

A STUDY OF
CAREGIVER EXPERIENCES
IN RAISING A DEAF CHILD

by

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ABSTRACT

The caregiver family plays an integral role in promoting the overall functioning of the family unit. The six caregiver families in this study were nuclear families in Manitoba who are of hearing status and are raising a child who has special needs in communication.

Caregivers shared their parenting experiences as they learned about deafness, took on new roles to meet the needs of their children, and carried out work to bridge the gaps between the deaf child and social systems, such as the school, recreational, and medical systems. The findings from this qualitative study share how caregiver families moved from knowing nothing about deafness to acquiring knowledge and specialized skills on deafness, and deaf-blindness, from their child's birth to school entry.

Several families described their struggles in obtaining resources for their deaf children. Two families relocated to a city so their child could attend a school for the deaf, who teaches academic material using the American Sign Language (ASL). Relocation experiences were described as a grieving process and required multiple adjustments in their life. The families undertook extensive work to establish a shared language in their home so the child could access family life. Once language was established in the home, caregivers further created social linkages between their child and social institutions outside the home. Families also provided recommendations on how hearing people could support the child and his or her family, and offered advice to caregivers and anyone else new to deafness with their perspectives on how others may address typical barriers that they may encounter along the way. This study refers to the Ecological perspective and Empowerment theory and is discussed in the literature review describing the caregiver roles, work and approach to facilitate the integrative linkages between their home, extended family, friends, school, medical professionals, and hearing public.

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I am thankful for the spiritual relationship I have developed with God in the past few years. I believe that God puts all opportunities, education, people, and gifts into our lives. My life has been deeply enriched as I discovered a depth of understanding of God's love and the meaning of the Lord Jesus Christ who is the way, the truth and life (John 14:6). God is love. An example of God's love working through people is demonstrated by caregivers who have poured endless care and love onto their children. God has the same love to us if we accept Jesus Christ into our hearts and spirit. Jesus Christ is the answer to everything in our life and the after life.

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CHAPTER ONE – INTRODUCTION

Background

Hearing caregivers who discover that their child is special needs deaf or special needs deaf-blind are often overwhelmed if they have not had any prior experience with deafness or deaf-blindness. A hearing parent is primarily and, possibly, exclusively, familiar with the use of oral communication skills. Hearing parents, however, quickly learn that deafness requires accommodation of the communication needs visually for the deaf child. Further, for the deaf-blind child, caregivers learn that communication occurs by touch and smell to enable the child to recognize his or her environment. As hearing parents know very little about deafness, it can also be very overwhelming to understand how much new learning is required. These challenges can be impacting for hearing caregivers who do not have good sources of information. They must stop and figure out how to parent a child who has appreciable needs with respect to communication and language development. These caregivers, as with other caregivers, must also maintain household and family responsibilities and ensure other family needs are met.

After receiving a confirmed diagnosis of deafness, hearing caregivers must deal with their own internal affective states; but at some point, caregivers realize they need to look beyond their grieved state and search for information or resources that will help their child. Refocusing and redirecting energy naturally situates a caregiver to shelve their own needs and attend to the immediate needs of their child. As caregivers begin to train their focus away from themselves and onto their child's needs, they experience a learning curve. Caregivers often stumble on the barriers that are encountered while attempting to find out basic information from the very people and professionals who should be helping

them. In a matter of time, the caregiver has moved from affective state, to new learning, to encountering barriers associated with attaining resources for their child. In the process, they learn more about deafness or deaf-blindness gaining much experiential knowledge. Social workers who work to assist families, who are raising a deaf or deaf-blind child, may discover they could assist families attain information about deafness, connecting the family with services and supports, namely sign language training opportunities. The role of the social worker will likely be ecological in nature, helping families connect with the social systems within their local and regional level of resources that may offer families with information and needed support.

Some hearing caregivers encounter difficulties with medical professionals. For example, caregivers are already in an anxious state due to medical professionals who may not be able to confirm their child's deafness. In some cases, the diagnosis may be a lengthy process that may involve testing and re-testing. The caregivers in this study are diverse and have had a range of experiences. My interest is to provide caregivers with an opportunity to voice their experiences of raising a deaf or deaf-blind child so that the public and professionals who work with these families may gain a greater understanding of the issues related to deafness and deaf-blindness and if the situation should arise, know how to offer support to such families.

Purpose of the study

Caregivers in this study shared their approach to move their family from a state of not knowing how to respond to their child to a level of competence, of knowledge and skills acquired over the years, leading the family to greater family functioning and well established relationships. Caregivers have used their success within the home and

extended their effective communication outside the home to extended family, friends and others who are hearing. In this research I studied caregiver experiences, including barriers, supports and successes to find out what has been most helpful to adapt to deafness. Caregivers reported the success of their combined approach of having established language in their home first, as well as creating linkages between their family with various social systems in the community and the use of supports, as effective in moving their family to adapt to deafness. Caregivers in this study also offer, through their lessons learned, recommendations for positive change.

This study sought the assistance of the *Manitoba School for the Deaf* and an audiologist to help in the recruitment of caregivers who are raising a deaf child. The researcher identified the recruiters that study participants needed to meet specific criteria: the child had to be congenitally born deaf and of school age; place of residence did not matter. The recruiters contacted several people whose child they thought fit the hearing level criteria and background of congenital deafness. The recruiters solicited caregivers to take part in the study by showing them an invitation letter that the researcher had written to potential parents who may want to participate. Interested caregivers contacted the recruiters and provided consent for the researcher to contact them directly. The recruiter was given permission to provide the research investigator with their contact information and the researcher contacted the caregiver scheduling a meeting time to interview them. Caregivers were asked to sign consent forms to participate in the interview. Prior to starting the interview process, a brief orientation was held to explain that the interview is completely voluntary and may be stopped at any time by the interviewee.

Six interviews took place at various locations within the province of Manitoba. Four interviews involved the mother only. In two interviews, both the male and female caregivers were present. The case study interviews were exploratory, but all caregivers were asked a set of research questions to help the interview process maintain a focus. The researcher had no influence on how study participants would be selected geographically; however, a good cross section unfolded. Two families are currently living in a semi-rural setting. Two families have always lived in an urban setting. Two other families have relocated. Formerly from northern rural communities, the latter had to make the difficult decision to move from their well-established home community to an unfamiliar urban community. This displacement presented complex relocation adjustments for these families. The cross section of geographic representation adds a richer blend to the data that is presented as each caregiver family shares its stories and resolution of hardships.

This study enables caregivers to share their experiences of their experiences with their child. Caregivers use extensive observation especially when there was no communication in the home, and when accessing information and resources caregivers gained experiential knowledge with the outcomes of their efforts. Most situations were issues that were related to communication however, there were also other situations in which caregivers witnessed injustices and many social misinterpretations of their child. Caregivers assumed yet another role, to educate and clarify both the child and others who are hearing. Often times, this meant assuming the role of a deaf interpreter, and realized that the role of deaf interpreter often benefit the deaf child as well as the hearing person which resulted in bridging a gap between the deaf child and others who are hearing.

The role of hearing caregivers is expanded from being solely a parent into being a

teacher, therapist, and communication facilitator for their child. Such expanded and specialized roles that were assumed by caregivers helped integrate their child into their family into ecological layers within the community including; school, programs, and activities in a hearing community, as well as the child's teaching for personal safety and preparation for independent living.

My thesis discusses other sections including the case study methodology that I used. My findings chapter will include the themes and sub-themes that I identified in the material presented by participant caregivers. The next chapter is composed of a discussion that outlines how research findings support, or do not support, the existing literature. My conclusion summarizes the research.

Research questions

The research questions are as follows:

- a) What were some of the major experiences in having raised a deaf child up to this point?
- b) How have the caregiver families responded to these significant events and experiences and how did they turn out?
- c) What was useful when others offered help and what was not so useful?
- d) What recommendations do caregiver families offer to others who may be interested in assisting them, such as helping professions, the public, extended family members, or a neighbour?
- e) What implications do this study's findings have for services and care for children who are deaf or deaf-blind?

Definition of terms

- a) *Congenital deafness* means the child has been born deaf and was medically diagnosed as such.
- b) *Acquired deafness* means the child had some level of hearing after birth but, for one reason or another, the hearing increasingly deteriorated so that the child is not able to hear sound at a normal conversation level.
- c) *Caregiver family* is the entire nuclear family with whom the deaf child lives. Although the mother is most often the primary caregiver, this term includes other family members who also assist in meeting the needs of the deaf child or deaf-blind child.
- d) *Family* means a two-parented family with a deaf child who lives with other hearing siblings within the home.
- e) *Special needs* is an accommodation to the child in the area of communication and language for a deaf child and a deaf-blind child. The term special needs does not equate with other physical health conditions.
- f) *American Sign Language* for purposes of this study is the language that caregivers self declare as having learned through their personal training, over a number of years to learn and currently use. In most situations, caregivers refer to their newly acquired language as sign language, when the formal terminology is the American Sign Language (ASL). The acronym ASL will be used in the thesis.

- g) *Functional language level* is a term used by caregiver participants in this study to indicate they have enough language to carry on a basic conversation with the ability of the hearing caregiver and the deaf child to be able to understand one another.
- h) *Increased competence* means the caregiver family has moved from knowing nothing about a subject, experience or learning goal, but through diligent work, attains a level of skill and knowledge that is sufficient to address a need. For example, increased competence with ASL could mean a family member having a demonstrated capability to converse with a deaf child where both have the capacity to understand one another.
- i) *Role strain* is defined by caregivers in this study as a state of tiredness that has resulted from having performed their many roles and responsibilities.

Statistical profile: Manitoba children

Information on the number of deaf people residing in Manitoba could not be located. However, an annual report from *Manitoba Health* (2005-2006) provides a general idea on the number of people who received services for “hearing impaired.” The term “hearing impairment” could encompass a range of hearing loss from mild, moderate, to severe and profound levels of hearing loss. According to the *Manitoba Health Statistics* (2005-2006), the number of people who were hearing impaired in 2005-2006 is outlined as:

- 1,058 pre-school (0-4 years)
- 1,701 School age (5-17 years old)

- 2,631 Adults (18+ years)

A national report, *A Study of Deaf-Blind Demographics and Services in Canada* (2004) indicates that there are 172 deaf-blind individuals with “118 (70%) living in Winnipeg and 50 (30%) living in rural Manitoba” (p. 123) These statistics are not an accurate reflection of the number of congenital deaf school aged children in Manitoba. However, they provide a general idea that the number of pre-school children is considerably less than adult cases. The number of school aged children is approximately the same as pre-school children.

In the chapter which follows, a literature review is presented in two sections. Section One will discuss an overview of the literature related to the differences between the deaf and the hearing, common issues that arise, recommended ways to resolve this gap, and areas of research that require further research exploration. Section two discusses the ecological perspective and empowerment theory and their relevance to deafness.

CHAPTER TWO – LITERATURE REVIEW

Section One

Deafness as a Communication Issue

The literature describes deafness as a communication issue. Williams and Darbyshire (1982) indicate that deaf children, compared to hearing children, may require more time and explanation when engaging in communication. This is because a deaf child relies on their visual abilities to receive information from around them and it takes more time to translate concepts visually compared to using quick oral words with a hearing child. This involves extra time devoted to parenting. For example, Calderon et al. (1998) report from their study that most caregivers interviewed spent a lot of time addressing issues and matters that are related to deafness.

Communication breakdowns occur between the deaf and hearing because a deaf child relies on a visual way and the hearing use oral language expressed through sound. This often results in frustration or conflict between the deaf and hearing (Maxon et al., 1991). In other situations, the deaf child may be less responsive and appear to be passive (Wedell-Monning & Lumley, 1980). Research tells us that maternal communication behaviors, particularly those that show sensitivity and ensure their child is engaged, can positively affect the quality of parent-child communication (Meadow-Orlans & Spencer, 1996). More recent research also demonstrates that maternal communication behaviors may appear more dominant but can be appropriate for the child, and hearing mothers need to be reminded to consistently use a visual communication with her deaf child (Koester & Lahti-Harper, 2010).

Hearing parents consider the communication difficulties between themselves and their child to be a significant issue (Lederberg & Golbach, 2002; Hintermair, 2006). Lederberg &

Golbach, (2002) found parents did not attribute their stress to their child being difficult to parent but rather attributed it to the overall dissatisfaction with their lives. Hintermair (2006) finds that there is less parenting stress when a child is “communicatively competent” (p. 508), implicating that family relationships are less frustrating when they have the ability to understand one another more.

