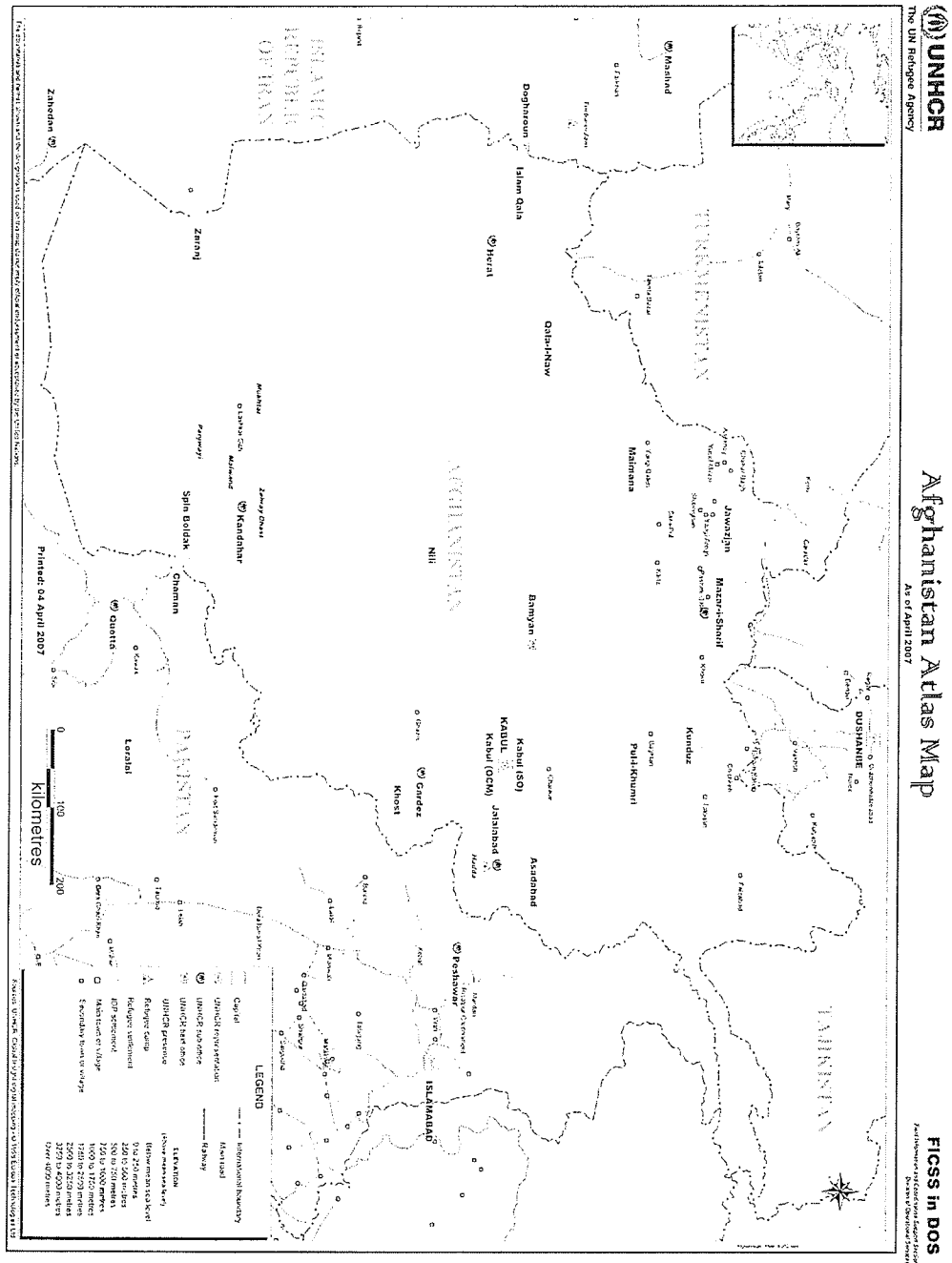
Following the Soviet withdrawal there was a great deal of infighting among rival militaries, making daily life in Afghanistan unsafe. In *The Kite Runner*, Rahim Khan describes the fear in Kabul during this time. He remembers "The infighting between the factions was fierce and no one knew if they would live to see the end of the day. Our ears became accustomed to the rumble of gunfire, our eyes familiar with the sight of men digging bodies out of piles of rubble. Kabul in those days ... was as close as you could get to that proverbial hell on earth" (p. 223).

In 1996, the Taliban took control of Kabul. The Taliban were a group of Pakistans, young and poorly educated, many who had lost their fathers in the Soviet occupation. They restored order by imposing extreme interpretation of Islamic law, severely restricting women's rights, and using fear and violence to control the people of Afghanistan. After the events of September 11, 2001, the United States invaded Afghanistan and overthrew the Taliban. In 2004, the current president of Afghanistan, Hamid Karzai, was elected. Today there are a considerable number of Afghan refugees living in other parts of the world, including Canada.

#### *Circumstances of Immigration*

When I asked Laila about the circumstances that brought her and her

Figure 1 – Map of Afghanistan



family to Winnipeg, she explained to Samira in Dari, "She (Laila) says they came from Iran. She says that in Iran the government doesn't let Afghan refugees to work or to go to school. They have problems living there. And they cannot go back to Afghanistan because Afghanistan does not have a stable situation. That's why they just applied to the UN and the UN sent them here. Actually since my (Laila) husband passed away, I didn't have any choice. I couldn't go back to Afghanistan. This was not an option. The way to survive was to get out."

I asked Laila who made the decision to come to Winnipeg. Samira interpreted for her, She says: "Yes, we apply to the UN and they sent us here because we didn't have any relatives in another city, and we didn't have a choice to pick out a country of destination."

#### *Cultural Perspectives of Disability*

When I asked Laila about the circumstances of Rushid's birth she said that he was born in Pakistan. Laila explained to Samira, "She doesn't want to have anymore babies, an unwanted pregnancy. She used lots of tablets to get rid of the baby. She pushed on her stomach to get rid of the baby. And she says that's why...She thinks that's why he became like that (Down syndrome)." Samira interprets, "She says that the Pakistani doctor told her that because she was so obstinate and angry, that's why he..."

I asked Laila about her beliefs about her family. Laila says to Samira, "She says, I like him more than my other kids." Everyone laughed. Samira continues, "But she says maybe the other people in the community have a



different view about him. They think that he has a mental communication delay or disability, but it doesn't matter to me what they think. Everybody loves him in the family and she loves him more than anybody else."

### *Rafael's and Dalia's Story*

Rafael, his wife Dalia, and their four children left behind many things when they decided to immigrate to Winnipeg from Argentina in 2003. Dalia returned to Argentina for a visit in 2006, and when she came back to Winnipeg she said, "Better we are here," even though it was difficult to leave family, friends, their house and their business.

Their daughter, Elana had an "epileptic seizure" at the age of seven months, Rafael explains. "It looks like she had a fever in the middle of the night. We didn't realize that. And she had some kind of epileptic episode for almost three hours. We have a lot of very sad stories about that."

Epilepsy, or seizure disorder, is a general term for a number of different conditions. A child is diagnosed with epilepsy if he or she has two or more unprovoked seizures. A seizure is caused by a sudden electrical disturbance in the brain. The brain is made up of billions of neurons (nerve cells) working together to process input from the senses, and to control the body's voluntary movements, i.e., walking and talking, and involuntary movements, i.e., digestion and heartbeat. Each area of the brain is very specialized. Normally, neurons fire singly or in small controlled groups. However, when a seizure occurs, many neurons fire all together in an uncontrolled way, like an electrical storm in the brain.

Epilepsy exists all over the world. The World Health Organization estimate that approximately 50 million people in the world have epilepsy, and that it is a major cause of disability.

The old terminology of “petit mal” and “grand mal” seizures was incomplete. The new classification defines seizures as partial or generalized based on whether they begin in part of the brain or in the whole brain at once.

A partial seizure is limited to one area of the brain, and lasts five to fifteen seconds. Complete consciousness is not lost, and may consist of staring or daydreaming, small muscular facial movement, or aimless activity. When the whole brain is involved, it is considered to be a generalized seizure. There may be convulsive movements, muscle stiffening and jerking, with some breathing difficulty. Making a diagnosis involves identifying the condition based on signs and symptoms: A thorough neurological assessment, and diagnostic tests including an EEG are performed. It is important that the family understands the diagnosis in order to make decisions about treatment.

The first choice of treatment for epilepsy is medication. Seizure control is the first step in treatment, however, children with epilepsy may still experience difficulties with learning, behavior, social interaction, and self-esteem.

It is very important for teachers and other school personnel to have information about epilepsy and its impact on the child in order to provide support.

The Hospital for Sick Children in Toronto, Ontario, offers a comprehensive resource guide for parents. One section contains information about epilepsy and

school and discusses how epilepsy affects learning and offers specific suggestion for classroom instruction ([www.aboutkidshealth.ca](http://www.aboutkidshealth.ca)).

Rafael's and Dalia's son, Aaron, 12 ½ years old, was displaying some externalizing behaviors at school. Dalia discussed the incidents, "He lie a lot. He said, 'my parents, my father...hurt me'." He also told his teacher that "My father divorced." Another time, Dalia said, "...they were playing outside, and he said one boy was teasing, and he said, 'O.K., kill me.' It's an expression. It's an expression in Argentina." Aaron was referred to a psychologist for an assessment, who felt that Aaron was on the "borderline."

Both Rafael and Dalia disagreed with this diagnosis. Dalia commented, "I complain, why? I think the school was look for resource from the government. But, Aaron doesn't need. Aaron needs more limits." She continued, "So, it's a fight I have with the school. I explained in the school what is the situation. An immigration situation, a family with four children, one of them with special needs, but not the rest!" Rafael also felt that the school did not consider their cultural background when it came to understanding their son. Aaron, Rafael remarked, "With Aaron how can I say? There was a lack of cooperation for a different kind of cultural ideas. They didn't see the background."

Students who have behavior disorders are characterized by dysfunctional interactions between the student and one or more elements of the environment, including the classroom, school, family, peers, and community (BC Ministry of Education). Behavior disorders vary in their severity, from mild to severe, and

there is an effect on learning, interpersonal relationships, and personal adjustment.

Children with behavior disorders may display two types of behaviors that cause concern: internalizing behaviors are those characterized as withdrawn or directed inward; and externalizing behaviors are those characterized as directed toward others by acting out. Examples of externalizing behaviors include: displaying recurring pattern of aggression, arguing excessively, noncompliance, exhibiting persistent patterns of lying, cheating, and/or stealing, exhibiting lack of self-control, and acting out behaviors (Kentucky Department of Education of Special Education and Rehabilitation Counseling at the University of Kentucky, 1999).

Rafael and Dalia rejected the North American categorization of Aaron's behavior as a "disorder". It is evident for them that the issue around their son, Aaron, is an issue of cultural mismatch in the interpretation of behavior difficulties. Rafael suggested that when new immigrants come to Canada, the school should, "...learn a little bit about the cultural background of each kind of immigrant which came here, to try to change the system in order to try to adapt a little wealth from the background."

### *Historical Orientation*

Argentina is located in the southern portion of South America. It is bordered by Chile, Bolivia, Paraguay. Brazil, Uruguay, and the Atlantic Ocean. The capital city, Buenos Aires, has a population exceeding 13,349,000 (National Geographic, 2008). See map 2.

In a forum held in Winnipeg on May 15, 2008, Professor Jorge Nallim, an immigrant from Argentina, who teaches Latin American history at the University of Manitoba, explained the circumstances which led to the Argentine Jewish immigration to Winnipeg. He talked about why more than one hundred and fifty Argentine Jewish families have moved to Winnipeg since the mid 1990's (Bellan, 2008). Professor Nallim discussed the military dictatorship that ruled Argentina from 1975 to 1983. He said that the Jewish population suffered disproportionately, "The Argentine Junta was not anti-Jewish. It killed everyone. But of 9000 who were killed, by the junta, 1000 were Jewish."

In the late 1980's Carlos Menem was elected president of Argentina, and imposed a program of large-scale privatization of public companies to encourage foreign investments. Nallim said that in 2001 a series of presidents rapidly succeeded each other and resigned, worsening both the economic and political situation. This instability caused many of the Argentine Jews to immigrate to other countries.

#### *Circumstances of Immigration*

In the late 1990's Canada's federal government began to decentralize the immigration process, letting provinces select immigrants based on their own requirements (Bellan, 2008). Manitoba set up a Provincial Nominee Program. The Winnipeg Jewish Community Council organized "exploratory visits" where prospective immigrants from Argentina could visit Winnipeg and assess the Jewish community, housing, and job prospects.

Rafael explained that the immigration process for him and his family began in the summer of 2000 when he bought his first computer, “one of the first dial-up connections, because I don’t come from the capital of Argentina. I come from the north of Argentina, from a little town in the middle of nothing, near Bolivia. I put in “Yahoo” search – Winnipeg, and I read some kind of article that says that the Winnipeg community is helping immigrants come here. So, I said ‘Winnipeg? Jewish organization?’ and talked to Dalia, and I made an application for a VISA in 2001, and we started the process of immigration in December 2001. And that’s it! The most important part here is that the Jewish community helps us a lot.”

Iael Besendorf, an Argentine Jewish immigrant, who works as a resettlement worker with Jewish Child and Family Services, described the challenges immigrant families often face. Jewish Child and Family Services helps in the transition process, ranging in areas such as housing, daycare programs, schools and English classes (Bellan, 2008).

Rafael talked about his experience, “The process of immigration is not

Figure 2 - Map of Argentina

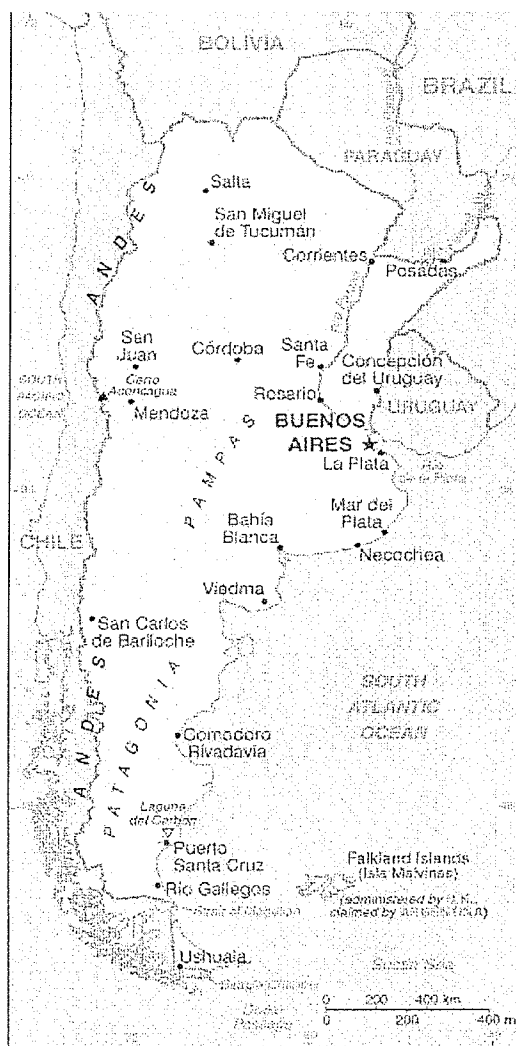
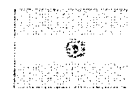
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## The World Factbook



### Argentina



<http://www.cia.gov/cia/publications/factbook/print/ar.html>

easy. We have to cross a lot of barriers – the medical barriers, getting acquainted with a new environment. It's very hard.” He continued, “A new society, with totally different kind of values, and a totally different orientation how to handle the situation. Here everything is totally, completely different than Argentina.”