Munoz-Baell and Ruiz (2000) indicate the communication barrier between the deaf and hearing continues to be the greatest concern to the deaf because access to information of the world is not readily accessible. They recommend that the hearing should not focus on deafness as “being disabled” (p.40) but, rather on the accommodations that need to be made so that the deaf can actively participate in a hearing world.

When the child is both deaf and blind, the communication gap between the hearing caregiver and the child is even more dramatic. For the deaf-blind child, the caregiver and home environment are the primary sources of communication. Vervloed et al. (2006) define deaf-blindness as the condition of an individual who has a combination of both deafness and blindness with “severe educational needs” (p. 336). Holte et al (2006) states a caregiver communicates to a great extent by observing her child’s behavior, reactions, vocalizations and body movements, and the caregiver responding to the events in which her child has reacted. This type of communication occurs between the hearing caregiver and her child as well as having the child use touch to associate the meaning of an object to an event (p. 331).

Research tells us that it is common for hearing caregivers to have difficulty to communicate with their child unless they intentionally make the effort to close the communication gap between themselves and their deaf child. This same communication gap becomes apparent in other social settings that the deaf child encounters, such as school and out

in the hearing community. Vandell & George (1981) examined the social interactions between deaf children and hearing children in a school setting and found that it is the deaf child who initiates communication and persists in communicating with other hearing children but the hearing children do not reciprocate, making the communication exchange one-sided. Charlson, Strong & Gold (1992) found that deaf students who were the most adjusted were those who attended a school for the deaf. This is because the school for the deaf uses ASL, which provides all attending students with a common language and eliminates communication difficulties often experienced in a hearing environment.

There are other reasons why gaps exist in various social settings, such as at the public school where the deaf child may be enrolled. Erting (1985) indicates it is the responsibility of a public school to deliver educational material to students in their school system. The difficulty is that when a deaf child attends a public school in a hearing community learning material is delivered in oral language that a deaf child has not yet mastered, creating a barrier in learning the material. Educators who are hearing forget that a deaf child should receive information in a visual way, including learning educational material through their visual senses not primarily through oral language. Komesaroff and McLean (2006), recognizing this difference recommend that the public school system needs to provide a deaf person with a means, language and/or deaf interpretation, so that they may understand and participate fully within the school they are attending.

The reliance on the visual tells us there are accommodations to be made for the deaf in our hearing society. Munoz-Baell- Ruiz (2004) stresses the importance of removing the communication barrier between the deaf and hearing, as the deaf often encounter situations in which members of the hearing society are not responsive to them.

Recommend improved communication

Some research focuses on the need to develop quality communication between parent and child as their quality of communication will affect their child's development (Erting 1985; Carver & Rodda, 1978; Ritter-Brinton & Stewart, 1992). Research demonstrates that maternal-deaf interactions are often one-sided and that the communication between a parent and child needs to be more effective (Plaginger & Kretschmer, 1991; Ritter- Britton & Stewart 1992; Bodner-Johnson, 1991). Meadow-Orlans (1996) interviewed dyad groups that included: hearing parent-deaf child dyads, hearing parent-hearing child dyads. They found that those who had the same hearing status could communicate well with one another. The deaf parent-deaf child dyad could also communicate well. However, hearing parent-deaf child dyads had difficulty communicating in terms of coordinating their conversation.

Research has focused on the communication between the deaf child and caregiver and has recommended how communication may be improved. Bodner-Johnson (1991) stresses the importance of having hearing families pay attention to non-verbal communications such as facial expressions and the subtle messages conveyed by a deaf child, as well as encouraging a deaf child to participate in family conversations. Others recommend that both conversation partners need to watch specific communication rules or processes between them, ensuring that synchronicity of timing and turn-taking is included and engages both partners (Cates & Shontz, 1990; Musselman & Churchill, 1991; Plaginger & Kretschmer, 1991; Ritter-Britton & Stewart, 1992). Others have offered other suggestions, such as following the child's lead in language development (Carver & Rodda, 1978) or learning from the communication behaviors used by deaf mothers who relate to their children (Waxman et al., 1996). Families are encouraged to have their deaf child observe social encounters between hearing people in social settings

(Kretschmer & Kretschmer, 1979), indicating that such observations will provide a deaf child with social knowledge that could contribute to their future language development.

Research has not yet captured the approaches and methods that hearing caregiver families use to facilitate relationships between their deaf child and others who are in the hearing community. This may include an investigation of caregiver family work that is done to establish effective communication within their home, and once accomplished, is the facilitation of communication between the deaf child and others outside their home, forming relationships with extended family, neighbors, and hearing public.

Situation of the Caregiver

Caregiver families

Initially, caregivers are in a difficult position of having little or no prior knowledge of deafness or deaf-blindness (Meadows & Schlesinger, 1972; Williams & Darbyshire, 1982; Jackson, Wegner & Turnbull, 2010). Janssen, Riksen-Walraven, and Van Dijk, (2003) found that there is much to be learned in acquiring roles that are related to deafness and that are unknown to them, and responding through trial and error.

Two concerns related to caregiver responsibilities is the need for information and guidance during a period when parents do not know how to connect with their child (Erting, 1985; Bailes, Erting, Erting & Thumann-Prezioso, 2009). Shein (1989) states that 90% of deaf children have hearing parents, while Mitchell and Karchmer's (2004) analysis of an annual survey conducted by the Gallaudet Research Institute in the United States suggests that this percentage is even higher. The implication is that most hearing parents will have had no previous experience with deafness.

Parental perception of barriers

As caregiver families move in to their new roles, they discover other types of barriers. There has been little Canadian research comparing rural and urban residence as a factor in deafness as experienced by hearing caregiver families. However, two Canadian studies address barriers experienced by some families. Williams and Darbyshire (1982) identified themes expressed by Canadian caregiver families: a lack of services; need for information; need for guidance on how to assist their child; counseling support; the provision of training required regarding hearing impairment; a greater recognition of their expert role as parents of a deaf child; and a concern with the shortage of professionals such as audiologists (p. 29). McKellin (1995) stated that access to services for confirming deafness is a problem especially for those living in rural communities where there are less communication options.

Jackson, Traub, and Turnbull (2008) recently examined parental experiences and identified them as themes and also made recommendations that their themes could be useful for developing early intervention programs. In a subsequent study, Jackson, Wegner and Turnbull (2010) interviewed families of 207 children who were receiving services from agencies in 42 states in the US and the following themes were identified: need information on deafness; experienced positive early intervention; had difficulty accessing educational programs; needed to access financial support; need for additional family supports and social networks; greater awareness by the hearing community on the impact of deafness on family life; and had concerns about a lack of community inclusion. Such research shows families lack many supports.

Jackson, Wegner and Turnbull (2010) in their literature review provided the following recommendations; programs are needed to build family capacity, socio-emotional supports are needed to help families deal with stressors (support groups; deaf role models; mentoring; social

network support), professionals need to be more sensitive to time and skills required for home interventions, service options to be explored, provision of respite, assistance accessing financial assistance and other resources for the purchase of assistive devices for their children. (p. 204).

McKellin (1995) states that, although an urban setting may offer a number of communication approaches, these approaches may not appear to be very organized, thus creating more confusion and stress for parents in the end (p. 1475). Kampfe (1989) reports that when services are available in Canada, the quality varies or it is questionable whether the program fully meets the specialized needs of the deaf child (p. 257). This has implications for medical confirmation of a child's level of hearing loss.

According to Sipal, and Bayhan (2010), services in Turkey are provided through the collaborative work of a parent-professional team that is connected to legislation. They stress the importance of having clear role distinction on their parent-professional team as this team determines how services will be designed for others. Other research has offered parents' perception of barriers as a way of determining what is needed for services. Williams and Darbyshire (1982) interviewed 25 Canadian families resulting in the following themes: their child's diagnosis; reactions to deafness; implication for family relationships and education; and lack of parent and professional support. They also provided recommendations: to increase service distribution; promote professionals' recognition of the parent's role as a valuable contributor; improve coordination of services and information; provide training; and encourage professionals to work more collaboratively with caregivers.

There is very little research written about caregivers in Canada, especially those living in rural communities, who experience difficulties in accessing services and resources. Rural

families are reported as having limited access to programs and not many follow-up services offered to them. Martineau et al (2001) found access to services to be an issue, with families generally receiving services by the time their child is between two and three years old and speech therapy being the most common type of intervention. Another aspect related to services is pointed out by McKellin (1995), who states that caregiver families have difficulty accessing programs and, if they are available, their child is generally grouped with other children with disabilities that may not be deaf specific, making it difficult to meet the unique situation of the deaf child. This is comparable to Bowen and Ferrell (2003) in Colorado who addressed issues for rural students who are deaf, hard of hearing, blind, and visually impaired, including the shortage of trained personnel in rural areas, and urgently called for changes in service delivery models and a need for additional resources.

Another concern is the situation for families who have to relocate so they may access necessary resources for their deaf child. McKellin (1995) and Williams and Darbyshire (1982) indicate that, due to the lack of adequate services in rural communities, families are faced with the decision to relocate to urban cities seeking the specialized programs their child needs. Calderon et al. (1998) report that caregivers in their study had also been forced to relocate their families. In some situations, it is the deaf child who has had to move away from their family to attend a distant school for the deaf, thus experiencing grief as they separate from their family. Kampfe (1989) agrees that relocation can be especially disruptive to the family.

The literature supports the need for more research that focuses on the deaf child, his or her family, as well as parental involvement (Benedict & Sass-Lehrer, 2007; Ingber & Dromi, 2009; Jackson & Turner, 2004; Young et al., 2005). Such research on family experiences could provide insight on what caregivers are doing to cope with the limited resources around them, or

problem solve the difficult life situations they are currently experiencing.

Although some research points to the need to identify the type of supports, deaf related services and resources that families could use. There appears to be a gap in the literature that does not acknowledge the extensive need for resources required by families who are raising a deaf child especially those living in rural communities in Canada.

Caregiver roles

Much of the literature that was accessed outlines the roles that are assumed by caregivers as they attempt to address issues related to deafness, but the literature does not describe the process and outcomes that are involved in many of the caregiver roles. Research has acknowledged that it takes a considerable amount of time to become accustomed to the roles required in caring for a deaf child (Calderon, Bargones, & Sidman, 1998; McKellin, 1995; Moeller, 2000; Williams & Darbyshire, 1982). Morgan-Redshaw, Wilgosh, and Bibby (1989) identified the many roles that caregivers perform, but also acknowledge the importance of asking 'how' caregivers may access the appropriate resources they need for their child and their families.

Some research has captured the work that caregivers provide to their child. Keilty and Galvin (2006) found that families created their own strategies to organize their family lives within their home, and urge those who are providing early intervention “not to replace what families are already doing” (p. 219), but to provide supports that will enhance the family’s strengths. In their study, caregivers are actively involved in their child’s learning, developing their own strategies that are responsive to their child’s needs, setting goals and plans that facilitate their child’s learning. Using this natural ‘process’ approach, parents assist their child, for example, the child completes one learning activity adapting and mastering it and then

moving onto another, enabling their child to become increasingly competent, celebrating an adaptation to each lesson each time. They describe how caregivers have combined their own abilities and a variety of supports and resources to assist them in facilitating their child's learning. In contrast, Meadow and Spencer (1996) state the roles that caregivers acquire are not natural when it comes to learning how to parent a deaf child. Caregivers who are raising a deaf child did not merely follow their intuition but were required to add new skills to their parenting role which includes learning to cue in to and read their child's non-verbal behaviors.

Jackson and Turner (2004) in their literature review identified issues that are common to families such as: accessing services and health care; not realizing that hearing families may not always have access to deaf resources; and families experiencing increased time demands as they attempt to accommodate the needs of their child within the family. Desjardin (2006) highlighted the influence of parental self-efficacy and involvement on children's spoken language development, and stressed the value of early intervention programs that capitalize on these strengths while, at the same time, also serving to further empower caregivers and increase their sense of self-efficacy.

There is very little literature that provides a family perspective on raising a child with special communication needs. Caregiver perspectives are needed so that services or early intervention can be designed based on the needs of caregiver families who struggle with the many areas of need within their nuclear family as taking time to establish relationships to others who may assist them.