Raphael was disillusioned with some of the practices that he encountered with the Canadian immigration system. He believed that the system needs to have “ a little more flexibility to learn the cases in which the culture is not exactly the same.” He illustrated this point by saying, “ For example, what's happening in Ethiopia? When someone is coming from Ethiopia, you learn what's happened to them. You don't push the Canadian system like a book, because the Canadian system and the system in Ethiopia is not the same.”

Raphael was also offended that he and his family were not given a separate designation, but rather were classified as “refugees”. He explained, “ I see, for example, that Immigration Canada put there in the same box as the refugees. We are not refugees.” Raphael proceeded to explain, “ I made the process of immigration by myself. It was my decision. I then promote myself. So, it's not the same. So, in certain ways the Canadian system is very, very conservative. They don't change anything. They apply the same rules sometimes for native Canadians and immigrants. We are not the same! They don't accommodate, they don't moderate, they don't change. I told sometimes to Immigration Manitoba, ‘ Be careful of the dinosaurs! You know why the dinosaurs are extinct? Because they didn't adapt to a new environment’.”



*Cultural Perspectives of Disability*

Elana has been on medication since the first episode as an infant. When planning their move to Canada, Rafael, who is a pharmacist by profession, talked about the transition for Elana. "I made a little research because in Argentina it was very hard to find adequate combination of epileptic drugs. So before we came here I was working very closely with the doctor. And we found a drug that was available here in Canada. So we changed the drug so that when she came to this country, she stayed on the same drug. Rafael continues with optimism, "Elana has not had any seizures. She has not had any for the last four years."

Both Rafael and Dalia felt that Aaron was reacting to the move from Argentina, as well as the attention that Elana was receiving. Rafael also feels that it would be "...a very good idea to learn a little bit about the cultural background of each kind of immigrant."

*Ria's Story*

Ria immigrated to Winnipeg from El Salvador twenty-one years ago, with her husband, six-year old daughter, her mother, and her brother. Ria and her husband had three more children, born in Canada, a son who is now eighteen, Marcus, who is sixteen, and a third son who is thirteen. Marcus has been diagnosed with autism.

Autism Spectrum Disorder, also called ASD, is a lifelong neurological disorder that affects how the brain functions, and causes a wide range of behavioral and developmental problems. A diagnosis of ASD means that a child's development is affected in three main areas, 1) social, 2) communication

and play, and 3) a narrow and/or repetitive range of behaviors or interests (The Hospital for Sick Children, 2003).

Unusual responses to stimuli and sensations, i.e., pain, touch, hearing, etc. may trigger unexpected behaviors. There may be an apparent lack of fear of real danger, or inappropriate screaming or laughing. Any change to a known routine constitutes a challenge, and the result may be withdrawal or panic in an attempt to cope (BC Ministry of Education, 2006)

Autism Spectrum Disorder is one of the most common developmental conditions. It is four times more common in boys than in girls (BC Ministry of Education, 2006) It affects people from all parts of the world, from every social class and race.

In some families there appears to be a pattern of autism which suggests there is a genetic basis to the disorder. At this time, no single gene has been linked to autism. Several ideas about the cause of ASD have now been proven to be false. For example, children with autism were believed to have a difficult time forming relationships with others because their parents were not loving enough, and mothers were particularly blamed.

It is usually diagnosed in preschool years and is based on observation of behavior. A clinical diagnostic assessment must be conducted by a qualified psychologist, pediatrician, or child psychiatrist, with extensive experience in diagnosing children with autism and developmental disabilities. The diagnosis of Autism Spectrum Disorder is clinical, based on the most current criteria in the

DSM-IV-TR (BC Ministry of Education, 2006). The assessment must also include interviews with the parent or caregiver of the child.

There is no medical cure for Autism Spectrum Disorder, but because of advances in medicine and education, there are programs that influence how the brain develops and works. With the right treatment, some behaviours can be changed.

Many parents have difficulty balancing the needs of their child with autism with the needs of their other children. These siblings have conflicting feelings about having a brother or sister with autism.

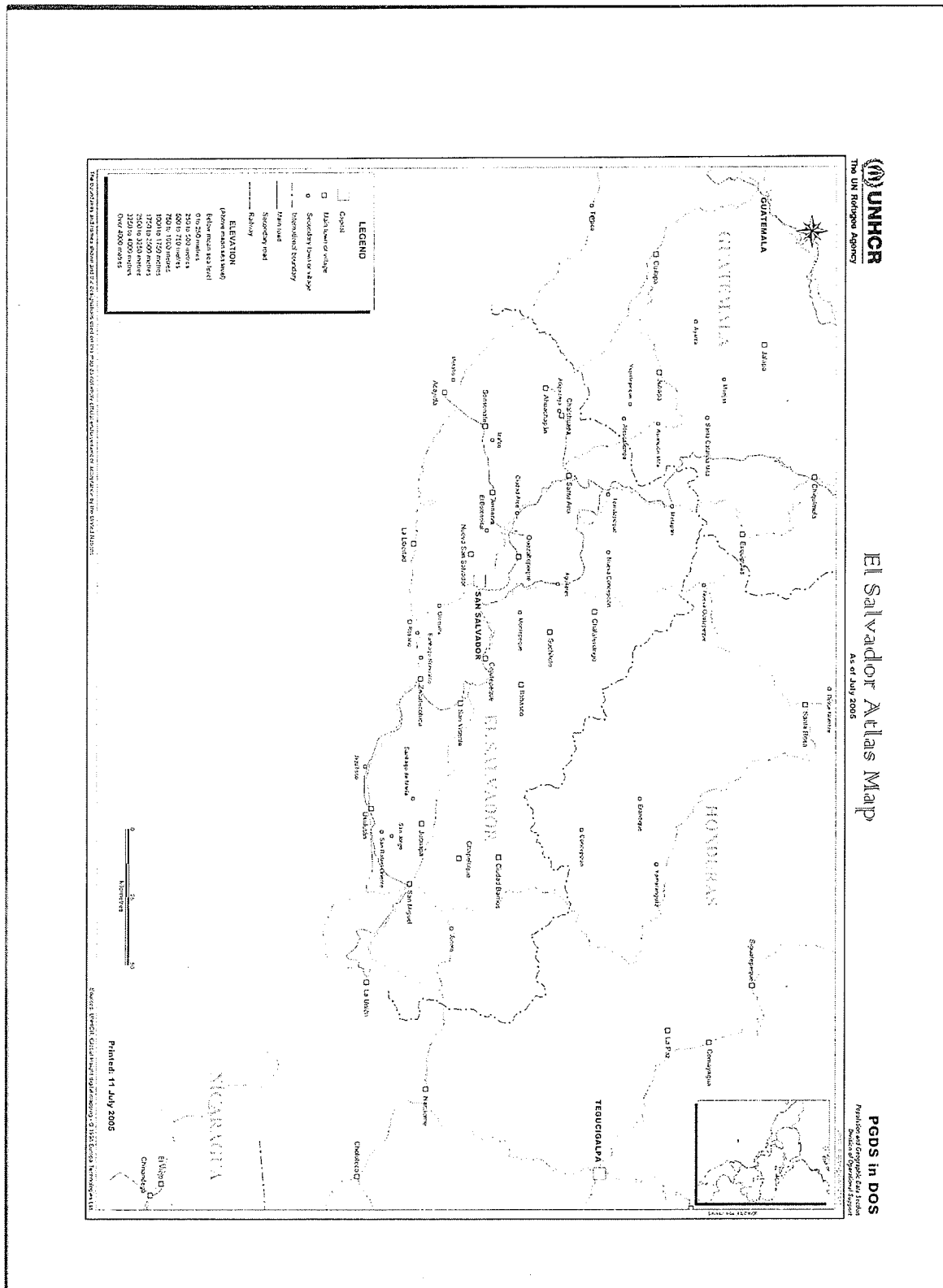
Parents of children with autism often have many concerns about their child's future. Planning for transition, and providing the student and families with information and resources is very important.

### *Historical Orientation*

El Salvador is the smallest, most densely populated country in Central America. The country borders Guatemala to the west, Honduras to the north and east, and the Pacific Ocean to the southwest. See map 3.

Following a deterioration in the country's democratic institutions, El Salvador was engulfed in a violent civil war between 1980-1992. During the twelve year civil war, human rights violations by both the government security forces, and left-wing guerilla were rampant (U.S. Department of State, 2008). In 1989, the murder of six Jesuit priests, their housekeeper, and her daughter, at the University of Central America shocked the international community into action (PBS, retrieved 2008). A U.S. task force was created to monitor El Salvador's

Figure 3 – Map of El Salvador



investigation of the murders. Congressman Joe Moakley of Massachusetts, selected to head up the investigation, discovered that the Salvadoran armed forces had been responsible for the murders of the Jesuits. Both sides of the conflict in El Salvador approached the United Nations for help in negotiating a settlement. The United Nations sponsored talks, which resulted in the January 1992 signing of the Peace Accords, ending twelve years of civil war (PBS, retrieved 2008).

The signing of the Peace Accords in 1992 marked the end of the civil war, during which much of El Salvador's infrastructure was destroyed, more than 75,000 people were estimated to have lost their lives, and over a million individuals were displaced (Gammage, 2007).

#### *Circumstances of Immigration*

Ria explained why she emigrated from El Salvador, "It was the war in my country, in El Salvador. "It was really hard to leave our country, but they kill my father and my two brothers." Ria said that she still has a brother and sister living in El Salvador. Ria and her husband, six-year-old daughter, her mother, and her brother applied for refugee status and were sent to Winnipeg. I asked Ria if they had chosen Winnipeg as a destination. She replied, "No. They told me that I had to come here. They say that you have to go to this place. Plus, you are safe. It doesn't matter. We came here, and we're still here."

Ria and her family received comprehensive assistance services including relocation assistance, health care, and education opportunities. Ria said that they did not know any other Salvadoran families in Winnipeg. When I said that it must have been difficult for Ria and her family, she said, "Oh yes, especially winter! But you know, it's a safe place. It doesn't matter if it's cold. It's safe."

Besides the winter, Ria is very grateful for the life that they have in Winnipeg. She will not travel or allow her children to travel, to El Salvador to visit her brother and sister. She feels that there continues to be criminal activity and violence in El Salvador.

### *Cultural Perspectives of Disability*

When I asked Ria about Marcus' diagnosis she said, "He was fine. He was talking like a normal kid. But at the age of two and a half, when Anthony was born, we saw then that he was acting different. First he was just moving, rocking himself, and making noises, and he stopped looking at everybody. He was acting different. He was playing with the toys backwards, and just with the cars (spinning the wheels). But...at the beginning the doctor said, 'maybe he's jealous of the baby. He stopped talking. He stopped looking.'" Ria knew that there was something different about Marcus, "...he was holding his ears all the time, and crying when I cleaned with the vacuum."

Marcus was diagnosed with autism by the medical community in a Winnipeg hospital. Ria was not familiar with what "autism" meant. Ria and her husband did some research at the library, but attending a parent support group at the hospital provided much-needed information and support. Ria said, "These

help us a lot. So many times they teach us and they give us the ideas how to deal with Marcus.”

Siblings often play important roles in the lives of the brothers or sisters with autism spectrum disorders (Bleach, 2001). Ria explained that when Marcus was young, it was difficult because they had other children, “...We never go out. The other kids now complain that we didn’t have time for them. They always have to go away for party, or with friends. Marcus was jumping all the time, and throwing things. And when the kids even start laughing, he was so upset.”

Ria also talked about feeling “isolated.” She said, “Even your friends, they don’t want to stay close to a family that has problems like that.”

I asked Ria how Marcus communicated with the family. Ria explained, “He says some words. Sometimes in Spanish, sometimes in English. But it’s really hard for him to let us know what he wants, or when he wants something he starts saying the same thing until he gets it. Well, if he can get. But, if he doesn’t get it...” Even going for a walk with Marcus was too difficult for Ria, “He runs in front of the car and the bus. I couldn’t handle that. And then he start hitting me.”

Ria and her husband qualified for respite but she said, “Even the two men who are coming to help me, sometimes they couldn’t take it.” They told her that, “...probably you have to put him in a different place.” This was a very difficult concept for Ria, “I said, ‘No, no, no. I don’t want him to go to a hospital or something. They are going to put more drugs’.”

One year ago, Marcus moved into an apartment with full time support. Another boy would be joining him in the near future. When I asked Ria how she felt, she said, "It's amazing knowing that he's safe. He has to live his life. We are getting old. We are very weak. I can't take care of him. And the others they have to live their lives. I don't know when I have to go, but it's better now to prepare him to stay and live his life, you know. And getting used to someone else looking after him."

Every Friday Marcus comes home and stays until Saturday afternoon. Ria looks forward to having him come home. "...He's also comfortable at home. He knows that he has his room, and he has his things."

Ria also talked about a woman she had met who had a daughter with Down syndrome. This woman taught Ria how to advocate. Ria said, "When you have these kids you are so scared, that even to ask about things. And she said 'you have to ask, and you have to let him go and be independent, because you never know when he's going to be away from you'." She also told Ria, "'Never say to your kids that they have to be responsible for him.' You have to live your life, Marcus has to live his life. I know that he's your brother. But he has to learn to be independent."

When I asked Ria about how it is to have a child with a disability in El Salvador, she described very different circumstances, "I have a friend, that...now I know that the girl has autism, also. But when I lived there, that girl always had to stay at home. And one day she ran away. She doesn't know how to talk. She got lost for almost a week...But one lady find her. If you have a child like that,



everybody says, 'Well, she's crazy'. She can't go to school. She has to stay in an institution, or at home. And now, well, the time is different. They have places but not like here. If you don't have money to pay even a little bit..."

Ria discussed the use of medication for Marcus quite often throughout the interview. She discussed how his medication had been increased recently "because he was so aggressive with the teachers." She was told it was "the change in his hormones." When the respite workers suggested that Marcus move out of the family home, Ria was reluctant, "I don't want him to go to a hospital or something. They are going to put more drugs."

Ria also believed that Marcus' doctor was not taking her seriously. "...Once I was complaining about the medication, and I noticed that the doctor was laughing, and I said, 'Well, probably you think that I'm not a doctor, I don't know nothing about medicine. But, I read a lot of things and I don't like the idea of giving him more medication. Because I noticed that as soon as he has the medication, he starts going down. He needs different therapy, not just medication'."

I talked to Ria about her religious beliefs. Ria said that the worker "prays with him at night. Because I teach him since he was a little boy. And my husband, too, will pray with him every night, I said, 'Could you please continue with that every night?' I told Ria that she and her husband should feel proud of themselves for advocating for Marcus. Ria said, "God gave me. There was a reason, always a reason. He knows that I can take care of him."

*Leben's Story*

I met Leben at a non-profit agency that helps refugees new to Winnipeg, where we had agreed to conduct the interview. He is a tall, handsome man from Sudan. His command of the English language was very good, and he extended his arm to shake my hand.

After we had reviewed the consent form, I asked him how long he had been in Winnipeg. Leben answered that he had come to Winnipeg six years ago with his wife and seven children. His daughter, Zara is nine years old and in Grade 3. Zara has cerebral palsy. They immigrated to Winnipeg when Zara was three years old.

Leben informed me that he had completed a Masters degree in England. He would have liked to continue with his Ph.D. but the Sudanese government suspended his scholarship. Leben was from the southern part of Sudan, and the government in the north felt that he did not need to continue. Leben said that, "...before coming to Winnipeg I was really exposed to the western world." He told me that he has been to the UK, Sweden, Norway and Denmark. I asked Leben what language he spoke at home with his family. Leben replied, "'we speak a mixture of many things, our local language Dur, D-U-R, Arabic, English."

Cerebral palsy is a neurological disorder caused by a brain injury that occurs before, during, or shortly after birth (BC Ministry of Education, 2006). Although the cause of cerebral palsy is not known for sure, there is evidence that links it to both the health history of the mother and child. It can result from a variety of conditions, including: infection during pregnancy, such as rubella or

toxoplasmosis, jaundice, Rh incompatibility, or oxygen shortage during birth.