Intervention

Early intervention focused on language development

Early intervention is described in the literature in several ways. One way of describing

early intervention is in terms of the process required with the child's diagnosis and the child's need for language. The literature emphasizes a need for early diagnosis because the earlier the diagnosis, the earlier the child can receive communication services and begin critical language development. Moeller (2000) stresses the need for early enrolment of a deaf child in children's programs to help facilitate development of language. Lyon and Lyon (1982) state that a late diagnosis is a concern for most families because a child must have hearing loss confirmed before they can be provided with the needed language intervention. Yoshinaga-Itano, Sedey, Coulter and Mehl (1998) confirm that it is critical for infants to have their hearing loss diagnosed prior to six months of age, as any delay of diagnosis has implications for timely intervention and onset of language development for a deaf child. They also confirm that having a diagnosis alone is not useful if early intervention does not follow soon after the confirmed level of hearing loss.

An intervention checklist is provided by Johnson & Newman & Danhauer and Williams (2011), who state that, despite almost universal newborn hearing screening, half of the newborns with positive screens are lost to follow-up; this means that there may be no further diagnosis or intervention for some children with hearing loss until they enter the school system without language skills. Moeller (2000) confirms that deaf children, who are unable to access information within a hearing environment, such as a public school are unable to connect or understand the hearing. Muma and Perigoe (2010) report that deaf children are more likely to follow typical developmental sequences of learning with early identification of hearing loss and family-centered intervention from infancy. Malaia and Wilbur (2010) also claim there is a relationship between linguistic proficiency (in signed or spoken language) and time of language acquisition, thus underlining the benefits of early language exposure. These

researchers are consistent in their message that a deaf child needs language intervention as young as possible.

Deafness affects many aspects of family life with adjustment being a difficult process. Meadow-Orlans (1994) showed that early diagnosis and effective intervention contributed to less stress for the family. Meadow-Orlans and Steinberg (1993) found a strong relationship between maternal communication behaviors with their deaf child and the social supports that mothers have. They recommend that early intervention professionals should assess family supports as part of the intervention planning for the family. Although much research stressed the importance of family focused services, Martineau et al (2000) discusses that some early intervention programs are still *child*-centered and are not adapted for the *deaf*.

Contextualizing early intervention

One suggestion to address the needs of the deaf population is that professionals need to contextualize the deaf experience, becoming keenly aware of the obstacles that are encountered by the deaf child and caregivers. Munoz-Baell and Ruiz (2000) state it is critical that deafness not be viewed as a pathology but, rather, as a specialized need for communication that requires accommodation in our hearing society. They also stress the importance of professionals focusing on understanding deafness, deaf specific factors, deaf culture, as opposed to referring to the medical aspects of deafness. There is also a need for the deaf to know how to navigate the health system (p. 44).

Some literature acknowledges a gap between parents and professionals. Law, Plunkett, Taylor and Gunning (2009) report tensions between parents and staff who delivered a program. They indicate that the characteristics of a successful program includes: knowing the families well; factoring in time to receive training as it relates to a family oriented approach;

recognizing the barriers encountered by those attending the program; and have staff possess the skills needed to deliver a family oriented program. They see the benefit of combining clinical intervention and the social context of families as an effective intervention for families.

Meadow-Orlans and Sass-Lehrer (1996) concurs who says that early intervention must proceed from the context of families that are raising a deaf child. In other situations, professionals can be in uncertain. Ritter-Brinton and Stewart (1992) indicates that the challenge for professionals is to design services that are molded to the communication needs of the family.

To summarize, researchers see the value of collaborative parent-professional teams, as combining the knowledge and skills of both. Caregiver expertise needs to be reflected in the literature to describe the caregiver strategies used, their use of supports and reported outcomes.

Intervention: family – child communication

Researchers recognize that deaf children desire to connect with their family members, and tend to use their behavior, emotions, body language, and non-verbal means to connect with those around them. The literature has also discovered that parental stress has an influence on the child's development (Hinterman, 2006) and that parental stress increases with the evolving stressors of raising a deaf child over time (Meinzen-Derr, Lim, Choo, Buyniski & Wiley, 2008).

Much research points to the family's responsibility to encourage their child to participate in family discussions (Desselle & Pearlmutter, 1997) which results in the deaf child being able to access family life (Bodner-Johnson, 1991). Steinberg and Davila (1997) found some families were learning ASL from their deaf child. It is recommended that parents be more attentive to these nonverbal cues so that communication between the parent and child is more effective, and the child is also engaged with the interaction (Bodner-Johnson, 1991; Morgan-

Redshaw, Wilgosh & Bibby, 1989; Musselman & Churchill, 1991). Buzolich and Wieman (1988) also state the importance of ensuring that deaf-hearing conversations are timed so that the parent-child conversation is synchronized and both the deaf child and parent are participating equally.

Studies show that caregivers have made the attempt to bridge the deaf-hearing communication gap with their deaf child, but that it takes time to adjust their communication behaviors according to the way their child will be engaging with them (Waxman, Spencer & Poisson, 1996). Parents with a high level of skill in ASL can impact their child in a positive way by enhancing the child's self-esteem, resulting in improved language development and reading skills (Meadow-Orlans & Steinberg, 1993) which also helps form closer relationships (Leigh & Stinson, 1991). In contrast, parents who have limited knowledge of ASL will have deaf children who present with lower self-esteem and language skills (Desselle & Pearlmutter, 1997).

Researchers show that parental involvement can be essential as part of the intervention process. Morgan-Redshaw et al. (1989) stated parents need to be involved with the school in their child's educational planning, and there is a concern that parents have no decision-making rights with regards to school curriculum content. Others see the role of the parent a little differently. Meadow-Orlans and Sass-Lehrer (1995) stated that, if they are to be partners, this means the role of the family is to become advocates for their children. More research is needed to clarify the role of caregivers as well as the role of professionals who are assisting them and define their shared partnership to one another.

Intervention - family level

Jackson, Traub and Turnbull (2008) acknowledge that deafness impacts many aspects of

the lives of families and, therefore, interventions should be designed to focus on the overall well being of families as identified in their study: impact of deafness on family leisure time; impact of deafness on child who is deaf; support services; and worries about the future (p. 96). Brown and Bakar (2006) interviewed 21 families who were involved with an auditory-oral intervention program and identified themes: family communication; capacity to support family members; provision of a nurturing environment; communicating about the child; socializing the child outside the home; family's level of confidence; family's capacity to be independent; and competence to make decisions. These themes could also be used as an assessment tool for other families who are raising a deaf child. Research now needs to focus on family perspectives. Having a family perspective could generate, not only understanding of issues, but also point to possible solutions to some of the troubling issues described in the literature.

Intervention based on family perception of need

To gain the perspective of families some research has moved toward asking caregivers for their input. Law, Plunkett, Taylor and Gunning (2009) recommend that program planning of parenting programs require input from the parents, as well as a need for greater coordination of information between agencies. They stress the importance of having a consistent flow of communication between professionals and parents so parents may access information about supports that they need. Having a clinical intervention and parent-family involvement could also help develop local policy that provides programming for parents. Benedict and Sass-Lehrer (2007) recommend that intervention can be most effective when professionals approach the deaf by seeking a good understanding about their experiences. They may also consider utilizing deaf adults as a resource to help bridge an understanding between the deaf and hearing. They indicate that such collaborations are successful because the deaf are viewed in

terms of their strengths and abilities.

To understand a family perception of family needs, researchers have interviewed families and gathered data that reflects some common concerns. Ingber and Dromi (2009) interviewed families to gain a better understanding of caregiver experiences, providing recommendations for improved intervention programs. They found that parental needs included; the need to identify resources; collaboration between parents and professionals; parents should be consulted when designing the intervention program; and professionals should not criticize parents.

Young et al. (2005) in their research in the United Kingdom, consulted with parents and professionals, and some of themes include: information is crucial for families; not all communication options are available in one's locality so it is erroneous to assume that caregivers have access to such communication options; families encounter barriers (related to deafness and others that are not related to deafness); parents vary in their confidence and skills; is a disconnect between parents and professionals; a need to implement different approaches as family needs are not all the same; decision making; families should not be grouped with others; acknowledge parents as experts; professionals need to respect and empower parents; a concern with poor resources (shortage of specialized staff); professionals may promote the resources affiliated with their own discipline (pp. 262-266).

Research about families has evolved in two ways. First, some information about family outcomes is generated by researchers who evaluate an early intervention program that involve a deaf child and his or her family (Greenberg, 1983). Second, researchers have begun to develop assessment tools whereby families can self assess themselves to assist them address their specific family circumstances. Poston et al. (2003) interviewed families and they

identified key domains or theme areas that are commonly encountered by families. Families may use these domains to self assess themselves but they could also be useful for professionals who work with families. Brown and Bakar (2006) recommend that early intervention professionals ought to be considering the needs of a family on a case by case basis, as families present with their own practices, history, needs, strengths, and priorities.

Current research is beginning to take greater notice of family functioning as an area needing further study and exploration. Ritter-Brinton and Stewart (1992) recommend family-centered service delivery systems as the direction for future research. Muma and Perigoe (2010) underline the value of this move towards family-centered service as well as the importance of ‘social-based’ interventions, beginning within the culture and context of the family and moving into larger social systems.

Macro-level Intervention

Some research indicates if the needs of the deaf are to be addressed some consideration needs to be given at the legislation level that acknowledges and takes responsibility for removing the barriers that are encountered by the deaf. Munoz-Baell (2000) mentioned five strategies: improving legislation to address communication barriers that the deaf encounter in a hearing society; providing information to the deaf; focusing on accommodation of the deaf rather than viewing deafness as a pathology; improving access in medical health care settings with visual means; improving doctor-patient relationships.

Adaptation

Research describes adaptation in various ways. Earlier literature describes adjusted families as possessing characteristics that enable them to enter the community and express openness about deafness in the community (Luterman, 1979). Seabrook and Rodda (1991)

state that factors such as personality traits of the individuals and families involved, status of marital relationships, and degree of supports are some factors that determine the length of time it could take to adapt to deafness. Recognizing that families are heterogeneous (Allen & Allen, 1979) makes it difficult for researchers to make standard predictions of adjustment. Kampfe (1989) states that the magnitude of stressors will indicate how 'disruptive' deafness can be upon a family.

Researchers provide recommendations for assist families in coping with the impact of deafness upon the family. For example, Kampfe (1989) states early support is needed once the family has received a confirmed diagnosis of deafness. Hintermair (2006) interviewed a large sample of parents and found a relationship between parental stress and the availability of resources, concluding that stress was lower when parents had access to personal and social resources and providing resources to families should be a part of early intervention that can help move the parent and family to a more empowered state. In their literature review, Jackson and Turnbull (2004) write about the positive benefits of social networks that caregivers and deaf children may use.

McKellin (1995) describes families as having a life long career with deafness in the family which results in a change in their identity. For example, this is because families become accustomed to participating in meetings, programs, schools, professionals and, in some situations, connecting with other families who were also raising a deaf child. At home they develop family routines that emphasize visual communication follow, schedules and social networks around deafness, experienced as an accommodation to the deaf child in the family. According to McKellin (1995) their changed identity of a "family of a deaf child" gives indication they may have adjusted to deafness.

Past research wrote about the adjustment of deaf child resulting with findings that the deaf child was lacking in some way; for example, studies reflected the view that the deaf child does not fully understand a social interaction and that this may contribute to continued and failed communication between the deaf and hearing (Marschark, 1993). Over time, research has taken a new direction, focusing not only on the deaf child, but on the involvement of the parents and the entire nuclear family. Adaptation therefore occurs when both the parents and the deaf child have learned to navigate and communicate competently between and connected to the deaf and the hearing worlds (Desselle & Pearlmutter, 1997).

Adaptation to deafness could also implicate an adjustment to parenting roles, including parents who are new to raising a child with special communication needs. Initially, such an experience could appear to be overwhelming. Wilkins (2005) explored the supportive or inhibiting factors that impact first time mothers in their adjustment to motherhood. This study found that mothers initially experienced a challenge because of the “newness” of their situation but, over a span of time and with supports, increase their knowledge and skill sets, which helped them to adapt to the role of parenthood. Likewise, my present study aims to illustrate that caregiver families, who were initially new to deafness and who have acquired information, gained experiential knowledge by learning life lessons that has lead them to an empowered state and adjustment to their role as a parent of a deaf child.