Cerebral palsy is not a progressive disorder, however, over time complications can occur.

Early signs of cerebral palsy usually appear before eighteen months of age, and parents are often the first to suspect their child is not developing motor skills typically. Infants with cerebral palsy are frequently slow to reach developmental milestones, such as learning to roll over, sit, crawl, smile, or walk.

There are three main types of cerebral palsy. The most common type, affecting approximately 70 percent of those with cerebral palsy is referred to as spastic cerebral palsy. This form is characterized by stiff muscles (a condition referred to as hypertonia). The primary characteristic of athetoid cerebral palsy is sudden, uncontrolled movement of the muscles of the arms, legs, hands, and feet, and occasionally the musculature of the face and tongue. Ataxia cerebral palsy is much less common. The main effect of this type is on the child's sense of balance and depth perception, resulting in awkward and unsteady movement of the hands and feet. There may be a mixture of these types in an individual who has been diagnosed with cerebral palsy.

Cerebral palsy may cause a number of other symptoms as well (Pellegrino, 2002). They may have vision or hearing loss, intellectual or learning disabilities, receptive and expressive communication disorders, or seizure disorders. This physical limitation may also cause problems with speech, swallowing, eating, or poor bladder control. The severity of the disability caused

by cerebral palsy will determine expectations and the lifestyle of the child (BC Ministry of Education, 2006).

### *Historical Orientation*

Sudan, an East African country of approximately 34.5 million (Cultural Orientation Resource Center, 2008), shares borders with nine countries, including Egypt to the north. The Nile River and its tributaries dominate the country. See map 4.

Since independence from Britain in 1956, Sudan has been engulfed in a vicious civil war (with the exception of a cease-fire from 1972-1983). The war in Sudan was a division of North against South (Mylan & Shenk, 2004). The history of the situation is summarized by Amnesty International:

“...the central government in the North has been fighting rebels from the South over political autonomy and economic power. With the imposition of Sharia law in 1983, and the establishment of the military government in 1989, the conflict took on religious and ethnic dimensions, as the government set out to reshape social institutions in line with its interpretation of Islam” (Amnesty International USA).

According to the United Nations, over 2 million Sudanese have died and another 4.5 million are refugees. The World Refugee Survey from the U.S. Committee for Refugees indicated that the Sudanese have suffered more war-related deaths during the past sixteen years than any other population (U.S. Committee for Refugees).

Caught in the crossfire were millions of civilians. Both sides have been guilty of human rights violations, including using children as soldiers (Mylan & Shenk, 2004). Furthermore, war-related problems have been aggravated by drought and periodic flooding, which have led to malnutrition rates of up to 40 percent, according to United Nations reports (UNHCR).

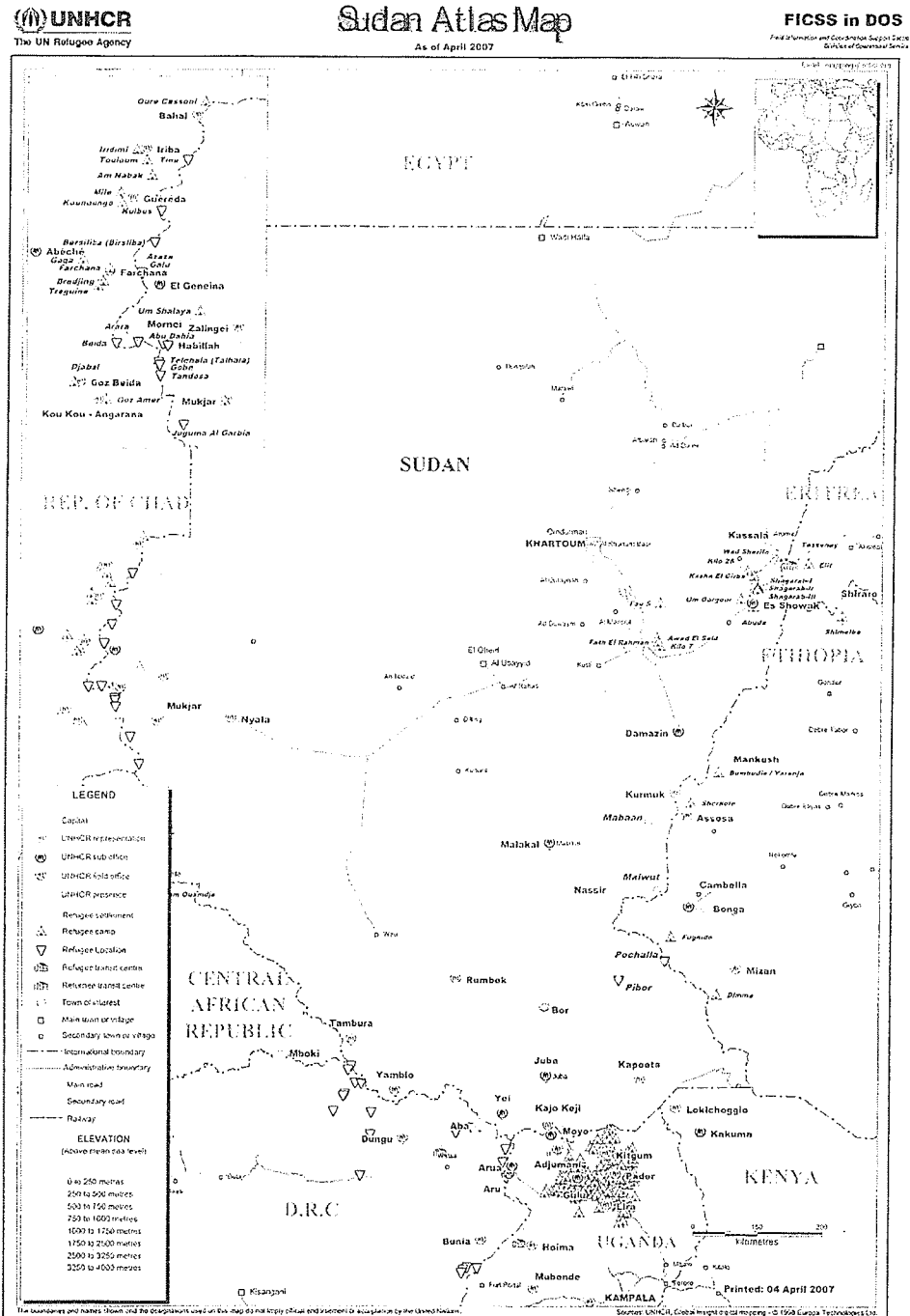
Many Sudanese, about 7,000 to 8,000 arrived in Egypt as refugees. However, refugees in Egypt are not legally entitled to work, and have no access to national health facilities, government schools, or subsidized housing (Hassan, 2000). Most refugees in Egypt are hopeful that they will attain formal refugee status from the United Nations High Commission for Refugees (UNHCR), and that they will have a chance to migrate to the United States, Canada, or Australia (Hassan, 2000).

#### *Circumstances of Immigration*

Leben explained that his wife fled Sudan to Egypt before he did. She was pregnant with Zara at the time. Leben arrived in Egypt at the time of Zara's birth. Soon afterwards they relocated to Tunisia.

When Zara was three years old, the United Nations High Commission for Refugees arranged to resettle Leben, his wife, and their children in Winnipeg to start a new life. Leben was encouraged when he discovered that they were coming to Winnipeg. "Well, first of all, when we were told that we're coming to Canada, I didn't worry. We were told that the health services in Canada were super, and that maybe something would be done to help her (Zara). And I was really relieved."

Figure 4 – Map of Sudan



Leben now works as a settlement counselor to help refugees new to Winnipeg. He feels that his situation is atypical, "My situation may not be a general one. First of all, I have limited language difficulties. I can communicate. Secondly, when it comes to some of the clients I'm working with who may not know where to go, they are in need of more information...One of my co-workers has a disabled child, and he didn't know where to turn, and the management said, 'Well why don't you talk to Leben'." Leben continues, "And he came to me and said, 'Now, how do I deal with this?' And I said, 'Okay my friend this is how to go about it'."

#### *Cultural Perspectives of Disability*

I asked Leben about the nature of Zara's disability, and he answered, "I think they say it is cerebral palsy." Leben explained that Zara was born in, "the asylum country, that is, Egypt." He then went on to explain the circumstances of Zara's birth, "My wife went before me. She went to Egypt before me...I think that something went wrong. What happened, during the labour she went to the doctor, and instead of delivering in the hospital, she was delivering in a private clinic. And, I think that something went wrong somewhere. And this child was abnormal from the beginning."

Leben was notably upset when he found out that his wife was delivering in a private clinic, "In places, in third world countries, doctors tend to mislead people. Instead of delivering good service they tend to take advantage of clients in terms of money. I think that that is what motivated this doctor to deliver my wife in the clinic."

Soon afterwards they left Egypt and relocated to Tunisia. Leben and his wife became aware that there was a problem, “ So the problem started in Tunisia. We started to realize that the child was abnormal.” Leben proceeded to explain their predicament, “...we went through a lot of difficulties, even then, trying to get her to hospital. She was subjected to electric shocks, and these sorts of things. We were really stuck. We didn’t know what to do. It was a very difficult situation.”

Leben was “relieved” when he found out that he and his family would be immigrating to Canada. As soon as they arrived in Winnipeg he and his wife took Zara to the hospital. Leben was very pleased with the assistance they were provided, “...a lot of services were put in place for her (Zara). Up to now the services are continuing. The hospital linked me up with a lot of services, a disability support agency, language therapy, speech therapy, all these sorts of things... A lot of services were linked up. That was great!”

When I asked Leben if he had any beliefs concerning Zara’s disability based on his culture, he answered “Mm, I don’t think so. You know, she is a disabled person...We consider this illness. So, what is the difference now? Because we are bound morally bound to take care of this person. So we are not seeing anything different anywhere.”

### *Rayna’s and Nadia’s Story*

I was contacted by Aleks, an interpreter from a refugee assistance agency in Winnipeg about Nadia, and her mother Rayna. Nadia and Rayna



immigrated to Winnipeg from Bosnia in 2006. Nadia is eighteen years old, and has had Type 1 diabetes since she was seven years old.

I met Aleksi outside Nadia's and Rayna's apartment, and we walked in together. Nadia met us at the door, "Come this way" she said with a pronounced accent. Rayna shyly extended her hand. We discussed the Consent Form and Aleksi translated what I told Rayna and Nadia about my research. "You are doing a good thing," Aleksi said.

Nadia and Rayna are from Bosnia, the former Yugoslavia, from a suburb of Sarajevo. Aleksi was familiar with "the small village where they are from." He recalled, "I was there a couple of times. I remember I was passing by." When I asked what language they were speaking, Aleksi answered, "They are speaking Bosnian language."

Diabetes is a disease in which the body cannot make energy from food. This is because the body doesn't produce enough insulin, a hormone that enables people to get energy from food. In a healthy person, glucose, a form of sugar produced when food is digested, is used to supply the body with energy (Juvenile Diabetes Research Foundation, 2007). To turn food into energy, the body requires insulin. Without insulin, glucose builds up in the bloodstream and overflows into the urine. High glucose levels in blood and urine are hallmarks of diabetes (Juvenile Diabetes Research Foundation, 2007).

There are two major types of diabetes, Type 1 and Type 2. Children and teens usually develop Type 1 diabetes (Hospital for Sick Children, 2009). In Type 1 diabetes, food is broken down and sugar is still released during digestion.

The sugar is absorbed into the bloodstream and is carried to the cells. However, the pancreas doesn't respond by making insulin, so the sugar can't move into the cells. The child may become tired because the cells are literally starved for energy. Meanwhile, sugar continues to build up in the blood. When the kidneys sense a high level of sugar in the blood, they start getting rid of it through the urine. When this excess sugar is eliminated, it also takes the water in which it is dissolved. As a result, the child urinates more often and in larger amounts to get rid of the sugar. This is called polydipsia. Excessive urination and thirst are usually the first indications of the high blood sugar (hyperglycemia) of diabetes.

When the pancreas doesn't make insulin, cells don't get energy. Over time, the body starts to break down fat and protein to be used as energy which causes weight loss. During this process, the body makes a poisonous byproduct, called ketones, or acetone. If the kidneys cannot filter out the ketones as fast as they are being made, they begin to build up in the blood. This leads to symptoms such as stomach aches and severe nausea, called diabetic ketoacidosis (DKA). Ketoacidosis is a very serious condition of diabetes. By giving intravenous fluid and insulin the situation usually will improve.

People with Type 1 diabetes must take insulin injections four to six times a day, or through insulin pumps. Diabetes control means keeping the level of blood glucose as close to the normal range between 4-7 mmol/L before eating as possible (Juvenile Diabetes Research Foundation, 2007). The goals of diabetes control include balancing three variables: food intake, physical activity, and insulin. While trying to balance insulin doses with food intake and daily activities,

there is still the possibility of two diabetes-related emergencies: hypoglycemia (also called low blood sugar or insulin shock) and hyperglycemia (high blood sugar). Despite maintaining a balance between food intake, insulin, and physical activity, there are many other factors that can affect this balance, including, stress, hormonal changes, periods of growth, illness, physical activity, and fatigue (Juvenile Diabetes Research Foundation, 2007).

The demands of diabetes management cannot help but have an impact on a student's school life. By understanding the important aspects of diabetes management, the teacher can ensure the student's adjustment to the classroom setting. Students who have Type 1 diabetes are entitled to an IEP if their health condition adversely affects their educational performance. Strengths and needs can range in the cognitive, academic, social/emotional, and behavior domains.

A student with Type 1 diabetes should have a health care plan at the school. A health care plan developed by the student's physician, a diabetes nurse educator, a diabetes dietitian, and social worker, describes the student's treatment regimes and procedures, including insulin injections, blood and urine testing, and having to eat regulated, scheduled meals and snacks. Teachers should become familiar with the signs of hyperglycemia, and notify the parents if the child has to leave to go to the bathroom more often. The school should also have a plan of action in place in case the student has a severe insulin reaction, administer sugar or juice if the child is conscious, an ambulance if the child is unconscious. A partnership with the student, family members and educator is essential to ensure consistency.

Teenagers with diabetes experience extra challenges (Juvenile Diabetes Research Foundation, 2007). Adolescent lifestyles require more flexibility in eating and insulin regimes. This may require the teenager to assume more responsibility and awareness of food intake, blood glucose levels, and insulin needs.

There comes a time when the teenager with diabetes needs to transition from paediatric to adult health care. In the adult system, teenagers are expected to gradually take complete responsibility for themselves (Hospital for Sick Children, 2004). She will be expected to practice more intensive management of her diabetes, aiming for tighter blood sugar control through more frequent injections and glucose monitoring. There will be changes in meal plans and exercise regimen. As she gets older, the teenager may have to monitor blood pressure and see an eye doctor more frequently. Routine foot care will be emphasized to prevent infections and identify signs of nerve damage (Hospital for Sick Children, 2004).

These demands can be overwhelming, and a teenager with diabetes might feel that she can't meet them. The support system of family and educators throughout this transition phase is important to ensure that the young adult continues with the care needed to manage her diabetes.

### *Historical Orientation*

Bosnia-Herzegovina, which is a region of the former Yugoslavia, has a long history of conflict and changing borders. With the end of the Cold War came the collapse of the Yugoslavia state and the ensuing Bosnian war. Bosnia is the

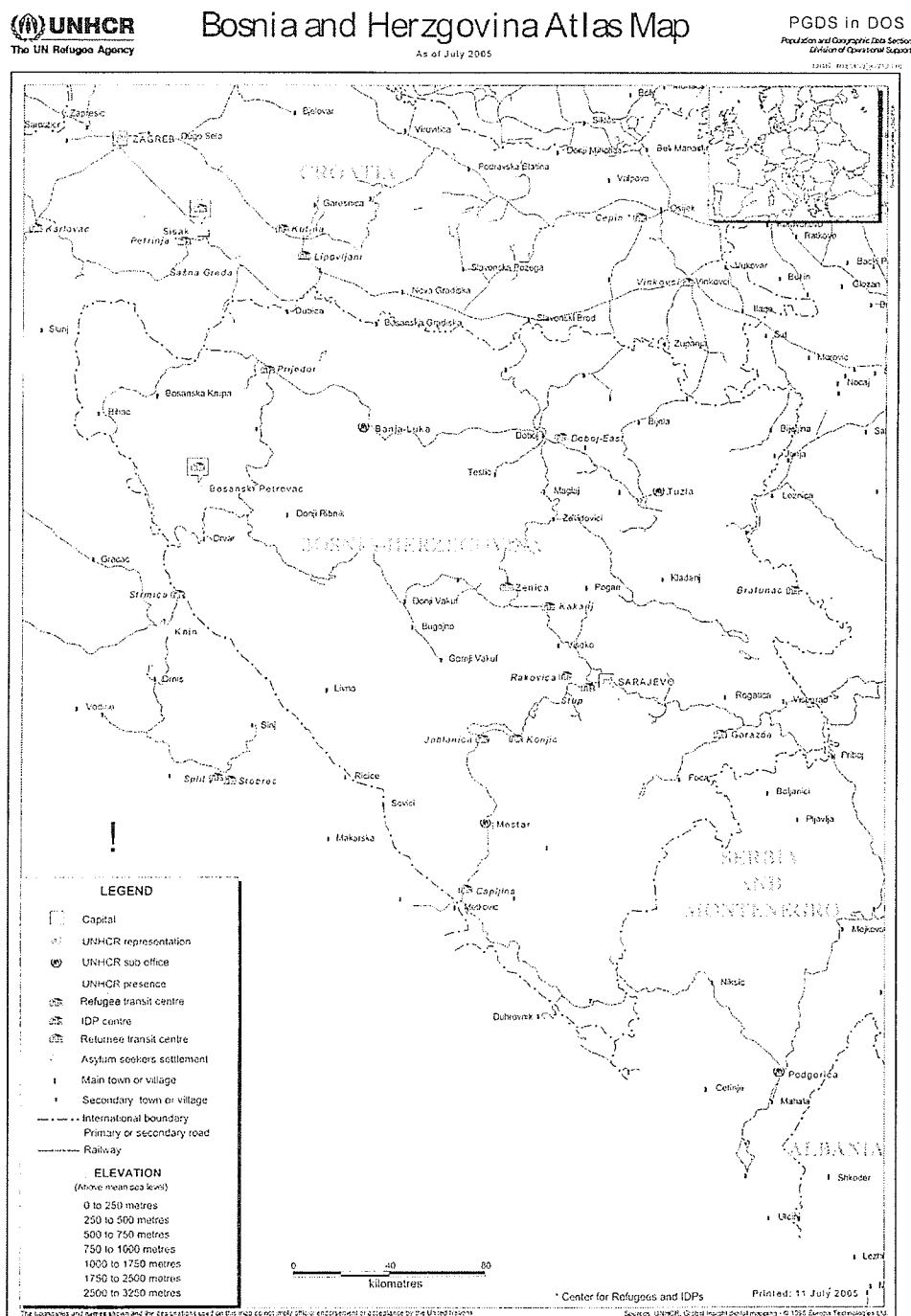
common name for the whole country. Herzegovina, a rural region of the country, is included in its formal name. Bosnia- Herzegovina borders Croatia to the north and southwest, Serbia to the east, and Montenegro to the southeast. The state's capital and largest city is Sarajevo. See map 5.

The former Yugoslavia was a combination of different ethnic and religious groups including Serbian-Orthodox, Croatian-Catholic, and Bosniak-Muslim. Widespread dissatisfaction with the central government, the Croats and Bosniaks, fearing Serbian domination, voted for declaration of independence from Yugoslavia in October, 1991. In 1992, the sovereignty of Bosnia-Herzegovina was recognized by the European Union and the United States, and it entered the United Nations. Many Bosnian Serbs opposed the new republic. The country erupted in war among the different factions over who would control which territory.

Bosniaks were forced from their homes and towns as part of an "ethnic cleansing" policy carried out mostly by the Serbs. Thousands were killed, many were placed in detention camps, and many more fled the country.

In November 1995, the Bosnian government and the leaders of Croatia and Serbia, met under United States auspices in Dayton, Ohio, and a peace agreement was negotiated. It called for the creation of two substates, a Croat-Bosniak federation to govern one half of the country, and a Bosnian Serb republic to constitute the other half, united under a newly created national presidency, assembly, court, and central bank. The accord also provided for the dispatch of NATO-led troops for peacekeeping purposes.

Figure 5 – Map of Bosnia



Currently, life in Bosnia-Herzegovina is peaceful, and relations between communities are relaxed (Lonely Planet, 2008). The recent and sudden death of Slobodan Milosevic, a Serbian who became the leader in the late 1980s, somewhat closes one era of the Balkan nation's history (Axworthy, 2006).

### *Circumstances of Immigration*

When I asked Rayna and Nadia about the reason for their immigration to Winnipeg, Alekski interpreted the question and Nadia replied in Bosnian. Alekski translated, "The first reason is health. The number one reason is health." He explained, "She (Nadia) was not feeling good before the war, but during the war she was really collapsing all the time. So they went to see doctor, and he said, 'Oh boy! You need to stay in hospital. It's really dangerous situation, because you have really, really high blood sugar'."

Alekski translated what Nadia told him, "Unfortunately war broke out, and situation was awful...no food, no running water, no nothing. On top of that, no insulin, no nothing." I asked Rayna and Nadia if they left Bosnia and came directly to Winnipeg. Alekski said, "What is happening, they were in a really tough situation because of the war, so what they did, they went to Serbia as refugees." He continued after Nadia explained to Alekski, "They came to Serbia in the refugee camp outside of Belgrave. In Serbia there were so many refugees in this camp. They were in three camps, one, two, three camps. It was an awful situation."

Alekski explained their predicament, "So, to make the story really short, what was happen, somebody came from Canadian Embassy to the camp, and

they figured out, 'Let's try to...' and they put their names in the paper. So, they went to the Embassy in Belgrade, the Canadian Embassy, and they brought the papers." Aleksi continued by explaining the immigration process to Canada, "A special program was from 1992 to 2001. And the Canadian government started the program because of this agreement signed in 1996. Then they say, 'Okay, we will have another four years'."

Rayna and Nadia came to Winnipeg in 2006. Aleksi said, "...I was really surprised when I saw these two people. You know, they came after they closed the program. So, since I have good experience working with the refugees, I knew that something special was with this family." Aleksi found out about Nadia's diabetes, and, "So what I did, I went to the hospital, and I met a couple of people there, and they told me, as soon as they arrive to bring them here. So that was great. Everything was very organized. Settlement agency where I work is like a bridge."

Alexsi is employed as a settlement counselor to welcome and assist newly arrived refugees in Winnipeg. He met Rayna and Nadia at the airport when they arrived, and provided information and orientation about life in Canada, particularly, Winnipeg. He facilitated access to the hospital, so that Nadia's medical needs were attended to immediately. Aleksi was also able to help with referral to community services, such as English language training, employment assistance, income supports, education, and financial services. He offered interpretation and advocacy to facilitate access to services in Winnipeg.



Aleksi arranged for Nadia to go to the hospital to address the diabetes, as soon as Rayna and Nadia arrived in Winnipeg. Aleksi emphasized the crisis. "...it was really hard to find out what is the level of the sugar, what to do? Pills, yes? Pills, no? Injection, yes? You know, very difficult. Dietician, psychologist, everybody was involved."

Aleksi also explained the need for a connection between the doctor and the pharmacy. He gave an example, "I remember a couple of months ago, they called really panicking, 'We don't have any insulin.' So, what I did, if I remember, correct me if I'm wrong, I remember I told you, you should go to see your doctor. And she went to the clinic and they told her, 'It's not a problem. We are going to supply you free, but you have to apply for...' 'Pharmacare.'" Nadia confirmed.

Aleksi feels that Rayna and Nadia do not need daily intervention now, but they can ask for help when needed, "So, I try not to be in their life anymore, but they know that they can always call and ask for help... They trust me. I trust them... So, the good thing in Canada is that the government has money to pay people like me and some others, to help those newcomers."

The housing situation for new refugees in Winnipeg is very discouraging. Aleksi describes Rayna's and Nadia's predicament, "...We are forced to locate people downtown. We are really suffering emotionally because of this. Your neighbor is a sex trade worker or heroin addict, or just came back from jail. There are some problems like peeking in the window, and so on." Aleksi suggested that they move into a social housing complex in a suburb of Winnipeg,

"...Since I have experience, I try to find something in this area, instead of downtown."

I asked Rayna if they have family in Bosnia. Rayna talked to Aleks in Bosnian, "So her family passed away, like, her mother, her sister, her brother...Rayna has a sister and a half brother in Bosnia. Her sister is saying she wants to come to Canada too. Maybe I can help. We'll talk about it. There is a way. Just tell her to start learning English as soon as possible."

### *Cultural Perspectives of Disability*

I asked Nadia what her understanding is of the diabetes. Aleks interprets what Nadia said, "March 10<sup>th</sup>, 1997, is the date when she got diabetes. She knows exactly." I asked her why she remembers the date. Nadia speaks in Bosnian and Aleks interprets, "I was seven years old. Mother was working. She came back from work. I didn't feel good. She went with me to emergency, and they told her 'Don't worry. Go home and sleep. Tomorrow morning you come back.' So tomorrow morning when mother came to the hospital, they told her 'We can't help her. We need to send her to a different city, because we don't have the resources here.' She was almost three months in hospital at this big health centre." Aleks continued, "And they didn't know what to do because of the sugar level was so high that they had to do it slowly because she can die."

Nadia talked to Aleks in Bosnian, explaining the situation, "So at that time they did surgery, connected to the diabetes. Her stomach was really hard like a stone." At this point, Rayna started to cry. She spoke to Aleks, "Mother was always saying 'I would be happy if I had the diabetes, not you'." Aleks then said

to me, "This is good because you came here. Not because of your Ph.D., this is good because you came here to meet with these people."

Once Nadia turned eighteen, Manitoba Health coverage transferred from child to adult care. Aleksi explained, "...So now she's not a child anymore, and they moved her file in a different place...She knows where to go, how to get there. She knows the phone numbers, emergency numbers, and all of these things."

However, as previously mentioned, teenagers with diabetes endure extra challenges. Aleksi asked permission from Nadia to discuss an incident that happened recently. He revealed, "So one day Rayna called me, she was crying, and she said, 'Nadia left her home. She doesn't want to stay with me anymore.' I said, 'Okay, just let's cool down. You are going to solve the problem, I know.' Thank God you know, after two days she's there. Everything was fine. So I didn't ask any questions what was happened. I knew that they will solve the problem from my experience working with people."

To achieve independence teenagers often form bonds with their friends. But peer groups require conformity, and conformity may create conflict for teenagers with diabetes. Nadia told Aleksi, and Aleksi interpreted, "She mentioned that she was not trying to hide it (diabetes), but what was really hard for her was to see other people eating whatever they want."

Overall, Aleksi feels that Nadia has adjusted very well, "You know, mentally she's fine, she's okay, in my opinion...You know, she's always smiling, she's always happy for discussion."

## Conclusions

In this chapter information was presented on the five families who participated in the study. Descriptive information on each family and the type of disability or disabilities were presented. I provided an overview of recent historical and political events of each country of origin, and the circumstances of immigration for each family. In the following chapter I present the findings of the study, and identify the themes and discuss implications.

## CHAPTER V

### PERSPECTIVES ON FAMILY-PROFESSIONAL PARTNERSHIPS

I conducted this study to examine the perspectives of new Canadian families and school professionals in identifying practices indicative of successful partnerships. In this chapter I present my analysis, and identify and discuss the themes that emerged. Each theme is supported by providing excerpts and details from the data. Eventually four broad themes were identified in the data. They are communication, cultural reciprocity, professional knowledge and practice, and advocacy.

The four themes fit within the context of current issues being discussed in the field of inclusive special education. The first theme, Communication, is essential to all interpersonal interactions, including students and their families, as well as other professionals who are involved with the students. The second theme, Cultural Reciprocity refers not only to the awareness of cultural difference, but to the willingness to learn about and understand the experiences of the families and to respect and accept these differences (Kalyanpur & Harry, 1999). The third theme, Professional Knowledge and Practice relates to both school professionals and families recognizing each other's knowledge, values and skills. Advocacy the fourth theme, involves providing information and support to the students and families.

The individual categories were conceptualized as sub-themes or recommended practices for the broad theme in which they were included. Specific behaviors and attitudes were identified. For example, the recommended practices for the theme of advocacy included working together as a team, providing support and reassurance, providing information, connecting to sources of support, and empowering families to advocate for their child. This analysis provided a “grounded theory” for the development of behaviors that can be observed and measured. The final result of this process was a total of twenty-one recommended practices organized into four themes.

The recommended practices were generated by responses from both family member and school professional participants. It was possible to compare the comments from family members and school professionals because they represented different transcripts. Both positive and negative examples of the same concept were presented.

The recommended practices that were formulated are interrelated and may correspond to two or more themes. The recommended practices provide a framework of principles that describe professional behaviors and attitudes essential for positive partnerships with families. Table 3.1 provides an overview of the four themes along with their respective recommended practices.

### Themes

Each of the four themes and sub-themes, or recommended practices, that emerged from the data is described. Following each description, I provide examples that include exact quotes and details from the data.

TABLE 3.1

***Four Themes and Corresponding Recommended Practices of Home-School Partnerships***

Partnership Theme	Recommended Practices
<i>Communication:</i> The members of the partnership exchange information and knowledge. Good communication is at the center of effective home-school collaboration. A plan must be implemented for positive communication between school and home.	<ul style="list-style-type: none"> <li>• Listening to both perspectives</li> <li>• Communicating frequently with families</li> <li>• Establishing and encouraging open two-way communication between the school and families</li> <li>• Providing translators for parent conferences</li> </ul>
<i>Cultural Reciprocity:</i> The members of the partnership engage in discussions regarding cultural values, and practice, acknowledge differences, and develop a reflective practice that will lead to effective home-school partnerships. Respect and trust are components of cultural reciprocity.	<ul style="list-style-type: none"> <li>• Regarding each situation as unique</li> <li>• Enabling members to learn from each other</li> <li>• Regarding each other with respect</li> <li>• Acknowledging both commonalities and differences</li> <li>• Reinforcing the commitment of school professionals to work well with families</li> <li>• Recognizing that it takes time to build trust</li> </ul>
<i>Professional Knowledge and Practice:</i> The members of the partnership acknowledge each other's knowledge, values, and skills. Educators show commitment to students, and demonstrate recommended practice to working with students and families.	<ul style="list-style-type: none"> <li>• Acquiring the skills to help each child succeed</li> <li>• Demonstrating active support from the school principal</li> <li>• Facilitating the transition planning process</li> <li>• Maintaining high expectations for every child</li> <li>• Collaborating with other professionals to address each child's needs</li> </ul>
<i>Advocacy:</i> The members of the partnership actively support the child, as well as each other, on behalf of the child and family	<ul style="list-style-type: none"> <li>• Working together "as a team"</li> <li>• Providing support and reassurance</li> <li>• Providing information</li> <li>• Connecting to sources of support</li> <li>• Empowering families</li> <li>• Providing knowledge of the school system</li> </ul>

*Format adapted from "Dimensions of family and professional partnerships: constructive guidelines for collaboration", by M. Blue Banning, J. Summers, H. Frankland, L. Lord Nelson, and G. Beegle, 2004, 70:2, p. 174.*

### *Theme One - Communication*

The importance of communication was emphasized by both the family member and school professional participants. Positive communication skills are very important for collaboration between families and educators. The members of the partnership exchange information and knowledge. School professionals can learn and apply communication skills, and incorporate them in a plan for positive communication between school and home.