A considerable amount of research also recognizes that the availability of resources is a large contributing factor affecting the adjustment to deafness. Some supports are formal supports as in services and there are also informal supports that provide social and emotional care to the family. Research discusses formal supports as: neonatal screening (Lyons & Lyons, 1982); extended family supports (Seabrook & Rodda, 1991); programs that are responsive to

family needs and the uniqueness of deafness (Carver & Rodda, 1987; Munoz-Baell & Ruiz, 2000); other parents of a deaf child (Kampfe, 1989); teachers who encourage positive and realistic expectations of their child (Seabrook & Rodda, 1991); deaf adults who are experienced with deaf issues (Seabrook & Rodda, 1991); and pediatricians to consult with professionals to ensure follow-up services are provided (Cherow, Dickman, & Epstein, 1999). Informal supports are described as social in nature. Cherow, Dickman, and Epstein (1999) recommended that families should receive emotional supports: informational supports, sign videos, resource professionals, encouraging parents to follow their child's lead, and building links with the deaf community.

Although informal and formal supports are described in the literature, the reality is that some Canadian families have difficulty accessing services, resources and support (Mckellin, 1995). Asberg, Vogel and Bowers (2008) found that parental perception of social support and their receipt of social supports were not always the same, and suggest that the 'perception of social supports and their use of social supports are distinct constructs. They recommend that caregivers clarify their meaning of supports.

Section Two - Theoretical Relevance

This section will discuss how my study draws upon both the empowerment theory and the ecological perspective to relate the caregiver experiences to a theoretical perspective.

Empowerment Theory

Perkins and Zimmerman (1995) refer to *empowerment theory* as the connection between a "person's strengths, competencies, natural helping systems and proactive behaviors" (p. 569). This theoretical construct views setbacks as strengths that will contribute toward a positive outcome. Empowerment theory promotes the use of proactive behaviors to produce a positive

outcome from a negative situation and looks at both processes and outcomes as a way that individuals and groups become empowered. As it relates to deafness, Meadow-Orlans and Sass-Lehrer (1995) state that the recent focus on family comes from the empowerment theory and that there is a belief that families can be actively involved and make their own choices. Earlier literature states that a combination of expertise by the parent as well as expertise of an interventionist could be beneficial in supporting a caregiver family who is raising a child with special communication needs.

My study looked at the caregiver experiences that identified specific processes and outcomes that led them to a state of competence possessing specialized knowledge and skills in deafness and deaf-blindness in the family. Empowerment theory has application in this study because participating caregivers have overcome numerous challenges and barriers and have learned how to effectively parent and meet the needs of their deaf child. This theory is relevant because the roles that the caregiver acquired are extensive and complex. The caregiver family has undertaken extensive work using themselves, for example, as they model their own social encounters with hearing people and their deaf child does the same. The result is the child has now made a social connection with others in a hearing community. Other roles such as advocating for their child formed and linked relationships with programs, contacts, agencies, professionals. In some situations, being in public can be challenging when, on some occasions, a hearing society is not responsive to the deaf child and the caregiver assumes an role to educate hearing people.

This study describes how families have moved from having no communication within the home to a state of good functioning through the use of effective communication within the home and then continuing to promote reciprocal relationships outside of the family, including

extended family, and others in the larger hearing community. This study also showed a comparative difference when caregivers knew nothing in the beginning and over the years, from the birth of their child to school age, caregivers have increased their skill and knowledge to a point of confidence that “they have overcome most of the obstacles now”.

Ecological theory

The ecological framework takes into consideration the complex interactions involved as caregivers assist their child, their family, extended family and others who are hearing to understand the gap between the deaf and hearing. Greene (1983) defines the ecological perspective, as it relates to the field of social work, as the “complex transactions between people and their environments” (p. 199). It is based on the premise that there is a relationship between people and their environment, which may include positive or negative influencers, and the manner in which people adapt to their environment depends on how effectively the environment is meeting their needs. For example, an imbalance of the person-environment may be created by the lack of essential resources the person needs, contributing to their stress and adjustment to deafness.

Deafness is complex

Earlier research has described deafness within a context of the affective stress that are commonly experienced by caregiver families. These include stages of emotionally draining events from a family’s first suspicion of deafness to a confirmed diagnosis and post-diagnosis, when they are learning to deal with the deafness (Meadow, 1968). Other researchers have described that deafness impacts at different levels: the individual, family, and community. These levels may also take into account social factors, such as life stressors, issues that are deaf specific, and social status indicators like age, gender, family income, family and parental

characteristics (Greenberg, Lengua, & Calderon, 1997). Also Harvey and Dym (1987) describe deafness in terms of dimensions “biological, psychological, family, professional, informal network, cultural and political dimensions” having relationships and inter-connectedness to various social institutions that could offer the family information and resource support (pp. 54-57). Research has begun to write about the full implications of deafness taking into consideration all its social complexity.

The literature describes deafness as an emotionally difficult process and is now also looking at the experiences by families. An ecological context embeds a caregiver family within and around many social systems and also takes into consideration the various dimensions of deafness. Social systems include extended family, schools, neighbours, medical community and other professionals, and the hearing public. The caregiver family and child are influenced by them, as well, caregiver families exercise their influence to these social systems, including professionals, the neighborhood, school, and the larger hearing community. For the parent, their encounter could involve discussing and advocating for the needs of their child. For the deaf child, their encounter is usually related to the communication differences or conflicts between themselves and the hearing. The relationship building and interaction with such social systems is a steady process that requires constant time and attention.

Part of the relevance of the ecological framework is that it allows one to look at the various ‘layers’ involved in assisting caregiver families. Helping professions need to recognize that families are diverse and they need to understand the many levels of experience they encounter. These layers could include the caregiver level; the family level; the professional level, comprised of various disciplines and policy and legislation levels.

Families in an ecological environment

Knight and Swanwick (1999) indicate there is a tendency for parents to be protective of their child anticipating that their child may experience communication barriers in the hearing community, but they recommend that parents need to realize that their child must live in a hearing world and encourage their child to connect with the hearing. Harvey and Dym (1987) suggest that, if a family is connected with social systems the family will likely adapt to deafness more easily.

Researchers recommend that for the families to feel supported, their voices need to be represented in program planning and development, as well as forming social policies. Meadow-Orlans and Steinberg (1993) point to earlier education and parental involvement as key aspects in improving services to the deaf and their families. Such policy change needs to emerge out of an ecological perspective, which does not treat the child as a separate entity but as an organism embedded in a complex environment (p. 421).

Summary

The literature demonstrates that the provision of early intervention requires family involvement, the deaf child's access to family and community participation, the provision of formal and informal supports to the family, gathering parental perception which could provide valuable knowledge of life at home. My study provides insight on a topic that is not well addressed in the existing literature – parental experiences and perceptions as they raise a deaf child from birth to early school years – and details the nature of their comprehensive work to close the gap between the deaf and hearing. This study has taken place in Manitoba, Canada, with participants living in both rural and urban areas, as well as those who have had to relocate to an urban area.

CHAPTER THREE - METHODOLOGY

The focus of the study is on caregiver perspectives of the overall adjustment process of caring for a deaf child or a deaf-blind child. Deaf children were not interviewed, although a lot of the content of this thesis is about them. The sole focus of the thesis, however, is to examine caregiver experiences and perceptions.

This research uses a qualitative design that is exploratory and descriptive in nature. Qualitative research views reality as socially constructed, that is, based on a person's own experience rather than something that is externally defined (Marlow, 2001). Qualitative research is appropriate in this study because it brings to light experiences, perceptions, and strategies to facilitate communication for a deaf child. In the research process, the researcher is not an expert but, rather, a person who is keenly interested in learning the details of the caregiver's unique story. This researcher-participant relationship is therefore based on a comfort level shared by both the participant and researcher knowing that the focus is about wanting to hear the caregiver's story and knowing that, by sharing it, others will benefit. Participants in the research helped build knowledge for those who are not familiar with deafness and deaf-blindness (Marlow, 2001).

My research is a collective case study, which involves the examination of multiple cases (Creswell, 1998). This collective case study includes a sample of six caregiver families and has involved collection of substantial data from each research participant. Each interview is considered a mini-research project that involved in-depth exploration leading to knowledge-building and an added understanding for others who are interested in learning about caregivers raising a deaf or deaf-blind child.

Data Collection

Semi-open interview

The researcher prepared an interview guide in advance to ensure the main questions were asked of caregiver families. The interviews took place at the informant's home and, as a result, I traveled to several points throughout the province. Caregivers provided consent to audiotape the two hour session for the purposes of ensuring that the information they provided would be accurately recorded.

Once participants agreed to take part in the research, the recruiters (Manitoba School for the Deaf and Audiologist) contacted the families and requested their permission to release their contact information to the researcher. Families gave their consent and the recruiters provided the researcher with their home contact and scheduling information.

Prior to starting the interview, the purpose and goals of the research were reviewed with each study participant. Participants were reminded that their participation was completely voluntary and no penalty would occur should they decide to withdraw from the research. The topic of consent to participate in the study was also discussed. The researcher informed participants that the purpose of audio-taping was only for ensuring accuracy of interview data. Prior to starting the interview, respondents provided their written consent to participate in the study and allow the interview to be audio-taped. The researcher explained that the interview data would be locked inside a cabinet and audio tapes would be destroyed upon completion of the research project. The researcher assured confidentiality by explaining that individual transcripts of participants would be compiled into one report, names would be changed and information would be mixed in with other

participants' comments, making it difficult to trace specific comments back to individuals. It was also explained that the study findings would be made available to them once the study was completed.

The researcher suggested a two hour in-depth interview, with flexibility to adjust this time frame. The respondents were informed that the researcher would be referring to an interview guide to help direct the interview. Field notes were written up immediately after the interview to record general impressions or themes derived from the interview process. These notes would be used to supplement the interview data.

Recruitment and Sampling

Purposive sampling is a request for study participants to meet specific criteria for a project. Due to the medical nature of deafness, the following criteria were provided to the both the Manitoba School for the Deaf and the Audiologist who assisted in recruiting research informants for this study. The specific criteria requested of informants in order to participate included the following:

- 1) One or two hearing caregiver(s); caregivers may be biological parents, foster parents, grandparents, or single parents;
- 2) The family unit must include a deaf school aged child;
- 3) The child must have medical confirmation of severe to profound deafness acquired at birth;
- 4) Family residence within Manitoba;
- 5) Consent to voluntarily participate in the research.

The researcher had no prior indication what geographic community they were

from as the invite was extended to both the northern and southern parts of the province of Manitoba. The researcher had no prior knowledge whether there would be participants from a First Nation community. However, if such a community were to participate, then specific procedures would have been followed to inform and engage their participation. The need to follow a protocol process was not necessary as no caregiver families residing in First Nation communities participated in this study. The result was six participants that included: two families from an urban area, two who continue to live a small city in the northern part of the province, and two families who moved from a rural community to a major urban area.

Recruitment for northern families occurred with the assistance of the audiologist from the Burntwood Regional Health Authority. The researcher mailed a letter to the Audiologist (Appendix B-1) explaining the purpose of the research study. The audiologist contacted families who fit the criteria of having a child with severe to profound deafness. The audiologist agreed that, if the family consented to take part in the study, the audiologist would notify the researcher giving the family's name, address, and phone number. Next, the researcher would mail a letter to the family (Appendix A) to arrange a meeting with them to further discuss the purpose of the study, the researcher's accountability, and consent forms.

Recruitment for southern families occurred with the assistance of the director of Manitoba Education and the Manitoba School for the Deaf. The researcher mailed a letter (Appendix B-2) explaining the purpose of the research study. The director contacted the principal of the Manitoba School for the Deaf and discussed possible candidates who may fit the study criteria. The researcher was informed on a process for recruitment. The

principal forwarded the researcher's invitation letter to families to inform them about the research. If the family agreed to take part in the study, the principal would then notify the researcher giving the family's name, address, and phone number. Next, the researcher contacted the caregiver families and agreed to a date and time that the interview would take place at the caregivers home.

Although participants were invited to participate in the study because their child had hearing loss of congenital deafness, caregivers in the interview said it was questionable as to whether their child's hearing loss was acquired at birth. Two caregivers spoke of their child having some residual hearing at different times from their preschool to early school years, and another caregiver had their child with both blindness and hearing loss. Three caregivers indicated their child had a severe to profound hearing loss.