The data revealed four recommended practices that are important for effective communication between family members and school professionals, which include a) listening to both perspectives, b) communicating frequently with families, c) establishing and encouraging open, two-way communication between the school and families, and d) providing translators for parent conferences.

#### *Family Member Responses*

Language barriers were particularly influential in determining the amount of involvement each of the families had with the school. Rafael expressed regret that he and his family did not have better English language proficiency. "One of

our greatest errors before we came here is that we don't know nothing of English." Dalia agreed, and described how she studied "...three years English in the high school in Argentina. But not speaking. And English is two languages – one speaking, and one reading."

Leben discussed how he had an advantage by speaking English when he arrived in Canada, "My situation may not be a general one. First of all, I have limited language difficulties. I can communicate."



Dalia described the need for professionals to listen, and to encourage family members to express opinions. She felt that the school professionals did not communicate their concerns about her son, Aaron. "...I talk with them, but they don't believe me...I explained in the school what is the situation. An immigration situation, a family with four children, one of them with special needs, but not the rest! And Aaron is the most susceptible boy. He's the three in four. And the school doesn't believe us." I asked Dalia if she felt that the teachers were not listening to her. She replied, "But they can see. They can see. He is very smart. He is very intelligent."

When the teachers suggested that Marcus may need more medication to improve his behavior, Ria said, "I know that I'm not a doctor, but I'm his mother", and she provided strategies to the teachers. Ria felt reluctant to express herself. "So many times you are scared of saying things, or afraid they are going to be bad with the kid if you complain."

The families were asked if there was one school professional who they felt had been supportive. Rafael responded that there was a resource teacher that communicated very well with them, "She sends e-mail, and I can send e-mail. When I take Elana to the doctor, I send an e-mail to her to explain everything."

Laila told Samira that Rushid has a very good relationship with the teacher assistant, and that, "...he doesn't listen to anybody else, he just listens to her!" Laila was very grateful that the teacher assistant accompanied Rushid on the school bus for one month, to prepare him to become independent. The teacher assistant communicates with Laila by writing down in a notebook, "what is

happening everyday, and she'd asked that Laila can write down anything that she has questions about."

Ria expressed how remarkable the coordinator of Marcus' program is, "She's wonderful. She understands. She's always fun with him. She has the magic words." Ria appreciated all of the school professionals who worked with Marcus, "Well, everybody is amazing in that job! I admire every teacher. You know, we don't do the things that they are doing everyday. We don't have the patience. I don't know how they can do it."

Leben explained that there are a number of support services that are working with Zara, but the "assigned teacher is with her at all times." I asked Leben if this was an educational assistant, or paraprofessional and he confirmed that she was.

The Individual Education Plan (IEP) meeting is the most important forum for family-professional partnerships (Kalyanpur & Harry, 1999). It is the formal conference in which the IEP is developed from contributions from both the family and school professionals. When I asked Ria if she and her husband were involved in the Individual Education Plan (IEP) for Marcus, she answered, "Yes. They always say that we are part of him. I always wanted to be part of the school, part of the program, and *know* what is going on with him."

Aleksi, Nadia's and Rayna's interpreter, discussed the IEP that was planned for Nadia, "...Maybe fifteen people! More than one hour! So the principal, vice-principal, counselor, social worker, everybody was there! That

was a good meeting. She was crying. It was hard. Everybody was concerned.” Nadia felt overwhelmed by the support.

When Laila discussed the Individual Education Plan, she explained to Samira, “She says, ‘I cannot go by myself, because I have a language problem’.” Laila also said that, “I cannot find my way. Somebody should accompany me to go there.”

Leben talked about how the assigned teacher implements the procedures of the IEP, “...this person is following up every step for Zara. And when we go for the Individual Education they work out a plan, and this person tries to put through all what has been agreed upon, and ensure that it is put in place.”

### *Educator Responses*

The school professionals also stressed the importance of frequent communication with the families. One of the resource teachers described how sharing information was so important with a new Canadian family who had a son starting kindergarten, “They were direct. The first meeting that we had in kindergarten, Mom was very direct about some of the challenges that she had with her child prior to school, and some of the delays that she had noticed, and that’s not always forthcoming.” The resource teacher also talked about how this family made the effort to collaborate, “Everybody pitched in. Dad came to the meetings. Mom came to the meetings. Everybody pitched in.” She also commented that they spoke English, “Dad’s English was better than mom’s, but we were able to communicate, and they were very clear about what their concerns were. I think there was a mutual understanding.”

One of the administrators discussed how some of the families “remain on the fringe.” A family’s choosing not to participate may reflect the family’s discomfort, or lack of understanding of the special education system. They also emphasized the need to make sure that families understand written information. One resource teacher commented on how difficult it must be for newcomers to understand “what school is like”, and, “Will the parents read it and reply? We can’t assume these things.”

Many professionals talked about the significance of providing information to new Canadian families. One teacher mentioned that teachers need to inform families about, “...the meaning of what an IEP is.” Another teacher discussed how some of the families do not have interpreters at the parent-teacher meetings. She felt that it might be because it stigmatizes the family and questions their competence, and also because of confidentiality. Instead, the families tend to rely on siblings of their child to interpret. Another teacher said that “...we send home letters saying that there are interpreters available, but there is no response out of the whole school.” This could mean that the families cannot read the letters, so it is important to make sure that they understand. She continued by saying that many of the families bring siblings to translate.

### *Theme Two – Cultural Reciprocity*

The data indicated that successful partnerships between new Canadian families and school professionals require cultural reciprocity. Cultural reciprocity refers to learning about and respecting each family’s culture, as well as making the effort to understand each family’s reality (Kalyanpur & Harry, 1999, p. 87). It

is important that professionals realize that each family-professional partnership represents the unique qualities of those involved (Kasahara & Turnbull, 2005).

Kalyanpur and Harry (1999) suggested that educators adopt a “posture of cultural reciprocity” in which educators engage in discussions with families regarding cultural values and practices, acknowledging differences, and developing a reflective practice that will lead to effective parent-professional partnership. Families should be included in decisions affecting their children because they provide valuable information on the nature of their child’s disability. One of the most important steps in developing a “posture of cultural reciprocity” is building an atmosphere of trust and respect.

To establish cultural reciprocity, the data revealed six sub themes, or recommended practices. They include a) regarding each situation as unique, b) enabling members to learn from each other, c) regarding each other with respect, d) acknowledging both commonalities and differences, e) reinforcing the commitment of school professionals to work well with families, and f) recognizing that it takes time to build trust.

#### *Family Member Responses*

Dalia and Rafael appreciated the effort made by the resource teacher to send a school psychologist who spoke Spanish. Rafael explained, “...Which makes a big difference. So the Manitoba government sent a psychologist who was in Nicaragua for a long time, and he spoke Spanish.”

However, Rafael felt that the school did not take into consideration their cultural background when it came to understanding their son, Aaron. Rafael

commented, "With Aaron, how can I say? There was a lack of cooperation for a different kind of cultural ideas. They didn't see the background." Rafael suggested that when new immigrants come to Canada, the school should, "...learn a little bit about the cultural background of each kind of immigrant which came here, to try to change the system in order to try to adapt a little wealth from the background."

Ria discussed how difficult it was as Marcus got older, "He had a terrible time last year because they say because of the change in his hormones. They changed the medication because he was so aggressive with the teachers...He start hitting me and my husband. And at home he was so upset. Probably he was also frustrated that we cannot understand what he wants." It was recommended that Marcus move out of the family home into a supported living environment. Ria was very concerned by this suggestion because, she explained, in El Salvador, "If you have a child like that, everybody says, 'Well, she's crazy, maybe.' She can't go to school, she can't go around. She has to stay in an institution, or at home. It's really bad." Ria reacted negatively, "No, no, no. I don't want him to go to a hospital or something. They are going to put more drugs. You always think it's going to be bad for them, you know."

Ria also mentioned that she felt reluctant to express herself at school. "Even at school, I don't know how to explain. I don't know how to talk. Probably, they're going to think, 'Oh well, she's from another country.' You know sometimes you feel like that."

Trust is a major component of cultural reciprocity, and it has many interpretations. Family participants referred to “trust” in the context of two distinct contexts. Firstly, trust meant making sure that their child is safe, treated with courtesy, and protected from bullying. Both Laila and Leben are so grateful to their children’s schools for welcoming them so unconditionally. Laila had discussed the treatment Rushid had encountered at school in Iran. “She says the other kids treat him so badly. His Mom has to take his hand and take him to school, and at the end of the day she has to go and bring him home.” Samira continued by translating what Laila expressed, “She says that Rushid in the morning is so happy because he wants to go to school because his teachers are so nice. And he loves to go to school, even on Saturday and Sunday his mother says he even wants to go to school.”

Leben relayed a similar scenario with his daughter, Zara, “She gets up early in the morning, and is excited about going to school...Everybody says, ‘Hi Zara’, ‘Zara!’ Well, she’s a very peaceful person. You know, she is liked by everybody.”

Rafael talked about Elana, “...the most important issue, the most important thing that I like *here* is the structure which surrounds her. Everything, we surround and protect her, like in a bubble.” He continued, “She feels safe, and happy. Very, very happy, and very, very comfortable with her environment. My biggest concern was to try and avoid any kind of isolation for her, or lack of relationships with the environment around her.”

Ria was very concerned about Marcus living away from the family home. Now that she trusts Marcus' homecare worker, she alleged, "And I'm comfortable with him. Because even in these places, something can happen. He doesn't talk, he doesn't know. Somebody can abuse him, or something like that. You're always scared."

Secondly, trust meant dependability, someone that can be relied upon. Aleksi discussed how his role as a settlement counselor with Nadia and Rayna has helped them to acculturate. Aleksi described his position, "I try not to be in their life anymore, but they know that they can always call and ask for help. And they would call me. They trust me. I trust them. And I know that."

### *Educator Responses*

Many of the responses from the family members were reinforced by the school professionals. When discussing families who have immigrated to Winnipeg, one of the educational assistants discussed the importance of, "...being sensitive to where they came from. I didn't know the big picture." She continued by saying, "I try to be very sensitive and I try not to push Canadian attitudes. We're from different places. As hard as it is to learn the ABC's, they're trying to learn a new language, and a new culture, a different way of life."

Regarding each family situation as unique was a practice that the school professionals understood. One teacher talked about a family who had recently emigrated from India, and the son had been assessed. The father told the teacher that, "In India, he got all 90s." This created a lot of tension both in the family, and at the school. Another teacher discussed a family from Poland,



whose daughter was assessed at four years below grade level. The parents sent their daughter back to Poland for twelve weeks in order, “to catch up.”

The physical education teacher in one of the focus groups mentioned a little boy from Jamaica who had Down syndrome. The parents felt that there was a “stigma attached to Special Olympics.” Eventually the parent agreed to let him participate, and the physical education teacher said, “Once he got in, he excelled.”

Another teacher discussed how difficult it has been to access resources for her own son who has a disability. She empathized with new Canadian families who were in the same position, “I really, really feel for these families now, because now I know. I can comprehend things pretty good and working in the field you’d think it would be easy. It’s ten times harder for these families who have English as a second language.”

The issue of trust was considered to be very important in terms of cultural reciprocity. One of the resource teachers talked about a family whose son had “very specific needs in terms of learning, academics, and cognitive needs.” She described their early meetings, “When I think back in terms of the early experiences when we met the family in kindergarten, trust becomes a really key issue. And once you’ve been able to earn their trust, then they kind of put you in their hands, and the family was fabulous! They did anything and everything that we would ask for them, and of them.” The resource teacher appreciated the effort of the parents to share information, “The first meeting that we had, Mom was very direct about some of the challenges that she’s had with her child prior

to school, and some of the delays that she had noticed. And that's not always forthcoming."

### *Theme Three – Professional Knowledge and Practice*

A third theme that emerged as an essential component of partnerships was professional knowledge and practice. From the responses of both the families and school professionals, it was revealed that families rely upon educators to have the knowledge and skills necessary to individualize instruction to meet their child's needs, and to provide the appropriate supports and services (Summers et al., 2005).

The five sub-themes or recommended practices which serve to define professional knowledge and practice include a) acquiring the skills to help each child succeed, b) demonstrating active support from the school principal, c) facilitating the transition planning process, d) maintaining high expectations for every child, and e) collaborating with other professionals to address each child's needs.

### *Family Member Responses*

Examples of positive and negative partnerships included comments about professional knowledge and practice. Ensuring that families and school staff could communicate in the language with which the family members were most comfortable was considered extremely important. Dalia and Rafael praised the system for accommodating the family by assigning a psychologist who spoke Spanish.

Home visits were greatly appreciated by Laila as an important way for the school professionals to get to know the family. Laila explained to Samira how, "The first month, Mindy (the teaching assistant) came and parked her car here, and then she and Rushid took the school bus together. For one month, or so."

The principal's role was regarded as a positive one by all of the families. The principal took the time to get to know the families and communicated on a regular basis. Laila commented that both Mindy (the teaching assistant) and the principal came to her home to fill out the information forms. Ria talked about how the principal at Marcus' school took the time to get to know Marcus outside of school hours. "He (the principal) watches Marcus at the Special Olympics."

The principal established a tone for the school that was positive and friendly. Leben's comments about the principal reflected his gratitude, "Well, the principal is our friend! He's also Zara's friend." Rafael approached the principal about Aaron, "I said to the principal the very first day, 'Be careful of Aaron. He's a very good actor.' So now each time Aaron comes to speak to him, the principal says, 'Okay, yeah, yeah. He will be a really good lawyer'."

The school professionals collaborated with other professionals to address each child's learning needs, and maintained high expectations for every child. The family members admired school professionals who provided concrete instructions for their child. Leben talked about how Zara is learning to communicate by using sign language. "I feel that the school is trying all the options to help her out. They have tried to teach her some sign language like

'more'." (Leben signed). He is also learning sign language so that he can communicate with Zara at home.

Ria also appreciated how the school explored options to help Marcus communicate, "But I notice that since he got the new communication board, he's more capable. His frustration is better because he knows how to express in the machine. He can say the things he wants, or he can point."

Many of the families had major concerns about the area of transition planning for their children. The transition planning process requires collaboration between students, families, school professionals, and government and community service providers. Cultural differences can have a considerable impact on decision making, so it is important to take the time to try to understand each family's perspective concerning the transition process (Luft, 2005; Steere, Rose & Cavauiolo, 2007). The families realize that there are more opportunities for education and training, financial support, and employment in Canada, compared to the countries that they have come from. Blue-Banning, Turnbull and Pereira (2002) conducted a study to address the perspectives of Hispanic parents of young adults with disabilities, concerning their hopes and expectations for their child's future. The families envisioned the acceptance of their child by family members, professionals and the community. Future living, employment and recreational activities were also emphasized.

The Manitoba government has recently updated their transition document, *Bridging to adulthood: A protocol for transitioning students with exceptional needs from school to community* (March, 2008). The goal of this document is to

help partners better support students with disabilities who require supports from the provincial government, its agencies, or Regional Health Authority, after leaving high school. The transition planning process facilitates the connection with supports in the community.

Nadia was unable to complete Grade twelve because she was dealing with so many different circumstances: emigrating, learning a new language, housing, starting a new school, as well as going to doctors and trying to manage her diabetes, and supporting her mother with her own health issues. Nadia explained, "I go to Kirkland High School. But because of my health I had many absences, and so they tell me, 'Either I can stay in school, but you know, I have to go regularly and everything, and I couldn't keep to that...so...' Aleksi continued, "So they called me from the school one day and they told me that she missed lots of classes, and they're not sure if she can continue. She need to go again...in Grade twelve."