Storage of Data

Upon obtaining signed consent, individual interviews were audio-taped and transcribed. A master copy containing the six interview transcripts was kept. The researcher created an additional binder master copy that contained the researcher's typed comments directly on the original transcript of each respondent. This binder copy was named 'the paraphrased copy of the Master Copy'. Interview data was backed up onto computer diskettes. The diskettes were labelled with code names protecting the identity of study respondents (Padgett, 1998). Study respondents were assured that written transcripts, audio-tapes, and computer diskettes would be destroyed once the research study was completed.

Names of persons and communities on written transcripts were deleted to conceal

the identity of the participant. Colours were assigned for each individual and the transcripts were printed in the assigned colour. This resulted in a binder holding six coloured transcripts representing the six respondents who participated. The second master copy of original transcript data was saved on computer files and backed up on computer diskettes. New computer files that were created were also saved on computer diskettes. Field notes and analytical ideas were recorded using computer files, handwritten notebooks, and an audio-recorder.

The researcher locked the two binders, master copies, mini-cassette audio-tapes, computer back up diskettes, three code books (27 x 20 cm) or scribbler notebooks and original signed copies of study participant consent forms in a locked filing cabinet.

Data Analysis

Coding data

The researcher coded the transcripts using two different methods. One method was use of poster boards. Transcript data was pasted onto poster sized bristle boards (22 x 28 inches). Each poster board represented a theme, and transcript clippings were categorized under each corresponding theme. The researcher stored thirteen poster boards in a portfolio in a private office. The other method was the creation of code books (26 x 20 cm notebooks). Transcripts were taped into a notebook with the name of the appropriate theme at the top of the page. Transcripts were placed in accordance to each theme in the notebook. This method resulted in three code books.

Organizing data into Research Constructed Categories

- 1) The researcher gathered all pertinent data: analytical notes, audio-tapes, transcripts, poster boards representing various themes, three code books with their

keys, various computer file documents.

- 2) The researcher transcribed the audio-tapes and was immersed with the data. The researcher read through the original copies of all respondent transcripts. The researcher left a column on the margin to the side of the document, enabling the researcher to write key words or ideas representing the data.
- 3) The researcher created a word document that included a listing of all key words or ideas of the data. The names of these ideas evolved into the formation of categories. Through a method of “open coding” each sentence was labelled as an idea and then each specific transcript section was filed under its appropriate category and theme on the poster board.
- 4) The researcher printed the transcript and cut them into individual clips. The clippings were organized into categories. The researcher labelled envelopes according to sets of categories.
- 5) At this point, the researcher took each labelled envelope and taped all transcript data on to poster boards. Each poster board was given a theme title. The researcher discovered sub-themes emerged from main themes and the researcher wrote the name of the sub-themes directly on the poster board. This exercise was followed until all transcript data was accounted for. The result was thirteen poster boards that included the various comments by different participants on a subject matter. During this exercise, the researcher made analytical notes as themes and correlations appeared from the data.
- 6) The researcher placed all thirteen poster boards on walls to see a visual on all the themes and sub-themes that were in the data. The researcher placed a sticker on

quotes that appeared to address a key point. This sticker or marking on poster boards identified significant points related to the theme. Large sheets of paper were used to list general categories at the top, with key words, concepts, ideas, and themes underneath the title. The visual map was created to help the researcher see any duplication among categories, possible relationships, specific statements, and emerging patterns in the data. Interview data was colour coded and enabled the researcher to see visual connections between and among categories and themes (Padgett, 1998).

- 7) The researcher made a computer file that captured theme and specific transcript quotations. The researcher made written notes about patterns and commonalities between what families said. The researcher ensured that all parts of the data have been accounted for.
- 8) The researcher created codebooks and taped all colour coded interview data into notebooks. The researcher created a key list for each codebook according to the page numbers on the code book. For example, caregiver roles are from pages 20 - 45. Through this system, the researcher was able to organize points and locate quotes. The researcher then assigned all raw data to assigned categories in each codebook.

Retrieval Systems of Themes and Sub-theme Information.

The researcher created a number of information retrieval systems to ensure specific quotations which formed themes, sub-themes with relevant quotes.

The researcher:

- 1) Created codebooks; researcher first sorted transcripts (by placing transcripts into envelopes and labelling per theme) code books were page numbered; and then quotes were taped respective to its category; then typed a key list with page numbers (e.g. caregiver roles for example were pg 1 – 31).
- 2) The code book list, table of content list, and the poster board visuals helped the researcher plan the next stage which is the writing of the findings chapter .
- 3) Data was analysed using two processes: First, the researcher used researcher-constructed categories to organize the data into themes. Second, the researcher used logical analysis, which involved looking at the relationships between ideas and concepts that are identified within these themes. In this process, new typologies are developed, creating sub-themes of the general themes (Marlow, 2001).
- 4) During the process of reviewing transcript data and the cross classification process (poster board visuals), the researcher wrote analytical notes to draw a relationship between two themes or concepts, record new insights during the analysis of data, and note insights gained from the study findings. The researcher noted similarities and differences in the data. This cross referencing continued until the researcher found nothing more to be learned from the data.
- 5) Once all possible connections were explored, a new computer folder was labelled as 'study findings'. The study findings chapter comprises the major themes and their sub-themes as they related to the research statement. The researcher used a visual of the research statement written on an index card as the findings were examined, and viewing how concepts related to one another and focusing on the research statement.

6) Once again, the researcher re-reviewed the literature review. The literature themes were examined this time in terms of: flow of literature themes and the study's relevance to empirical based or measured studies. Differences were sought and determinations were made of where the study findings supported or refuted the literature themes. This analysis is presented in the Discussion Chapter.

The researcher used a combination of visual poster boards, layers of outlines (high level outlines and specific ones) for each theme and chapter. For example, the communication theme had many sub-themes and many sub-points to the sub-themes. Bulleted key words were used to capture what needed to go into each theme and sub-theme. This became a very detailed procedure. An introduction and definitions of the theme and sub-themes were added. Narrative descriptions were written and the researcher was careful that the narrative and specific quotes matched and were reflective of one another.

Credibility

To verify the construction of researcher categories, the researcher asked a person who had completed a Masters degree in another profession to construct categories based on the transcript that she was provided. This individual did not know what type of categories the researcher had constructed for this particular transcript. The researcher and colleague compared to see if the categories that each constructed were congruent. If there had been any discrepancies, the researcher would have re-read the transcripts and reviewed the steps to determine any revisions to be made to constructed categories. However, the researcher and colleague agreed to a set of categories that reflected the data.

Transferability

Marlow (2001) states that a large sample size will provide richness in the data. However, it will not be possible to generalize to the greater population of families with a deaf child. The sample size in this study is not representative of caregivers who are raising a child with special communication needs. The information shared by participant caregivers, however, has been very rich to help readers to understand some aspects of family life. It is a starting point for further research in this area.

Ethics

The researcher has tried to protect the identity of research informants. However, with the closeness of small rural communities and close deaf networks it is possible that someone's identity could be revealed. The researcher explained the purpose and goals of the research, emphasizing to respondents that their participation is completely voluntary and that they may withdraw at any time without penalty (Marlow, 2001). Families were informed that the researcher's previous job, until 2005, was with the Society for Manitobans with Disabilities (SMD), an agency that provides services to persons who are deaf. Caregiver families were assured that their participation in the study would not be discussed with SMD and that the role of the researcher was strictly for this research only. It was explained that this research would not affect their current receipt of services nor affect current or any future relationships they may have with the Society for Manitobans with Disabilities. They were assured that the responsibility of the investigator was to report accurate and non-biased research, a criterion set by the University of Manitoba.

CHAPTER FOUR – FINDINGS CHAPTER

The findings Chapter is discussed in two sections. Section One will provide a profile of caregivers raising either a deaf or a deaf-blind child. Section Two will discuss the findings based on the voices of these caregivers who have lived and experienced the deaf-hearing social encounters and barriers through their deaf child.

Section One – Family Caregivers

Section one provides background information on all family caregivers. Fictitious names are used in an effort to maintain anonymity of the respondents. All caregivers interviewed are two parented and include a deaf child and one or more hearing siblings.

Susan and Wayne

Susan and her husband, Wayne, are health professionals. They live in the suburbs of an urban area. Their family includes two parents, a deaf child, and one younger hearing sibling. The languages used in the home are English and ASL, but the primary language is ASL. There is no history of deafness on either side of the family. Deafness was abrupt as there was “no landmark” (Susan, November 2004). Having had no prior experience with deafness, the diagnosis came abruptly and both parents, initially, did not know how to respond to it. When their child was confirmed deaf, their immediate reaction was to read volumes of literature to gain a better understanding of deafness. For Susan and her husband, this was their usual approach to any presenting problem – to thoroughly understand a problem and then decide on a course of action, as opposed to worrying about decisions made (Susan, November 2004). Their next course of action was to explore what options and resources were available in their urban community. Based on literature they had read, they reached an understanding that deafness points to *a need for*

language. Susan's initial view of her child's deafness had been that it was a disability. However, after reading and gaining an understanding of deafness, her perception changed to "No, he's not [disabled]!!" (Susan, November 2004). Since she understood deafness as a need for language, she concluded that, once her child received the necessary language, then she and her family would be just as functional as any other hearing family.

These caregivers thought of everything that they could do to provide for their child, and the key was to establish language within the home. In learning ASL and finding out what resources are required for the deaf, Susan gained experiential knowledge and this has been a continued evolving process. Susan's experience of helping her child over the years has led to a specialized role and expertise, an unexpected benefit for the caregiver. Factors that helped with the adaptation processes were: the family became informed of deafness, learned a visual that the deaf child could also understand, and built wider network connections to extended family members and friends, both in the deaf and the hearing communities.

Their child was confirmed deaf at fourteen months old and, immediately, Susan and Wayne did not wait for answers to come to them. After much reading, they were relieved to find that deafness is merely a language issue. Once the family provided language to the deaf child, a language which could be shared by both deaf child and the entire family, the anxiety of deafness in the family was much relieved. Susan and Wayne taught their deaf child basic ASL and, themselves, pursued more advanced levels of ASL. A hearing child joined their family membership with two years difference between herself and the deaf child. The hearing child also learned the ASL as she attended daycare centers that used ASL as the primary language.

Once the family learned that deafness was a language issue, they felt it was a matter of formally informing others close to the family that their choice was to go with ASL as their main communication within the home. Extended family members were encouraged to learn ASL, but some had and continue to have difficulty adapting to a new language, thus often leaving a need for the family to interpret to bridge the deaf-hearing communication gap.

They encountered relocation experiences for a brief one year period, moving from one urban area to an out of province urban area and experiencing the grief and loss of leaving a supportive family behind. However, the joy of returning home within a year provided her deaf child a smooth transition back into the school for the deaf, where he had already been a student before. A strong characteristic of this family was that they self initiated, searched for deaf resources, and took a very active role seeking out information to help in their decision- making.

The deaf child is now eleven and has been attending the school for the deaf, thus having had much opportunity to develop a strong skill in ASL, which is the primary language used there.

The deaf child who, at the time of the interview, was in grade six, is extremely proficient and advanced in ASL and will generally approach those who he thinks will understand him best. Susan has worked very hard to ensure that her child has a strong home and social network, giving him the confidence to participate in sporting and children's program activities in the hearing community. Their deaf child integrates within activities offered by the hearing community with ease since he has a strong communication network at home and other deaf peers with whom he can relate. Thus, he

is comfortable with social interactions that are deaf/deaf encounters, and also has enough observation and practice skills in deaf/hearing mixed communication settings. In fact, he has some English as well as ASL skills from having observed and initiated communication with hearing family members. His skills in English are such that, in some situations, he could accommodate the language needs of hearing persons such as his grand parents.

Thus, providing language to her child had become the primary family focus. Her next step had been to figure out how to get both her deaf child and family on the path to establishing a common language in the home. She had also realized it would be much easier for the hearing family to learn the child's visual language rather than the deaf child to learn oral language that requires oral skills.

During the transition of learning a new language, learning about deafness, and encountering experiences along with her child, Susan gained valuable experiential knowledge attained from both formal and informal informational sources. Once a functional level of shared language was established in the home, signs of adaptation to deafness in the home and family were experienced. However, in Susan's mind, there was still a need for further social relationships and her plan was to ensure that her family had a wide network of extended family and friends that included the school for the deaf, as well as the deaf and hearing communities.

Susan believed that, if she provided her child with a well established social network and a home that accepted and used ASL as the main mode of communication, this would give her deaf child the confidence to participate and integrate into a hearing community. Susan modelled social interactions with hearing people and reminded her son

that other deaf role models were also capable of interacting with hearing people in a hearing society. In addition, she has been promoting independence in her deaf child as well as her hearing child so that each in their own way grows accustomed to interacting with others in a hearing community.

Brenda and Sam

Brenda and her husband, Sam, moved their family from a smaller city situated in a large rural geographic region, to an urban area. They have two children, the eldest child being deaf and the youngest hearing. Brenda is a health professional and her husband is employed in other work. Languages used in the home are rural English and ASL, and the child is also provided with speech therapy in the home. These parents had no previous experience in parenting, nor had they had any previous prior exposure to deafness in the family.

At the time of the interview, the family had recently moved from their small northern community. They expressed how new they were to the neighbourhood and the city as well as great difficulty with this transition. Feelings of grief, anger, and resentment accompanied a feeling of having been coerced to move to the city in order to better access resources for their deaf child. They felt that it was unfair that moving away from their home community had been necessary because of the lack of essential resources for the deaf.

Prior to the move the deaf child had attended a school in the hearing community for kindergarten and grade one and had managed very well. Brenda indicated that his hearing level was eighty percent deaf but, with hearing aids the hearing level was about fifty percent. Prior to the move the communication method used by the child had been a

combination of ASL, voice, and lip-reading.

The deaf child had begun to experience increasing challenges at school, falling behind in his grades. He had attended a school in a hearing community and had been assigned an educational assistant whose primary role was to be his communicator. While living in their rural community, the deaf child had received speech therapy and the female caregiver had become a home therapist, following the steps and goals for oral speech and therapy of the visiting speech pathologist. Although the deaf child had good oral skills, the academic gap continued to widen and pressure upon the child was only expected to increase as the child got into higher grades. The caregivers made the choice to relocate based on two reasons: firstly, the school for the deaf was suggested as an option that would meet the communication needs of the deaf child and also enable the child to benefit from quality education. Secondly, this was the optimal time to move to the city, before the child became so frustrated with the abstract levels of school work involved with higher grades. Brenda saw the deaf-hearing communication gap widening in the school setting and had initially thought that oral skills would help bridge that gap. However, it became apparent to her that this was not enough to close the deaf-hearing communication gap occurring at the school. Visiting consultants had been a great resource to Brenda and her deaf child. Brenda sought advice from this person, and this helped her to make an informed decision to move to the city so that her child could attend the school for the deaf. The move occurred July, 2004, and the time of the interview was November, 2004.

With their home community eight hours away from their new city home and the deaf child having attended the school for the deaf only a few short months, the child was

having some problems transitioning from a communication system that involved voice to an ASL exclusive communication system at the school for the deaf.

The child had been diagnosed at the age of three and was seven at the time of this interview. The relocation was a sensitive topic to the family since they had only been in their new home about three months they had no social supports. However, they were astounded by the large number of opportunities for the deaf child to participate in community events, sports, and children's programming. This was a dramatic shift from their previous rural community experience, where no deaf-related resources of this kind, including deaf interpretation services, were available at all. The child was partaking in an after school art program at the school for the deaf and the parents were considering letting him join boy scouts in the future.

Conflicting work schedules of both caregivers was adding to the challenge of trying to coordinate a family child care schedule. Brenda would often get called to work on short notice and her husband was working nights - thus making it difficult to spend time with one another and be a support to one another.

Glenda and Jeff

Glenda and her husband, Jeff, live in a rural community, and have three children – the eldest and youngest children are hearing, while the middle child is deaf. Both caregivers were working full time at the time of this interview. Languages used in the home are English and ASL. The previous experience of parenting had been very limited as the eldest hearing child and deaf child are only a few months apart in age. Though both caregivers are employed, the mother's job is flexible enough to allow her to attend to her deaf child should the need arise.

The caregivers were experiencing a significant amount of stress as there was some uncertainty on the part of the medical profession regarding the actual diagnosis. At the time, the caregivers had been informed that there may be life threatening elements to their child's condition. Glenda's child was diagnosed at a week old along with other health complications. At the time of this interview, her child was able to make some speech sounds but they were not clear. Hyperactivity was another aspect of the child's condition and, as a result, the child slept on average four hours per night.

The child attended both a preschool program as well as a school in a hearing community. Prior to going to preschool, Glenda did her best to teach her child ASL by posting pictures and the visual directional signs that show how to sign the label concepts. Glenda herself was learning the basics while teaching her child ASL. The experience of living in a rural community was very difficult for this family. The biggest challenge was in conquering the deaf-hearing communication gap within the school setting, and this was not being resolved. Glenda shared: "The school did not have any prior experience with deafness here." Her child was the first to have an FM system and an interpreter, something that was new to the school (Glenda, November 2004). Although her child received some support, the deaf-hearing communication gap remained unresolved.

The widening hearing-deaf communication gap became even more apparent as her assigned aide, school peers, and school staff members were not at the ASL proficiency level of the school aged deaf child. In addition, the deaf child had limited opportunities to sign with anyone in the hearing community because no one in the hearing community knew ASL. The child did not have access to any resources as her community had only the bare minimum of resources, such as a visiting speech therapist.

The caregiver had to search very hard to find any kind of useful information that would be of benefit to her child.

As a result of the widening communication gap, the family was forced to make a decision to relocate the deaf child to the school for the deaf. The parents actively initiated and negotiated an arrangement in which the deaf child would live in a dormitory on week days and travel home every weekend. The experience of having the deaf child live apart from the family was a transition that stimulated a great sense of grief and loss, was a huge transition, and created much stress for the family.

During the transition, the caregivers needed to weigh which was more painful, the loss of loss of their child for five days of the week or having the child endure the horribly abusive situations that the child experienced while attending a public school in her neighbourhood. The caregivers, however, were somewhat reassured when the child began to seem more happy and pleased about how many friends she had and her remarkable progress in the school. At the time of the interview, the deaf child had attended the school for the deaf for about three years. Prior to that, she had attended a public school in the hearing community up to grade four. She was now in grade seven at the school for the deaf her primary communication method was ASL. The positive benefits of living at the school for the deaf outweighed the disadvantages of missing her. Since being at the school for the deaf, she had advanced extremely well in ASL, she had deaf peers to relate to, was involved in career planning, and had volunteered to be a bigger sister to another younger deaf child. She was also gaining more confidence through her participation in social outings that linked her with the hearing community.

Rosemary and Robert

Rosemary and her husband, Robert, are grandparents of the deaf child. This family is Aboriginal with Cree being their first language, English their second language, and ASL now being their third language. The deaf child became deaf as a result of contact with rubella measles at birth. The grandparents have children who are now adults and an opportunity to care for one of their grand children was presented to them. In their aboriginal custom, it is common that the grandparents adopt one of the eldest grandchildren, so the grandparents and the biological parents came to an agreement; the biological mother did not agree at first but, in time, had agreed to this arrangement.

The grandparents and deaf child moved from a rural community to an urban area. The grandmother has a teaching degree and the male caregiver is a traditional hunter and fisherman. They detested the idea of living in the city, as it is a sharp contrast from living rurally; however, their decision to relocate was made in order to put their deaf child's needs first and set aside their own desire to remain in their home community. After the deaf child and the caregiver had had an opportunity to visit the school for the deaf and the child participated in classes during this visit, the child had repeatedly asked the grandparents to return to the school for the deaf. Another factor supporting the decision to move was that the child also had other health conditions and physical disabilities (including the need for open heart surgery) that required medical appointments every two weeks and, thus, frequent long distance travel (six hours per trip).

At the time of the interview, the child was eleven years of age and was attending the school for the deaf. Prior to moving to the urban centre, the child had had the opportunity to attend a child development program in the rural community school. The caregiver had encouraged the child to attend mainly for the purposes of social contact

with other children. However, the need for language had become increasingly apparent, and this helped determine their decision to move to the school for the deaf where the children would attain the language that he needed.

The grandparents relied on faith that they would be able to make this transitional move. Their only means of income was their child's tax benefit and, if lucky, any money gained from their hobby craft work. Although they had a temporary place to live, they encountered difficulty in accessing housing once they made the decision to remain in the city. "We went on faith...that the good lord would take care of things".

Carole and George

Carol and her husband, George, reside in an urban area. They have two children – one hearing child and a deaf child who are one year apart. The deaf child is a foster child who has been residing with the family for several years.

Having the hearing child exposed to various communication settings in which ASL is used has helped both the hearing child and the deaf child become progressively advanced in ASL. The hearing sibling has assumed many care roles in relation to the deaf sibling that often involves interpretation, teaching self care, and other appropriate things around the house such as using the microwave. The child is able to hear to a small degree with hearing aides and has recently expressed an interest in being hearing once again. The child has attended day cares that use ASL and is also attending the school for the deaf.

In addition to being deaf, this child has another health condition that affects his motor skills and coordination. He also has frequent temper tantrums, which are now managed through medication and setting clear parental boundaries with the child.

The communication between the hearing sibling and the deaf child was well established, so much so that she is able to clarify situations to the caregivers if necessary. The caregiver has taken ASL classes, participates with some of the ASL training opportunities offered in the urban centre, and is not afraid to go ahead and use both oral skills and ASL. She uses both so that she can have her child read her lips as well as look at the signs. Carol indicates she is learning further ASL from her child. She considers her level of ASL equivalent to or near the level of the deaf child, and admits that she would have difficulty conversing with a deaf adult who is highly advanced in sign.

Learning ASL has been progressive. The family is now bilingual English/ASL. Both caregivers are professionals, with one of them being in the health field. Although they have prior parenting experience with their hearing child, they have had no previous experience caring for a special needs child. The deaf child is acquired deaf and was diagnosed at about the age three. He was twelve years of age at the time of the interview.

This family relies on formal supports verses informal supports. There is an ongoing issue regarding accessing reliable specialized child care for this child. They can not rely on either maternal or paternal extended family members to provide child care. Paid respite workers or a baby-sitter is the usual option. They rely on friends as supports rather than turning to family members. They also have a connection to the deaf community and rely on the valued supports offered by the school for the deaf.

Alice and Daniel

Alice, her husband, Daniel, and their five children reside in a rural community. Two of the five children are their biological children and the others are foster children. They are raising a child who is deaf-blind, through a foster placement. Their eldest child

is also a child with special needs, which means Alice has had previous experience raising a special needs child. Her family also comprises other family members, four other special needs children.

The child was born deaf-blind with other accompanying complex health conditions, involving many medical appointments, and the services of many medical professionals. At the time of the interview, the deaf-blind child was seven years old and had been with the family since birth. He was attending a school in a hearing community. The caregiver reported that the initial contact with the child and her agreement to be his caregiver had been an emotionally draining experience. She had been warned that he had many medically complex health conditions and that it was not certain how long he would live. This wide range of disability did not stop the compassion that Alice felt for the child but, rather, her decision was to do whatever she could for the child who needed a caregiver. Her heart made the decision, not the visible health complexities.

Her experiential knowledge from raising special needs children has given her an ability to recognize the strengths and abilities of a person despite having an apparently physical disability. To her, attending to the physical needs of her special needs child is routine – disability as an everyday thing. The key, she says, is to know your child very well. Added to the provision of physical care for the deaf-blind child was a need to set up her home environment in a way that would create a sense of safety for the deaf-blind child. In her caregiver experience, she realized that providing a structured home environment was, in essence, a mode of communication for the deaf-blind child. That is, for the deaf-blind child, home routines, smells, the arrangement of furniture and settings, and the patterned behaviour of family members reside in this setting were all sources of

communication.

The role of providing care for the deaf-blind child was initially intense due to multiple health conditions. Caregivers indicated that their care-giving responsibilities were mainly focused on the facilitation of communication within the home, with health service providers, with the school, and ensuring everyone in the family was trained and assisting with the responsibilities in the home. The mode of communication with the deaf-blind child was through object association – through touching an object and ascribing meaning to it. For example, the child would touch car keys and the door knob to know that he was going for a ride in the vehicle. This communication method was implemented when the child was four to six months old and was still being implemented at his current age of seven years. In addition, the deaf-blind child would make different whines, cries, and noises to convey basic needs such as “I want out of this chair” or “I want out of this bed”. Alice is convinced that the child is able to reciprocate communication back to her. Anyone else, however, in the hearing world would have difficulty understanding the meaning of the sounds, but Alice and her child did establish a system of reciprocal communication. Alice emphasized the importance of hearing people being attentive enough to recognize such communication – often very subtle responses being sent by the child.