Aleksi talked about the importance of completing high school, and then planning for postsecondary education, "I tell her, your plan in Canada is going to be nurse. Because you have diabetes, you have good experience with these things. Maybe next year you'll go again in school. We will see. Or there is adult high school." Nadia was in agreement, "Well, I would like to go to school to finish Grade 12 now. I'll think about it, whatever, to go to university. At school they ask, 'Do you want to go in nursing?' But right here, I'm choosing between day-care, kind of because I love kids, or nursing. So I don't know. Whichever one is easier!" Aleksi told Nadia that the next step is to "do some volunteer work

with Diabetes Association.” He felt that this would improve her chances of being accepted at a postsecondary institution. In Bosnia, Aleksa said that the only support would have been family support, “Maybe family – but they didn’t have a family there. No support. Alone. No future. No education.”

Rafael talked about Elana’s transition into the community, “My first concern would be the future. And you know, here the Canadian government, and the provincial government take care of these kinds of things – And they have a tremendous web, a network, to provide some kind of coverage for these kind of things. In Argentina we have nothing. Nothing.” Rafael referred to the IEP meeting, and planning for Elana’s transition, “So, I know next year I know what I have to ask. I will send an e-mail to Morah, ‘Okay, so we will have a meeting’ and together we are there for her.”

Laila discussed how even the experience of going to school was a challenge for Rushid, “She says the other kids treat him so badly. His mom has to take his hand and take him to school and at the end of the day she has to go and bring him home.” Everything has changed since Rushid started school in Winnipeg. He is able to identify his interests and talks about life after high school. Samira interpreted what Rushid said about what he likes about school, “Football, soccer. Here he wants to buy computer. He wants to buy a cell phone. He wants to go to work.”

Ria talked about Marcus’ work experience at school, “He start this year. They say that they take him to a place where they do recycling. He stays for a half an hour, and then for an hour. He’s doing okay.” She said that Marcus will

continue at his high school until the age of twenty-one. Ria feels relieved that Marcus has successfully made the transition from his family home into a supported living environment.

### *Educator Responses*

Professional responses focused on determining whether students have disabilities, and providing an appropriate education. One of the special needs resource teachers discussed one student's difficulties, "There isn't a clear diagnosis for this student's special needs. The first year, no language, or Spanish, but even the Spanish-speaking kids were having difficulty understanding her." The vice principal described this student's behavior as, "withdrawn, refused to speak with kids in class. Would hide. Screamed and yelled all the time. Two years later – can't shut her up!" The vice principal continued, "...involved with athletics, the musical, art, writes poetry..." When I asked what they felt the change was attributed to, the vice principal answered, "Teachers, the staff." The special needs resource teacher talked about acquiring the skills to help this student succeed, and adapting approaches to meet her individual needs, "I attribute it to a "gentle" teaching approach. ...I truly think that in this case, for that child, that's what we needed to do. It's that acceptance."

Responses by both teachers and administrator mentioned the difficulty in obtaining cumulative education files from the students' home countries. One teacher commented, "So we've found that kids who have come from different countries, 'What are the standards, and how are they evaluated'?"

The school professionals commented on how they perceive their role, as well as collaborating with other professionals to address each child's needs. The English as an Additional Language (EAL) teacher discussed how her... "role, first of all is to make the child comfortable." Her professional role is to... "teach the child language." One of the educational assistants outlined her role, "I myself work with the teacher, the resource teacher and the other T.A. I get my instructions from the teacher and the S.E.R.T. It's wonderful when the parents are involved, too."

#### *Theme Four – Advocacy*

The participation of new Canadian families with children with disabilities is affected by the availability of support networks. The five families in this study relied on supports which included settlement agencies, disability support groups, ethno-cultural programs, community organizations and school professionals. The support received from these networks helped the families with coping strategies and seeking information about their children's disabilities. Talking about their challenges, and recognizing issues they all shared as families of children with disabilities, empowered the families to be better equipped to advocate for their children.

Six sub-themes, or recommended practices, that emerged from the data were a) working together "as a team", b) providing support and reassurance, c) providing information, d) connecting to sources of support, e) empowering families, and f) providing knowledge of the school system.

#### *Family Member Responses*



The five families that were interviewed for my research study came from countries that did not provide comparable services available through the Canadian education system. Therefore, they did not realize what services were available, or if they had the license to access these services. Without assistance, it was also very difficult to navigate the services that are available.

When Leben arrived in Winnipeg he and his wife took Zara to the hospital, where they were directed to a disability support agency. Zara was provided with speech and language services, physiotherapy, and occupational therapy. Leben said, "I would say from the time we came we were able to connect up with services." Leben's circumstances may not be typical. He was able to speak English, and he knew how to advocate for his daughter, Zara.

As a settlement counselor with new refugees, or asylum seekers, in Winnipeg, Aleksi advocated for Nadia and Rayna. He contacted the hospital before they arrived, and provided interpretation with the doctors. Aleksi also participated as an interpreter at the IEP meetings at Nadia's school. Nadia and Rayna were overwhelmed at the number of school professionals who were involved. Aleksi translated for Nadia, "Wow! So many people take care of us!"

Rafael and Dalia have always advocated for Elana. Dalia acknowledged how everyone worked together as a team, "When we came here, we talking to the school about our daughter's problems. I think it was a great job between the doctor, the school, and the government. I tried to make this same working group in Argentina, but was impossible." Rafael explained that they were concerned for the welfare of all of their children, "We're trying with all of our children. There

is a lot of effort, time, money. That is the reason we emigrate. We are trying to find something better for our children.” Rafael and Dalia felt the weight of their decision when considering Elana’s challenges, “We made a very important choice in her (Elana’s) case – a very important choice. It was like to go to the casino, and put a lot of money on only one spot. It was tremendous!”

Limited English language proficiency has influenced the amount of involvement Laila has had with Rushid’s teachers. An interpreter from an ethno-cultural program has facilitated the process by providing translation services in Dari. Both the educational assistant and the principal assisted Laila by making home visits to discuss Rushid’s educational program.

When Ria and her husband were told by the doctor that Marcus had autism, they had no knowledge of what that meant. Ria described the circumstances, “The doctor told me that. And then we start looking around. Getting information from the library. And then we went to these information evenings that they have at the hospital.” Ria continued, “These help us a lot. So many times they teach us and they give us the ideas how to deal with Marcus. A parent support group. It’s a good thing. It’s a very good thing.”

Ria also discussed getting to know a woman in Winnipeg who had a daughter with Down syndrome. She explained, “...how this woman, when you have these kids you are so scared, that even to ask about things. And she said, ‘You have to ask, and you have to let him go and be independent, because you never know when he’s going to be away from you’.”

There were a couple of instances in the family interviews where the parents encountered issues that required collaborative problem solving. When the school suggested that Marcus may require an increase in his medication because of his behavior, Ria explained to his teacher the reasons he may be acting this way, "In the morning they noticed that until about 11:00 he's fine. But sometimes, two or three hours that he's upset, or that he doesn't want to go out with them, and he starts kicking the walls. And I said, 'Probably something is bothering him.'...They said that we have to talk to the psychiatrist, and I said to them, 'I know that I'm not a doctor, but I'm his mother.' I noticed that when he's upset, it's *something*." Ria suggested strategies as to how to manage his behavior at school.

#### *Educator Responses*

The school professionals recognized that supporting and advocating for families involved more than providing information or making referrals. They realized that it is a matter of developing trust. Turnbull et al. (2006) have referred to social support as a source of comfort found within relationships and emotional support as care, encouragement, and understanding. When the administrators were asked what type of support they provided, one of the resource teachers replied, "Probably everything from A-Z...Certainly, academic support, social support emotional support." You know, very similar...the emotional support, social support, organizational support, keeping with the integration into the schools. You know, it's hard, when parents don't have the connection.

The principal also discussed economic family support, "The one I haven't heard yet is financial support. There's the financial support for the families in order to come to the school...We subsidize who comes to the programs, via retreats, via to go to this field trip...No kid is ever excluded because they can't pay. There are very few newcomers that can afford to come here and pay the full shot."

In one focus group one of the educators discussed a situation in which the family was unaware of resource support for their seven-year-old daughter who had a severe disability. "I mentioned to them, 'How much respite hours are you getting...?' and the mother looked at me and said, 'Sorry, could you say that again?' English was a second language. She didn't even know that there were respite hours available for her. I think because of the language barrier, being newer to Canada and maybe not associating with people who had disabilities, they were 'out of the loop', for lack of a better term. But I thought it would be really neat to see the school play the part of a liaison between us and family service, or us and the social worker, because that was really what she needed so that they could get support."

### Conclusion

A variety of data was gathered for this research project. Although much has been written on the subject of home-school partnerships little has been written about how families and educators actualize this process. The purpose of this study then, was to provide a representation of the perspectives and experiences of new Canadian families of children with disabilities, as well as

educators involved in home-school partnerships. Four themes emerged from the data, organized first by category, and then by comparison of family and educator responses.

In the next chapter I attempt to analyze the overarching themes that have emerged from the data. Implications for further research and practices in the field of special education and home-school partnerships will be presented. Additionally, the final chapter addresses the limitations of the study.

## CHAPTER VI

## ANALYSIS AND DISCUSSION

The purpose of this study was to determine the recommended practices of school professionals associated with collaborative partnerships from the perspective of new Canadian families of children with disabilities and educators. The results included a synthesis of data from interviews with five new Canadian families, and three focus groups with teachers, educational assistants, and administrators. The four themes, a) communication; b) cultural reciprocity; c) professional knowledge and practice; and, d) advocacy, and corresponding recommended practices, were based on the responses from both family members and educator participants.

In this chapter, I interpret the four themes that emerged from the data in relation to the literature and research. I analyze the theoretical framework from which to view home-school partnerships. I also provide a rationale for the use of cultural capital to advance research and practice, necessary in the facilitation of collaborative partnerships. Lastly, I provide implications for current practice, study limitations, suggestions for future research, and significance of the study.

*Communication*

My findings are compatible with other studies that emphasize the importance of communication for effective family-professional partnerships (Blue-Banning, et al., 2004; Friend & Cook, 2007; Kalyanpur & Harry, 1999; Lynch & Hanson, 2002; and Turnbull, et al., 2006). Blue-Banning et al., (2004)

characterize family-professional communication as including seven components: being positive, being open, listening, communicating clearly, displaying honesty, providing resources and coordinating information. Lynch and Hanson (2002) stress the importance of both verbal and non-verbal communication, critical to cross-cultural competence.

In communication between home and school, it is important to listen to both perspectives. A culturally competent teacher tries to understand parents' perspectives and helps them feel comfortable enough to share their concerns, hopes, and goals for their children. For example, Dalia felt that the school did not adequately communicate their concerns about her son, Aaron. Dalia was aware that her son had behavior issues, but she felt that the school should have considered their circumstances, they had recently immigrated to Canada from Argentina, Aaron was learning a new language, as well as learning to adjust to a new school. Listening to both perspectives would have made the communication much more successful.

Communicating frequently, and establishing and encouraging open, two-way communication between the school and families is also important. Rafael discussed how the resource teacher communicated through e-mail. He also responded through the internet, explaining any concerns he had, or what Elana's doctor had said. Finding out the best ways of communicating from school to home and vice-versa can be made through informal conversation. Factors such as parents' literacy in English, and their preferred mode of communication (e.g., personal contact, via the student, written notes) influence the success of

teachers' attempts to communicate. For example, Laila told the interpreter Samira, that Rushid's teaching assistant communicates with Laila by sending a notebook home describing Rushid's activities during the day.

In this study, both the family member and school professional participants discussed how language barriers interfere with collaboration (Cantor, 2003; Pena, 2000; & Turnbull & Turnbull, 2001). This affects both parents and educators, and has a significant effect on communication. The vast majority of new Canadian families are very interested in learning English. Rafael expressed regret that he and his family did not have better English language proficiency. Leben discussed how he had an advantage by speaking English when he arrived in Canada. For example, Laila was very reluctant to attend Rushid's IEP at the school because she has "a language problem." She also would feel more secure if someone could accompany her.

Knowledge of issues related to the use of translators and interpreters is important for school professionals. Communicating with linguistically diverse families often requires individuals who are fluent in the family's primary language to explain or clarify information related to programs and services (Ohtake, Santos & Fowler, 2000). By ensuring that an interpreter was present for the interview with Laila and her family, as well as Rayna and Nadia, the family members appeared very comfortable.

Educational assistants, or paraprofessionals often can be valuable sources of information about students' and families' culture-based ways of



communicating, as they work very closely with the student. Laila discussed what a wonderful relationship Rushid had with the teacher assistant.

### *Cultural Reciprocity*

As Kalyanpur and Harry (2004) point out, “developing culturally reciprocal relationships with family involves an understanding of each family’s uniqueness and the recognition that the relationship is an outcome of the interactions of all the variables of cultural identity of both the family and the professional” (p. 532). The cultural beliefs and practices of families, as well as the decisions they make must be valued to the same extent as those of the school professionals (Kalyanpur & Harry, 1999).

When a teacher and family share the same culture, the interaction is quite straight forward. This dynamic the ZPD, or “zone of proximal development”, as Vygotsky theorized, is a very powerful tool because it allows the student and family the tools for thinking and problem solving that are appropriate to their culture. When the teacher and family bring different cultural frames of reference and communication style to the interaction there can be a disconnect between the teacher’s and family’s way of understanding as a result. Cultural differences then must be bridged in order to activate the ZPD.

Reciprocity seeks to balance power between persons in dialogue (Barrera & Corso, 2002). It is the recognition that each person in an interaction has equal status. Reciprocity does not require denying that one person has expertise or knowledge in a particular area. Reciprocity requires acknowledging that the

experiences and perception of every person in an interaction are of equal value (Barrera & Corso, 2002).

The family systems model by Turnbull, Turnbull, Erwin and Soodak (2006) describes how events in life affect the family system. The family participants all experienced leaving their home country and immigrating to Canada. Three of the families, Laila's, Leben's, and Rayna's came as convention refugees. Ria and her family escaped war in El Salvador and immigrated as a protected person. Rafael and Dahlia and their children came to Winnipeg from Argentina with the Manitoba Provincial Nominee Program. Rafael talked about his experience, "The process of immigrants is not easy. We have to cross a lot of barriers – the medical barriers, getting acquainted with a new environment. It's very hard." He continued by comparing Winnipeg and Argentina. Becoming familiar with a new country, a new language, a new school was difficult for each of the families.

One of the most important steps in developing collaborative relationships is building an atmosphere of trust and respect. As educators come to respect the beliefs and values of the family, they become able to communicate their efforts in areas that can help facilitate the family-professional partnership (Harry, Kalyanpur & Day, 1999). Both Laila and Leben are grateful to their children's schools for welcoming them. Rafael talked about how Elana feels safe and comfortable at school. Trust was also an issue for the educators: One teacher said that, "Once you've been able to earn their trust, then they kind of put you in their hands."

*Professional Knowledge and Practice*

The third theme that emerged in this study was concerned with professional knowledge and practice. Being a skilled professional was one of the categories in the study by Blue-Banning et al. (2004). The authors described the indicators as taking action, having expectations for child's programs, meeting individual special needs, considering the whole child or family, and being willing to learn.

The school principal plays a vital role in promoting home-school partnerships. It is important that the principal demonstrates support for home-school collaboration through policy, staff decisions, and behaviors (Waterman & Harry, 2008). By the principal attending meetings with the parents in order to hear and respond to parent questions and concerns, was important to all of the families. Laila appreciated that the principal and the teaching assistant made home visits to help her fill out school forms. Ria talked about how the principal at Marcus' school made the effort to watch Marcus at the Special Olympics.

Collaborating with other professionals and maintaining high expectations for every child, was also considered extremely important. Leben appreciates the supports that the school has provided for Zara, such as speech and language therapy and teaching her sign language. Ria discussed how the school has explored options to help Marcus communicate.