Alice feels that her role as a caregiver has exceeded that of a “full time job” and has a real need for respite services to give her a much needed break. One essential role is that of coordinating medical services providers and ensuring that all team players are working together in an optimal well-communicating system for the benefit of the child. Alice shares that her earlier parenting experience with her first child had been traumatic

but, at the same time, she gained a competence that has transferred into her current experience of raising a deaf-blind child, which is a new experience for her. Through her care-giving experiences, she has acquired a state in which she is more sensitive to persons with disabilities rather than the common public who tend to take things for granted” (Alice, November 2004).

Thus, caregivers in this study have had three different residential experiences which have, in turn, shaped their experience of resource acquisition for their deaf and deaf-blind children. Two families have always lived in an urban setting and have not had any experience living in a rural community; two have relocated to an urban setting, having previously resided in a rural community with limited resources; and two currently live in a rural community where they continue to experience limited resources. In one case, an arrangement has been made whereby the child resides in a school for the deaf but travels home on week-ends.

Section Two – Caregiver Experiences

This section discusses the experiences of participants who raised children with special needs related to communication. All children discussed were deaf, while one child was also blind. Caregivers shared how they have responded to their children’s needs and, over a period of time, have gained valuable learning and insights. They provided recommendations on how others, new to the experience of deafness, may potentially reduce the number of hardships in their new role.

The following four themes emerged from caregivers’ descriptions of their experiences of raising a child with special communication needs: (a) barriers face by caregivers; (b) how caregivers responded to barriers and/or challenges; (c) how

caregivers and family adapted to having a deaf child; and (d) insights and recommendations made by caregivers.

Experience of Barriers

Coping with a new diagnosis

Caregivers shared how they eventually had their children's deafness confirmed. Receiving a confirmed diagnosis was hard for them, making it very difficult to 'take everything in'. As Brenda described, when her child was first diagnosed:

...everything is going over your head. Should you go with just speech, go with signing? Like, there is a lot on your plate. There is a lot you have to learn. So it's a lot of decision making. But a lot of it is hard decisions because you don't know what is best for them." (Brenda, November 2004).

Caregivers agreed that the main challenge in the early stages of intervention was determining which communication method to use with their child. The added challenge was that they did not feel adequately supported in this decision-making process by 'communication professionals':

The first challenge was which way should we go with him. We felt we were being pushed that he should only be oral, that we shouldn't sign with him, and that he should just use his ears... (Brenda, November 2004).

The majority of caregivers felt heavily impacted, while others were not as greatly impacted due to other life threatening stressors at the time. For Alice, it was a tremendous shock and she cried for two days:

Then you can only cry for so much...It's a process. You feel sorry for yourself, you feel sorry for the baby, you're mourning that child. When you bring a child

home with that kind of disability or any kind of deaf disability...that child is not going to have the life that you visualize for them. It's overwhelming and you need someone to talk to because you find you go through a lot of grief (Alice, November 2004).

Once the shock has subsided, caregivers reported that they felt overwhelmed due to the visible complexity of needs of their child. The caregiver of the deaf-blind child reflected on how her child would be like this forever. "By the time you take him in the house he has gone around the curve. Coming up the stairs he doesn't know where he is. Wouldn't you be scared? Could take six months, doing the same thing [or] ...three years" (Alice, November 2004). Alice's comment indicates concern about safety of her child both now and in the future, as he needs to learn to manage an environment that he cannot see or hear in.

Another issue mentioned was the lack of information about deafness or deaf-blindness. Many caregivers initially viewed the special communication needs of their child as new territory which required much learning ahead for them. They did not know where to go to locate resources. Caregivers found that information about deafness was not readily available to them, and most had to search for it themselves. Glenda, for example, stated that no one spoke to her when she left the hospital. She added that she did not think there was sufficient information available for the family and what is available "is scattered" and only comes in fragments (November, 2004). Alice mentioned that, when her daughter was born, "I was learning things really slow...I was educating myself and...talking to other parents [with] older kids and similar situations" (Alice, November 2004).

Caregivers did not know what kind of resources, services or supports to request from health professionals. Alice explained that this could be because some caregivers are intimidated by professionals:

A lot of the parents are, I don't know, they're Aboriginal parents, they seem to be very shy and they almost feel like they are intimidated by others. Like how many parents [who] have a deaf child, like say a three year old or a four year old, know what the resources are? How do you know what you should be asking for? [emphasis]." (Alice, November 2004).

Glenda concurred, stating, "Nobody is going to say, 'Here, this is what you have to do.'"

Early parental concerns

Caregivers reported concerns about risks to their children's safety, particularly before a shared language had been established in the home. In one instance, a mother reported that she had gotten up at 7:30 AM one morning only to find that her child was missing and there was no way to call out to her:

...she got up one morning and left the house...She was only three or four... Oh my gosh, where is she?! And going to look for her. She isn't a hearing child. And it's not like another child, where you can go outside and yell for them...So you are running around looking...She was picking flowers around the corner. (Glenda, November 2004).

Caregivers experienced a variation in the time period that elapsed until they received formal intervention and receipt of services. For example, Glenda did an independent search and received services for her child within a year. Her daughter was a year old by then. Caregivers from rural regions commented on the long waiting time

before receiving supports, which was longer than for urban care providers:

By the time you have a social worker set up [from] children's special services...[and] they come around, you could be [a] basket case already. You can go into [a] serious depression [and] the baby could be at risk... It could be very serious." (Alice, November 2004).

The caregivers of deaf children noted that the time required to wait for services was a concern to them. Their situation was in contrast to that of Alice, whose deaf-blind child was immediately referred to a medical team that made referrals to a number of health professionals for services. "There were all kinds of people coming in with different ideas and suggestions and different professions". (Alice, November 2004).

Caregivers added that, once referred, gaining access to services was often a prolonged step-by-step process that did not always meet the child's needs in a timely way. Once the child's deafness is known, the family faces numerous processes and referrals. Usual milestones, such as being toilet trained, may be interrupted and delayed due to all of these other critical concerns:

Then [by age] five he is not toilet trained yet. Sometimes you get together with Children's Special Services, five years go by already; three years for sure went by and there has been no speech therapy, no OT [occupational therapy], no PT [physiotherapy]. ...Let's say, the child came home; the child is deaf and the paediatrician tells you he's deaf. They always refer the child to SMD [Society for Manitobans with Disabilities] or some kind of an organization. Then they'll do an evaluation, give you a recommendation. So whoever attends a meeting, whether it's the mom, the dad, or the aunt, whoever, they have to pass that on to

the rest of the family. 'This is what's happening, this is what we are doing'. Because by the time you get home and he sees the pediatrician and the pediatrician puts in a referral and they get the referral-- yaddah, yadda, yadda-- it takes time." (Alice, November 2004).

As Susan sums up, "Anxious is exactly the word." (Susan, November 2004).

Need to establish mechanisms for communication

Caregivers experienced an obvious need to establish a mode of communication with their children. In lieu of an established communication system, children were only able to express themselves behaviorally. Rosemary described communication challenges with her son as follows:

The way [he] wanted to get a point across was through a fit of anger. But the behaviour part is what we couldn't handle...when he turned about 6 or 7 year old... he started expressing his emotions...How do we stop this? ... For me as a mother it don't matter if he was a little monster, eh? I hugged him because I was afraid he might throw something or hurt himself, eh? ...Because I always done that for my children when they were angry about something, I would just hug them, eh? For him, I guess it was different, he didn't know how to react to it. (Rosemary, November 2004).

Caregivers stated they had no mechanism for communication of any kind. This was certainly the case with Joey, who is deaf-blind. With no connection between the child and others in the home, the level of frustration was high and there was no developed basis for a relationship with family members:

We found it hard. We went through a very frustrating year where we just didn't

understand each other. We were getting over the frustrating period. We didn't know how to communicate with each other. We couldn't get our points across. (Brenda, November 2004).

Rural vs. urban accessing of resources

Parents/caregivers discussed several factors which made their situations stressful. These were often related to the added work of searching and accessing services, which was more of a challenge if one lived in rural areas. Furthermore, once resources were secured, families often encountered pressure from medical professionals, rather than receiving the support they were looking for.

Rural areas under-resourced

Four caregivers stated that non-urban communities are severely under resourced with regard to specialized resources for deaf populations. Alice felt strongly that "we don't have enough resources to meet a child that is only deaf ...from what I've seen...[a family] would be better off...in [name of city] where there is that hard of hearing school and deaf school (Alice, November 2004).

Rural caregivers also indicated they had no supports to assist them with decision making:

We didn't have resources up in (name of rural community). So you had to do a lot of research on your own. There isn't a lot of supports in (name of rural community) to help you make those decisions...The people that did help us were wonderful. However you need other families going through the same instances and we didn't have those supports. (Brenda, November 2004).

Urban services were described as specialized services whereas rural services were

merely generic services. This posed a challenge to rural families who, therefore, needed to access urban resources. Five caregivers reported having their child's hearing assessed at the largest city in the province. It was especially burdensome for rural caregivers to travel a full day to access these services. Brenda, for example, stated that getting her child's hearing diagnosed was an arduous process. Because her child was quite young, they were advised to have his hearing re-tested after a six-month period; however, after this time, the rural medical professional (audiologist) was still unable to provide her with an accurate assessment of her child's hearing loss. "Finally I brought him down here [name of city] and...received a confirmed diagnosis... We lost that [time] when we could have done something [intervention] in those six months (Brenda, November 2004).

...So I wish right from the beginning I would have pushed and had him come down here and have his hearing test done down in (a city). When we finally did push and have his diagnosis done, it was...through an auditory brain response where the child goes to sleep and they use different electrodes to test their nerve stimulation...it made me angry that it took a whole year to get him diagnosed. We first had to see the specialist...But then we had to wait until he referred us to the audiology department. That's a lot of red tape...I felt that no one cared about us. But we had to push. (Brenda, November 2004).

The irony, according to Brenda, was that many medical professionals pressure caregivers to "get on top of matters", only to encounter barriers that make it very difficult for them to do so:

Every literature I've read, every doctor I've spoken to, said you have to get on top of it right away, right, so that they don't fall behind in their learning. Well our

system took a year!! Everyone kept saying, “Oh, you have to do it right away! You have to do it right away! But no one was pushing. I felt as a parent we were the only ones pushing to get things done. That made me angry!! I felt...we didn’t have...supports whatsoever...doctors said, “Oh well, we got to wait”...We felt like we were a number not a person. (Brenda, November 2004).

Alice stated that, due to the limited rural resources, it was common for her son, Joey, to receive specialized communication services for the deaf-blind only twice a year from a visiting professional. In the interim, he received speech therapy on a limited basis at the public school that he attends – once every week or two. (Alice, November 2004).

Another issue identified was the limited opportunity to study sign language. “Because the ASL classes are not held very often, twice a year in (name of rural community) we couldn’t always make it to the second one so it was once a year we were learning sign.” (Brenda, November 2004). Glenda also commented on the limited access to sign language courses in her rural community, which only offered them once a year, without exception. Glenda stated “there was not much (louder voice) up in [northern rural community] at the time...[sign language classes] were mostly in Winnipeg...wasn’t anything being offered up here.” (Glenda, November 2004).

Caregivers further stated that the provision or cutting of services was not within their control. For example, Alice stated that the school provided services “at their discretion...whatever they think that he needs.” Alice, November 2004).

In desperation, one caregiver from a rural community inquired about a needed resource for her child, but was advised by an urban based agency that her best option would be to move her family to the city, where her child, could be offered more

resources. “That’s the message I got; I phoned Children’s Advocacy in [name of city].” (Glenda, November 2004).

Although she considers herself a “true northerner”, Brenda actually moved her family to the city in order to access more resources for her child. She was thus able to draw comparisons on the availability of resources based on rural or urban residency. She felt it was a priority that more resources be made available in the north. “Maybe all the families [should] get together once a month [to] just vent their frustrations on what they have done and different things they have tried [that] didn’t work and just be more of a support that way.” She is committed to remaining in the city for her child’s schooling, but moving has been difficult for her, and she would like to back up north. I wish that the government would realize that we need more up there (Brenda, November 2004).