Elements of transition planning, such as moving into an independent residence, or pursuing employment options were concerns that many of the new Canadian families had for their children with disabilities. However, it is important that educators realize that not all families share identical values. The complexity

with which cultural beliefs and values affect life transitions is significant. The ultimate goal of transition planning is for students to experience personal fulfillment as adults living in the community. Rafael discussed his concerns for Elana's transition from school to adult community life. He was very appreciative of the Manitoba government that there is a process in place, as he lamented that Argentina does not have a transition plan for youth with disabilities. Ria also talked about Marcus' transition from his family home into a supported living environment, and that he will continue going to high school until he is twenty-one years old.

One aspect of the family systems model is a family's culture. As Luft (2005) described, cultural differences have a substantial impact on decision making, so educators must take the time to understand each family's perceptions of the education process. The family systems model helps educators to understand that major life events, including the transition from school to adult community life, a major concern for the families that were interviewed, affects the entire family.

### *Advocacy*

Interviews with families and educators revealed important elements of advocacy and access to information (i.e., cultural capital), as well as relationships and connections between people (i.e., social capital). Wolfensberger (1977) described advocacy as the act of speaking and acting on behalf of another person or groups of people to help address preferences, strengths, and needs.

The families relied on supports from settlement agencies, disability support groups, ethno-cultural organizations, and educators. For example, Ria and her husband relied on a parent support group to help them understand what “autism” meant, after they were told of Marcus’ diagnosis. Ria also reported that gaining access to information on autism influenced her choice for Marcus’ current education program, as well as ideas about her son’s transition to adulthood. As a settlement counselor with new refugees in Winnipeg, Aleksi advocated for Nadia and Rayna when they came from Bosnia. He arranged for a medical assessment, as well as being present for IEP meetings at Nadia’s school.

Some of the families incorporated knowledge and information about disability categories as they advocated for their child. Before Rafael and Dalia emigrated from Argentina, Rafael researched medication for epilepsy in Canada so that Elana could start a regimen before coming to Winnipeg. In another instance, Ria advocated against the use of medication which had been strongly suggested by the school.

Language barriers also affect families’ participation and advocacy (Cantor, 2003; Pena, 2000; Turnbull & Turnbull, 2001). Parents who are dominant in languages other than English need access to information about assessment, educational programming and special education documents, as well as interpreters during meetings. For example, Laila had limited contact with Rushid’s teachers because of limited English language proficiency. The educational assistant and principal supported Laila by making home visits.

Leben realized that the IEP is an important document that functioned as a record of what should be happening at school. Zara was provided with speech and language services, physiotherapy, and occupational therapy. Leben had access to cultural capital (i.e., English language proficiency) as well as social capital (i.e., service providers), and was able to advocate for Zara using approaches that resulted in success.

Educators also advocated on behalf of student with disabilities. However, school personnel must respond to both the needs of the organization they represent (e.g., to provide cost-effective services), and the needs of individuals. Conflicts of interest may arise, assigning the responsibility of advocacy to the parents (Trainor, 2008).

It is important that school professionals realize that many new Canadian families with children with disabilities are unaware of what services are available in Manitoba schools. As one educator who advocated for a new Canadian family said, "I think because of the language barriers, being newer to Canada, and maybe not associating with people who had disabilities, they were 'out of the loop' for lack of a better term. But I thought it would be really neat to see the school play the part of a liaison between us and family services, or us and the social worker, because that was really what she needed so that they could get support." As Harry (1992) maintained, without assistance, or cultural capital, they are unable to navigate the special education system.

## Home-School Partnerships through a Cultural Capital Lens

Cultural capital is not really part of the special education vernacular (Trainor, 2008). Although research, Manitoba legislation, and practice in special education acknowledge the importance of information and knowledge that are established through communication with newcomers of children with disabilities, more attention needs to be dedicated to cultural and social capital. Educators need to recognize their role in facilitating the access to cultural capital for new Canadian families of children with disabilities. For teachers to acknowledge their own resources of capital and to share this with the families requires teachers to be culturally responsive including communicating and collaborating with families (Trainor, 2008).

The family participants all had particular “cultural capital” that they could contribute to their children’s education. All the parents in this study, regardless of country of origin and time in Canada, the type of disability the child has, or the length of time their child has attended school, are involved in their children’s learning and want their children to do well in school. However, access to support and information varied in each country of origin. For example, Dalia said that she tried to gain support from Elana’s school in Argentina, but to no avail. Laila discussed how she had to accompany Rushid to and from school in Pakistan, for his own safety. None of the families that were interviewed doubted whether their children required special education services, however, two families questioned the approaches to solving difficulties in school. Ria was against the use of additional medication for Marcus, while Dalia and Rafael disputed the opinion

that Aaron's behavior was a result of a behavior disorder, rather than problems related to his experiences.

Many new Canadian families of children with disabilities do not have the cultural capital (i.e., information and knowledge) to be involved in home-school partnerships in Canada (Waterman & Harry, 2008). They are often not aware of the meaning and impact of special education placement, what resources are available, and how to access these resources (Waterman & Harry, 2008). Success and efficacy in home-school partnerships for newcomer families of children with disabilities benefit from a combination of cultural capital (i.e., knowledge of IEP process) and social capital in the form of relationships between key players (e.g., teachers and disability support providers, other parents with children with disabilities) (Trainor, 2008).

According to Kalyanpur and Harry (1999, 2004) school professionals have the responsibility to share with families the "cultural capital" or the knowledge that will help them to negotiate their way through the special education system. Helping teachers understand that access to capital resources (both cultural and social), plays an important role in home-school collaboration. School professionals must share the practices and expectations of the school with families, so that the families can make decisions that are based on a common set of knowledge (Kalyanpur & Harry, 1999). However, this information must be presented to parents in a way that is understandable and within the context of respectful, culturally responsive relationships (Waterman & Harry, 2008). Written



communication needs to be translated and in a manner that is familiar to the families.

How do families come to successfully challenge the structures that have prevented equal opportunities for their children with disabilities? (Trainor, 2008). All forms of capital mediate the acquisition and use of power (Bourdieu, 1986). In order for families and educators to collaborate, both cultural and social capital are necessary. For example, during Elana's IEP meeting, Rafael discussed the need to plan for her transition. The information and knowledge about the transition process as well as parents' rights would be considered cultural capital. However, the communication skills necessary to participate in this process also requires social capital (e.g., extended family, other parents with children with disabilities, teachers, disability services providers, and administrators).

Bourdieu's (1977) theory that class distinctions include differences in the acquisition and use of both cultural and social capital and that these are connected to access to human capital is clear in this study. Laila, who had recently arrived in Winnipeg as a refugee from Afghanistan, had limited access to cultural capital in the form of information and knowledge about special education, as well as the self-confidence to acquire information. Leben, however, who had arrived in Winnipeg as a refugee from Sudan, was able to communicate in English and accessed multiple sources of capital.

The cultural beliefs and practices of families, as well as their decisions and actions must be recognized and valued in the same manner as those of the school (Kalyanpur & Harry, 1999). Acquiring both cultural and social capital

empowers families to become effective partners in the educational decision-making process.

### Implications for Current Practice

The results of this study indicate that improving partnerships with new Canadian families with children with disabilities can occur through clearly defined strategies. A description of each of these strategies follows:

Schools could use the recommended practices to provide professional development opportunities for establishing high-quality relationships with families.

A series of dialogues between families and educators using the recommended practices might result in increased understanding. Discussion between families and educators in each school setting is important because it provides an opportunity for clarification of the meaning of such terms as “cultural reciprocity,” “respect,” and “advocacy” in the context of each community (Blue-Banning, et al., 2004). It is also important that educators hear directly from families their impressions about how various actions or inactions have impacted their family. Alternatively, families need to hear from teachers and other school personnel about how and why certain decisions were made.

Good communication is at the core of effective working partnerships between families and educators. If the school regards families as resources, then communication will be reciprocal, initiated by both teachers and family members. Improving interpersonal communications skills and attitudes of both

novice and experienced educators is critical to the collaboration process (Friend & Cook, 2007; Lynch & Hanson, 2002; Turnbull & Turnbull, 2001).

Educators need to learn as much as possible from families about their cultural experiences, values, and beliefs. By becoming a “cultural researcher” (Thorp, 1997) through reading, interaction and involvement it is possible to increase cross-cultural awareness. Learning about the historical and political situation of the country, and circumstances of the family’s immigration, are very important to increasing the understanding of the family’s situation.

As educators come to respect the beliefs and values of the family, they are able to communicate their efforts in areas that can facilitate the collaborative relationship (Harry, Kalyanpur & Day, 1999). Kalyanpur and Harry (1999) suggested that educators adopt a “posture of cultural reciprocity” in which educators engage in discussions with families regarding cultural values and practices, acknowledging differences and developing a reflective practice that will lead to effective family-professional partnerships.

Educators need to educate families about how the school system works and how they can have access to it in order to advocate for their children. For example, inclusive special education handbooks in the first language of the families, with a glossary of terms and clear descriptions of possible provisions and family participation in decision-making, might help overcome the problem of limited proficiency in English (Cantor, 2003).

A family representative provided through disability and ethno-cultural organizations, could act as a liaison between families and educators.

Collaborating as part of the special education navigation process, the family representative would ensure that family concerns are addressed in the family's first language.

Teacher education programs in special education need to assume the initiative in preparing educators to develop effective home-school partnerships. A course focusing on home-school partnerships would provide preservice teachers in special education with both the knowledge regarding best practices, and the skills to actively include the families in the educational process. Theories and research that support family-centered practice should be explored. For inclusive special educators already in the field, professional development opportunities should be designed to meet the needs of these teachers (Cantor, 2003). Issues related to diversity should also be embedded throughout all of the teacher education courses.

Educators need to take a leading role to empower new Canadian families to be active and informed participants in the transition planning process. Families and school personnel need to engage in explicit discussions regarding the transition planning process (Trainor, 2003). Engaging in more frequent communication would help family members, students, and educators feel more involved. Educators need to recognize that families and students are important contributors to the transition planning process. Bridging the resources of school personnel with the resources of families increases the prospect that students will have the opportunity to pursue a variety of postsecondary options.

### Study Limitations

There are limitations to the research study that should be acknowledged when interpreting the findings. The naturalistic research context presented me with particular challenges related to bias and research effects. The researcher's own biases and beliefs had to be constantly analyzed and verified against the data as they emerged. In attempting to understand the family's viewpoint, I had to be conscientious to maintain perspective as well as to establish a sense of rapport with the family.

The families represented a range of disability categories, cultures and ethnicities, and circumstances of immigration. However, a larger sample size would have allowed me more of an opportunity to explore the issue of how cultural capital contributed to the conclusions.

The value of a study of five families lies in the close-up and meticulous view of the participants' perspectives and the ability of such data to guide our practice. A second interview with each of the families would have given me the opportunity to build rapport with the families, and engage in extended exploration of their experiences and concerns. In retrospect, I realize that a second interview would have provided more details concerning the families' cultural interpretation of disability. A face-to-face member check with each of the families would have ensured that I had interpreted their concerns and information accurately.

Another concern was that this study was limited by having only one researcher to conduct the interviews and focus groups. A second researcher would have been beneficial in the focus groups to operate the audio tape

recorder, and to take accompanying notes including key discussion points, quotes, and group dynamics. It also would have been valuable to have had a second evaluator to read, code, and interpret the data.

Interpreters were required during the interviews with families who did not speak English, in order to provide interpretation to the family and to the researchers. The data analysis process did not include a review by the interpreter to ensure accuracy of the interpretation.

One of my concerns as a researcher was the extent to which the participants were a representative sample of the population to which the research was being generalized. The participants in this study came from only one city in Canada. Therefore, the results cannot be assumed to generalize to other populations. It may be that new Canadian families and school professionals from different cities or from rural centers may have had different perspectives specific to their location.

A further concern is that sampling bias may have occurred. The families in this study had voluntarily accessed the support and services of disability support groups or ethno-cultural groups. This could have influenced their perceptions of their roles and responsibilities. Other families might have reacted differently.

#### Implications for Future Research

The analysis of data provides an indication that the unique considerations of new Canadian families of children with disabilities should be the subject of further inquiry. While the question of the impact of cultural identity on partnership

with educators was fundamental to the inquiry, there are several implications for future research that emerged in the course of the study.

Home-school partnerships look differently in various schools and at different grade levels. Historically, research on parent involvement has focused on the elementary level. During preschool and elementary school years family involvement is supported. As students enter middle and high school, patterns of communication between the families and educators change for many reasons, such as accommodating multiple teachers and larger schools. Attitudes and expectations of school staff about acceptable forms of family involvement may also be affected as students transition to secondary schools. Research on home-school partnerships at the secondary level would be a next step in this study.

This research study has implications for future research on how new Canadian families differ from Canadian-born families of children with disabilities.

It is possible that the type of disability impacts the perceptions and behaviours of educators more significantly than did the families' immigration status. The effect of disability and circumstances of immigration, and the perceptions and behaviours of educators merits further study.

In my study there were family member participants who were concerned about the transition of their child into the adult community. These references suggest a need for a more focused study exploring home-school collaboration with new Canadian families during the transition planning process. Research must continue to provide a clearer understanding of the perspectives of new

Canadian families concerning the transition process, and their preferences for culturally responsive support.

Future research may look at whether geographic differences between new Canadian families of children with disabilities in urban or rural areas plays a role.

What are the implications for new Canadian families of children with disabilities who are excluded from opportunities to access cultural capital?

Future research should consider how cultural capital is an important component of a theoretical framework from which to help families to advocate on behalf of their child, and participate in the educational decision-making process (Kalyanpur & Harry, 2004).

### Significance

Perspectives of the family member and educated participants are useful in the exploration of partnerships and collaboration in the field of special education. While the perceptions of families in this small sample cannot be generalized to represent those of all new Canadian families of children with disabilities, they are instructive in that they describe what participants in this study were experiencing and thinking in regards to partnerships with educators. The comments from both the family members and educators can be used to provide support for existing research and support for expanding the directive of future inquiry. Results from this research study have important implication for practice and research, but must be interpreted cautiously, as there were limitations.

While some researchers suggest that the notion of cultural capital is not developed enough, I found cultural capital to be very useful in exploring



partnerships between educators and new Canadian families of children with disabilities. The struggle to define what counts as theory should not obscure the recognition about what theory is supposed to do, to “inform research” (Brubaker, 1993). Despite the focus on cultural capital, no real consensus has been reached among researchers regarding an operational definition. In my study, cultural capital provided a framework from which to address home-school partnerships.

This research supports current knowledge in the area of home-school partnerships (Blue-Banning et al., 2004; Harry, Kalyanpur & Day, 1999). It strengthens education in Manitoba because it highlights emerging dimensions of family-professional partnerships (i.e., the four themes) with new Canadian families in Manitoba. Knowing what recommended practices are crucial in determining the qualities of effective family-professional partnerships facilitate current and future practice. One of the most important outcomes of successful partnerships between new Canadian families of children with disabilities and educators is improved quality of life for the families and their children (Blue-Banning et al., 2004).

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## Appendix A: Family Conversation Guide

## Opening Questions

1. Who are the members of your family? Are there extended family members who provide you with support and assistance?
2. What were the circumstances that brought you to Winnipeg?

## Potential Probe

- Did you apply through the Manitoba Provincial Province Program?

## Transition Questions

3. What is the nature of \_\_\_\_\_'s disability? What have others told you about it? Do you agree?
4. What is a typical day like in your family?
5. So much of \_\_\_\_\_'s day is spent in school. What is your view of how things are going at school?

## Key Questions

6. Of all the teachers or school personnel who have worked with \_\_\_\_\_, who has had an especially good relationship with \_\_\_\_\_ and your family? Why do you think that situation was so successful?
7. Can you describe a situation that was very difficult when a teacher or other school professional was not particularly helpful to \_\_\_\_\_, and your family? What can we learn from that situation to make sure that it isn't repeated?
8. Based on our cultural background we all have certain values and beliefs that influence our families. How would you characterize your family's culture?

9. Is there anyone from your cultural or religious community that you would like to participate in educational conferences or school events?

10. After thinking about the issues we have talked about today, which one is of most importance to you?

#### Summarizing Questions

11. I will summarize the important issues that were discussed today.

#### Potential Probe.

- Is this an adequate summary?

12. Is there anything else that you would like to include related to the topics we have discussed?

## Appendix B: Focus Group Protocol

## Introductory Information: Purpose of the Session

Thank you for agreeing to be part of this focus group. The group discussion will last about one-and-a-half to two hours in length. What you say in this group will be kept confidential. Your participation is voluntary, and you may leave at any time during the discussion if you wish. There are no right or wrong answers to any of the questions I will ask you. I hope that you will talk freely about your experiences. I will be tape-recording the focus group discussion.

## Questions: Teacher Version

## Opening Questions

1. I'd like you to introduce yourselves. Could you please tell us your first name and how many years you have been a teacher?

## Transition Questions

2. What professional role do you provide at your school concerning students with disabilities?

## Key Questions

3. Would you describe a partnership with a family with a child with a disability from a diverse culture that you feel was positive?

## Potential Probe

- What made the relationship successful?
4. Would you describe a situation that was difficult?

## Potential Probe

- What actions did you take?

- What can we learn from that situation to make sure that it isn't repeated?
- 5. How can teachers ensure that families receive effective, understandable, and respectful consideration that is compatible with their beliefs, practices and preferred language?
- 6. What suggestions do you have which would ensure successful partnerships with families with children with disabilities from diverse cultures?

#### Potential Probes

- What education and training would you like to receive about culturally and linguistically appropriate service delivery?
- 7. After thinking about the issues we have talked about today, which one is of greatest concern to you?

#### Summarizing Questions

8. I will summarize the important issues that were discussed today.

#### Potential Probe

- Is this an adequate summary?
- 10. Is there anything else that you would like to include related to the topics we have discussed?

## Questions: Administrator Version

## Introductory Information: Purpose of the Session

The purpose of this research is to gather information on the perspectives of families and school professional about recommended practices associated with collaborative partnerships.

## Opening Question

1. I'd like you to introduce yourselves. Could you please tell us your first name and how many years you have been an administrator?

## Transition Question

2. What administrative support do you provide to the teachers and/or the families in your school?

## Key Questions

3. Would you describe a partnership with a family with a child with a disability from a diverse culture that you feel was positive?

## Potential Probe

- What made the relationship successful?
4. Would you describe a situation that was difficult?

## Potential Probes

- What actions did you take?
  - What can we learn from that situation to make sure that it isn't repeated?
5. How can administrators ensure that families receive effective, understandable, and respectful consideration that is compatible with their beliefs, practices, and preferred language?

6. What suggestions do you have which would ensure successful partnerships with families with children with disabilities from diverse cultures?

Potential Probe

- What education and training would you and the teachers in your school like to receive about culturally and linguistically appropriate services delivery?
7. After thinking about the issues we have talked about today, which one is of greatest concern to you?

Summarizing Questions

8. I will summarize the important issues that were discussed today.

Potential Probe

- Is this an adequate summary?
9. Is there anything else that you would like to include related to the topics we have discussed?

Appendix C: Letters of Recruitment

1. Disability Support Networks and Ethno-Cultural Groups

Research Project Title: Cultural Interpretations of Disability:

Perspectives on Family-Professional Partnerships

Dear \_\_\_\_\_:

I am a graduate student at the University of Manitoba, completing my dissertation for my Ph.D. in Inclusive Special Education. The purpose of this research study is:

- To examine the immigrant experience in negotiating the special education system in Canadian schools;
- To document the perspectives of new Canadian families of children with disabilities, as well as school professionals, regarding their perspectives on family-professional partnerships; and
- To make recommendations intended to promote and operationalize new directions for model to support more effective partnerships between families and school professionals.

In order to perform this research, I plan to conduct individual interviews with six to eight families who have children with disabilities, and who have immigrated to Canada within the last fifteen years. If the researcher does not speak the same language as the families, then an interpreter will be hired to assist with the interviews. The interviews will be held at mutually convenient times, for about one-and-a-half to two hours.

I will audio tape the interviews for later transcription. I will also take written notes during the interviews. All information will be kept fully confidential, and pseudonyms will be assigned to the family members, school professionals, schools, community agencies and individuals.

The involvement of the participants in this study is voluntary, and they may refuse to answer any questions, end any sessions, or withdraw from the study completely, at any time. In consideration for the families' involvement, each family member will be given a gift certificate for \$20.00 at a community store. Reimbursement for child care and transportation will also be provided for families if necessary.



After the research is complete, I will send a summary of the results of the study to each of the families who have participated.

I would appreciate if you could recommend families of children with disabilities who have immigrated to Canada within the last fifteen years and who you believe would be interested in participating in the study. Letters will be sent to the families and followed up with phone calls to explain the purpose of the study and request the families' agreement.

If you have any further questions regarding this research study, please contact me, Lynne Cantor, at 474-7946, or my advisor, Dr. Zana Lutfiyya, at 474-8299.

**This research has been approved by the Education/Nursing Research Ethics Board (REB). If you have any concerns of complaints about this project you may contact any of the above-named persons of the Human Ethics Secretariat at 474-7122 or e-mail [Margaret\\_Bowman@umanitoba.ca](mailto:Margaret_Bowman@umanitoba.ca). A copy of this consent form has been given to you to keep for your records and reference.**

Your cooperation and assistance in this study are greatly appreciated. Thank you for your time and support.

Sincerely,

Lynne Cantor

## 2. School Divisions and Professional Networks

Research Project Title: Cultural Interpretations of Disability: Perspectives on Family-Professional Partnerships

Dear \_\_\_\_\_:

I am a graduate student at the University of Manitoba, completing my dissertation for my Ph.D. in Inclusive Special Education. The purpose of this research study is:

- To examine the immigrant experience in negotiating the special education system in Canadian schools;
- To document the perspectives of new Canadian families of children with disabilities, as well as school professionals, regarding their perspectives on family-professional partnerships; and
- To make recommendations intended to promote and operationalize new directions for model to support more effective partnerships between families and school professionals.

Focus groups will serve as the primary data collection method for school professionals in order to encourage participants to share ideas and perceptions with one another related to positive partnerships. I plan to conduct three or four focus groups with school professionals. The school professionals invited to participate will include regular classroom teachers, resource teachers, special education teachers, educational assistants, special education coordinators, and administrators who provide direct service to new Canadian families with children with disabilities.

When structuring the focus groups for school professionals, classroom teachers, resource teachers, educational assistants, and special education teachers will be placed in separate groups from special education coordinators and administrators. If there is a power differential, some participants may be reluctant to express themselves (Krueger & Casey, 2000). The interviews will be held at mutually convenient times, for about one-and-a-half to two hours.

I will audio tape the interviews for later transcription. I will also take written notes during the interviews. All information will be kept fully confidential, and pseudonyms will be assigned to the family members, school professionals, schools, community agencies and individuals.

The involvement of the participants in this study is voluntary, and they may refuse to answer any questions, end any sessions, or withdraw from the study completely, at any time. School professionals will not be paid for their

participation. However, tea and a light snack will be provided to promote a relaxed atmosphere.

After the research is complete I will send a summary of the results of the study to each of the school professionals who has participated.

I would appreciate if you could invite classroom teachers, resource teachers, special education teachers, special education coordinators, and administrators who provide direct service to families of children with disabilities who have immigrated to Canada within the last fifteen years, and who you believe would be interested in participating in this study. The focus group sessions are tentatively being planned for (month). Letters will be sent to the school professionals, and followed up with phone calls.

If you have any further questions regarding this research study, please contact me, Lynne Cantor, at 474-7946, or my advisor, Dr. Zana Lutfiyya, at 474-8299.

**This research has been approved by the Education/Nursing Research Ethics Board (REB). If you have any concerns of complaints about this project you may contact any of the above-named persons of the Human Ethics Secretariat at 474-7122 or e-mail Margaret\_Bowman@umanitoba.ca. A copy of this consent form has been given to you to keep for your records and reference.**

Your cooperation and assistance in this study are greatly appreciated. Thank you for your time and support.

Sincerely,

Lynne Cantor

## Appendix D: Consent Forms

### 1. Consent Form - Families

Research Project Title: Cultural Interpretation of Disability: Perspectives on Family-Professional Partnerships

Researcher: Lynne Cantor, Ph.D. Candidate in Education

Dear \_\_\_\_\_:

**This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.**

**This paper is called a consent form. It is yours to keep. It will tell you a bit about the research I am doing and what you will be doing as a participant. If you need some more information about this research or about anything in this paper, please ask. I will go over this paper with you to make sure you understand everything that is in it.**

I am a graduate student at the University of Manitoba, completing my dissertation for my Ph.D. in Inclusive Special Education. The purpose of this research study is:

#### 1. Purpose of the Research:

- To find out about the experiences new Canadian families who have a child with a disability, have in Manitoba schools;
- To understand your feelings about the relationship you have with the main person, or persons, who works with you and your child, such as the classroom teacher, resource teacher, educational assistant, or school principal; and
- To help improve policies and services for children with disabilities and new Canadian families.

#### 2. Research Procedure

In order to do this research, I will ask you a number of questions, based on your experiences, about relationships you have with school professionals who work with you and your child. The interview will take about one-and-a-half to two

hours, and will take place either at your home, or somewhere you feel comfortable.

I will tape record the interview. I will also take written notes, to make sure I remember your comments. After the interview is over, I will type up everything that was said, so I have notes to read over.

### 3. Risk Assessment

Is there a risk if you participate? There is no risk or harm to you for participating in this research study. You might appreciate the opportunity to discuss issues about relationships you have with your child's teachers at school.

### 4. Confidentiality

Keeping your name a secret. As I mentioned, I will tape record the interview, so that I will remember what you had to say. No one will know who you are because I will not use your real name; I will give you a different name. Keeping who you are a secret is called confidentiality. Even though the tape will have your voice on it, only I will hear the tapes. The tapes will be kept in a locked room.

### 5. Participation and Compensation

Everyone who is part of the interview will get a \$20.00 gift certificate to a community store for your help with my research. Being a part of this research is your choice. You may refuse to answer any questions, end the interview, or decide not to take part. No one will be mad or upset with you. You can even change your mind part way through if you are not comfortable talking or answering questions. You can still keep the gift certificate. If you need help with child care or transportation, please let me know.

### 6. Interview Feedback

After the interview is over. I will send you some notes about the interview for your information. I will ask you if this is what you said, and if you have any additional comments; and to return any new information within 10 working days.

After the research is complete, I will send you a summary of the results of the study.

**Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from**

**the study at any time, and/or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.**

**When you sign this paper, you are agreeing that you understand what is in this paper and agree to be part of the research study. You don't give up any legal rights by signing this paper. You can change your mind and not take part in this study any time. No one will be mad or upset with you. You can also decide not to answer a question or a few questions. You should always ask questions if you are unsure about something or don't understand something.**

If you have any further questions regarding this research study, please contact me, Lynne Cantor, at 474-7946, or my advisor, Dr. Zana Lutfiyya, at 474-8299.

This research has been approved by the Education/Nursing Research Ethics Board (REB). If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Secretariat at 474-7122 or e-mail Margaret\_Bowman@umanitoba.ca. A copy of this consent form has been given to you to keep for your records and reference.

Your cooperation and assistance in this study are greatly appreciated. Thank you for your time and support.

\_\_\_\_\_  
Signature of Consent

\_\_\_\_\_  
Date

\_\_\_\_\_  
Position

\_\_\_\_\_  
Signature of Researcher

\_\_\_\_\_  
Date

Please include your mailing address where the summary of the results of the study can be sent.

\_\_\_\_\_

\_\_\_\_\_

## 2. Consent Form – School Professionals

Research Project Title: Cultural Interpretation of Disability: Perspectives on Family-Professional Partnerships

Researchers: Lynne Cantor, Ph.D. Candidate in Education

Dear \_\_\_\_\_:

**This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.**

I am a graduate student at the University of Manitoba, completing my dissertation for my Ph.D. in Inclusive Special Education. The purpose of this research study is:

- To examine the immigrant experience in negotiating the special education system in Canadian schools;
- To document the perspectives of new Canadian families of children with disabilities, as well as school professionals, regarding their perspectives on family-professional partnerships; and
- To make recommendations intended to promote and operationalize new directions for model to support more effective partnerships between families and school professionals.

In the focus group process, you will be asked a number of questions, based on your experiences, concerning partnerships with families who have a child with a disability, and who have immigrated to Canada within the last fifteen years.

Each focus group is expected to take about one-and-a-half to two hours, in a small group of 4-6 participants. The interview will be conducted at a mutually convenient time and location.

I will audiotape the interview for later transcription. I will also take written notes based on the interview discussion. Your confidentiality will be maintained, and pseudonyms will be assigned to school professionals, family members, schools, community agencies, groups or individuals you may mention during the course of the interview. At the end of each focus group, a summary of the interpretations will be sent to you along with a self-addressed stamped envelope. The letter will request input as to whether the summary was an accurate

interpretation of your perspective, and the group you represented. I will also ask you for any additional comments, and respond within 10 working days.

Your participation is completely voluntary, and if you choose to participate in this study, you may refuse to answer any questions, end any sessions, or withdraw from the study completely at any time with no repercussions. There is no compensation for taking part in this interview, however, a light snack will be provided.

After the research is complete, I will send a summary of the results of the study to each of the school professionals who has participated.

**Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and/or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.**

If you have any further questions regarding this research study, please contact me, Lynne Cantor, at 474-7946, or my advisor, Dr. Zana Lutfiyya, at 474-8299.

This research has been approved by the Education/Nursing Research Ethics Board (REB). If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Secretariat at 474-7122 or e-mail Margaret\_Bowman@umanitoba.ca. A copy of this consent form has been given to you to keep for your records and reference.

Your cooperation and assistance in this study are greatly appreciated. Thank you for your time and support.

\_\_\_\_\_  
Signature of Consent

\_\_\_\_\_  
Date

\_\_\_\_\_  
Position

\_\_\_\_\_  
Signature of Researcher

\_\_\_\_\_  
Date



Please include your mailing address where the summary of the results of the study can be sent.

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## APPROVAL CERTIFICATE

26 March 2007

**TO:** **Laurelyn Hope Cantor** (Advisor Z. Lutfiyya)  
Principal Investigator

**FROM:** Stan Straw, Chair  
Education/Nursing Research Ethics Board (ENREB)

Re: Protocol #E2007:016  
 “Cultural Interpretation of Disability: Perspectives on Family-Professional Partnerships”

Please be advised that your above-referenced protocol has received human ethics approval by the **Education/Nursing Research Ethics Board**, which is organized and operates according to the Tri-Council Policy Statement. This approval is valid for one year only.

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.

**Please note:**

- if you have funds pending human ethics approval, the auditor requires that you submit a copy of this Approval Certificate to Kathryn Bartmanovich, Research Grants & Contract Services (fax 261-0325), including the Sponsor name, before your account can be opened.
- if you have received multi-year funding for this research, responsibility lies with you to apply for and obtain Renewal Approval at the expiry of the initial one-year approval; otherwise the account will be locked.

**The Research Ethics Board requests a final report for your study (available at: [http://umanitoba.ca/research/ors/ethics/ors\\_ethics\\_human\\_REB\\_forms\\_guidelines.html](http://umanitoba.ca/research/ors/ethics/ors_ethics_human_REB_forms_guidelines.html)) in order to be in compliance with Tri-Council Guidelines.**