Rural Social Isolation

Being under-resourced was one factor that contributed to a rural caregiver’s sense of isolation. The other was social isolation, which was described as not having deaf peers for their child, no access to the deaf community based in a distant urban area, and no other families to connect with who shared similar experiences. Glenda commented as follows:

[My daughter] has no one else that can speak for her. There is no one up here (rural northern community) that could communicate with her...no friends that can talk to her [and] go out and play with her. Nobody understands her and its hard for hearing kids to take the time to learn to communicate with her to be her friend. (Glenda, November 2004).

Glenda added that the deaf community is only available to families who reside in larger

urban centres:

And the deaf community only works down south. They help more up here [smaller city] now that we have been asking for it. But they are still down south. (Glenda, November 2004).

Relocation

Two participants moved their entire families to the urban centre that could offer them more resources for the deaf than their current rural communities could. One family arranged for their child to attend the school for the deaf that offered a live-in student residence. Aspects of relocation experiences included decision-making that led to relocation to an urban area, the relocation itself, adjustment to a new home, grieving, and slow adjustment.

Getting ready to relocate the family. Brenda was angry that her family was forced to relocate in order for her child to access the quality education that the school for the deaf is able to provide. They realized that he needed the “deaf school” in order to keep up with his education, but they did not want to leave their extended family up in the north:

We had to... We don't want our child to suffer either. He has to live in this society. So the decision was to move to [name of large city]. It took about a year for me to find work, to be able to move down. (Brenda, November 2004).

In one situation, the decision to allow the child to live in a residence at a distant school for the deaf was a very difficult decision. The adjustment process involved a grieving period for both the deaf child and family as described below:

“Well it's not that easy... It's hard to send your kid [at age] seven or eight, they are gone somewhere else...living in a dormitory. It was difficult. It was very

difficult to say bye. And then she come home and stuff. She was so happy to go to school in [name of city] with peers that could speak to her. The first year was really hard (Glenda, November 2004).

Grieving and Multiple Adjustments. Once the family moved to the city, the adjustment entailed a grieving process for the whole family. The transition was difficult because of the need to adjust to multiple events: adjusting to a new home, a new community, and a new lifestyle.

Relocating from a rural community to an urban setting is a very difficult process and the adjustment process is compounded with heavy feelings of grief and loss. Brenda stated that her child would cry himself to sleep every night. He would “beg and plead, “Why can’t we move back home where all our family and friends are?”” Challenges included starting new work and the children having no friends, as well as missing their old friends and their old school. You just kind of hold it together. It is the best thing for your child and you need to keep that in focus. It does get easier as you go (Brenda, November 2004).

Rosemary and Robert were faced with the added adjustment of living in an apartment that was quite confining:

You can’t make noise in here too, eh? Not like I’m doing over there [name of rural community]. Had to change all that. Yeah , like the things you do over there, things you can do over there. Like you go out in the morning and go hunting.

(Rosemary, November 2004).

Coping with Relocation. Three caregiver families expressed a similar coping strategy. They coped with their difficult situation by clinging steadfastly to the idea that the deaf

child would benefit in the long run. Caregivers stated that the school within their hearing community had not been meeting the special communication needs of their child and there had been no obvious efforts made by the public schools to effectively close this gap.

Rosemary and Robert focused on the belief that their deaf child was benefiting from the move, and this is what kept them in the city:

He is the only reason we are here [larger city]... I have lots of things back home [rural northern community]... It's more important that we be here [city]. We left it all so that he [deaf child] can have proper schooling. And that's all that matters... It's not easy, its not easy. It may look easy but to us, doing this is hard. But still eh? I want to go home... But again its more important for him [deaf child] to learn, eh?... I wouldn't be anywhere else because I really love [deaf child].

(Rosemary, November 2004).

Brenda added that relocation due to the lack of rural resources should not be forced upon families as in their case:

How come we had to move? Like to offer... [appropriate education] to him, because we are in the north [we] can't get those resources. That made me angry. I know it costs a lot to train people. It's harder to get interpreters up in the north. But why do people have to relocate to get the proper...education for your child? You have to make a lot of sacrifices moving – or even living in the north, compared to down here. I don't think that's fair. I think that we should all be equal, be it the north, be it the south. We should have the same. Maybe not the whole same amount but you should be pretty equal. (Brenda, November 2004).

An added challenge for families that relocated was the total unfamiliarity with the

city – being all alone and not knowing anybody at first, including the deaf community. Susan mentioned the importance of having a “signing sitter, and not just anybody, I wanted to know it’s a safe person” (Susan, November 2004).

Issues with the ‘hearing community’

Caregivers reported some situations where they experienced negative reactions from the hearing public, particularly people who did not seem to understand the implications of deafness. The common response was to abruptly shut down the communication they had begun with the child once they learned that the child was deaf. When a caregiver was present, people tended to address the caregiver instead of attempting to communicate directly with the deaf child. Most deaf children are offended by either of these responses. In the following case, the deaf child was initially considered to be hard of hearing:

They [hearing people] keep getting louder and louder and louder. “It doesn’t matter how loud you are, they are not going to hear what she is saying.” So there is lots of screaming at her. And people, they just stop talking to her because she can’t hear. (Glenda, November 2004).

Susan reported that her son is now old enough to be out on his own, and is learning to handle such situations, for example, by writing a note to let clerks or other people he may encounter know that he is deaf (Susan, November 2004).

One caregiver was certain that some people in her community would rather avoid the family with the deaf child for fear of saying the wrong thing and risks insulting the caregiver. “You don’t try to push on them what they don’t want to know, eh? They don’t want to insult you...rather just stay away from it. They don’t want to say anything.”

(Rosemary, November 2004).

Caregivers described situations where they witnessed their deaf child being treated unfairly. Carole expressed frustration that her sister-in-law would not allow her son, who was 8 or 9 years old at the time, to play with his cousins in another part of the house. “Well, it’s just that I don’t want him touching anything,” her sister-in-law had said. Carole further stated:

And she brought out a tiny Fisher Price little toy train. Way under his age...That’s when I said to her, he’s deaf, he’s not dumb... She doesn’t seem to understand that, and she’s a nurse with a BN, a degree and she doesn’t seem to understand that... She still treats him like he is dumb and he’s got no brains. I keep telling her, he’s in grade 5 he’s not dumb, he’s smart. (Carole, November 2004).

Carole also experienced negative reactions from people in other public contexts:

“...people figure...he’s signing, so he’s gotta be dumb. He isn’t. Just because you can’t speak they’re not dumb, or because he’s deaf, he’s dumb, too. It’s very hard to have people say that when you know that they’re smart (Carole, November 2004). Four caregivers encountered situations in which their deaf child was regarded as inferior or dumb.

Caregivers claim they have had more problems with hearing adults than with hearing children. Hearing children will directly ask why the deaf child talks in a funny way, whereas hearing adults will label the child as deaf and dumb. Susan stated that her son drew attention during a visit to McDonalds because he spoke more loudly than everyone else, being unable to self-regulate the volume of his voice:

It kind of made me angry because her kids were being just as loud. “Listen he

can't even speak properly – he must be dumb,” and on and on and on she went...

So I've had more problems with adults than I have children...I find the adults tend to label more without getting the facts (Brenda, November 2004).

Caregivers admit that such rude encounters do not happen often but do occur. And on other occasions, reactions from the public can also be positive. Brenda indicated that people will sometimes ask questions when they notice you using sign language, and she prefers to deal with questions rather than rudeness (Brenda, November 2004). Other caregivers concur that, in their experience, reactions from the hearing public have been mixed, depending upon the individual. For example, Susan described her experience with her child's baseball coaches:

If it's a...a new team or a new coach or whatever they are awkward. Then as the season progresses they relax. They realize the kid is a normal kid...then next year we have a coach who...right away demonstrates and puts them in the right position and cheers them on and immediately wants some signs – like tell me how to say good job, tell me how to say whatever. Really depends on the teacher and some people are so uncomfortable. (Susan, November 2004)

'Hearing children' who expressed curiosity and asked questions were regarded favourably by caregivers, who stated they would rather respond to the questions of children as opposed to listening to adults who have a tendency to label. They find that children are often fascinated by how deaf children communicate with one another, just like other “normal kids with lots to say”, and that they often “want to learn some signs” (Susan, November 2004). They feel that children are more open-minded about deafness than hearing adults:

Children come up [and ask the caregiver], “What are those things in his ears?” If you explain to them that his ears don’t work properly, they help his ears hear you and they’re all excited. And if you sign, what’s the sign for this one, what’s the sign for that one. The kids want to learn, they want to be a sponge. (Brenda, November 2004).

However, a few caregivers did report that, in some instances, their deaf children were mistreated by hearing children. Glenda stated that her daughter “tended to make noises” while at school that she was not aware she was making. “The way they [noises] felt in her mouth...the kids thought there was really something wrong with her – that she was handicapped” (Glenda, November 2004). Glenda went on to say that one of the students had followed her out of school, saying that she was retarded. “I [Glenda] said to him, “Who is the one who has the problem? You are calling her names and she can’t even hear you.”” The following were some of the most offensive incidents her daughter experienced:

And they threw matches at her one time. They [hearing children] did lots of mean [things]. There was one child. He had spit at her and she was covered in spit. So then my husband went to look for her. We found her and brought her home. I just about got sick. It was just gross!! We had to shower her. We had to wash her clothes. And then the next day she went to beat him up because he [the bully] didn’t have his friends. And the school gave her disciplinary notice. I said it wasn’t fair because the kid had done this to her so they removed the discipline. (Glenda, November 2004).

In another incident at an outdoor restaurant setting, Glenda’s daughter was subjected to a

boy who, in the company of his father, was throwing balls at her head and calling her retarded. The adult, who was with Glenda's daughter at that time, complained to the management, and the father and son were asked to leave. "...these things go on all the time." (Glenda, November, 2004).

Caregiver Work

Caregivers shared how they have responded to deaf specific barriers as well as the outcomes of their efforts. They also described the work they undertook to create linkages between their deaf children, and the deaf blind child, with 'hearing' others. Three approaches were used to facilitate such linkages. Firstly, it was necessary to build their knowledge base in order to respond appropriately to the needs of their children and families. This involved seeking information and resources regarding language development options in order to establish a mode of communication that was appropriate to each child's needs. Secondly, as they responded to the uniqueness of their children's needs in the pre-language stage, they began to lay the foundation for language and communication and acquired specialized knowledge and skills in the area of deafness or deaf blindness that would facilitate this process. Thirdly, once they developed a functioning language in the home, they were better able to link their deaf children with other social systems around them in both the 'deaf' and 'hearing' communities – in order to empower them to be able to function more independently in the larger community. Throughout this process, caregivers adopted a wide variety of roles and related skills in order to facilitate the best outcomes for their children.

Building a knowledge base

The pre-language stage

During this period of new learning, the caregiver experience was very intense. Caregivers in this study relied upon observations of their child's behavior, which provided them with experiential knowledge of their child's needs. In the period where there is no language within the home, the caregiver is left to figure out what the child wants. The starting point for most caregivers was to understand the uniqueness of their child. Alice explained: "Once you get to know your child, you just know what he needs" (Alice, November 2004).

Once caregivers had a general idea about the unique needs of their deaf child, the next step was to learn more about deafness. Caregivers gained information from organizations, printed material, and computer searches. Glenda had participated in a few workshops at the St. Amant Centre, and had obtained some information from them about different avenues to take. In her efforts to acquire relevant information about her child's needs, she had filled two binders with information (Glenda, November 2004). Susan stated that, once she and her husband have thoroughly researched an issue or a problem, they do a comparative analysis of the pros and cons and then are quick to take action (Susan, November, 2004). Some caregivers sought and located deaf resources within their community, within the province, and internationally. As Glenda stated: "[You] just [have] to go out and find the services for [your]self...you had to make phone calls, look in phone books, research, different types of things you had to look for. No, it wasn't given to you" (Glenda, November 2004).

Resources that promote sign language development

Sign language training opportunities available at a city were described as positive experiences. Urban caregiver families had easier access to sign language training

opportunities, even if it meant paying a tutor to come to their home and teach them sign language. As well, urban caregivers could enrol both their 'hearing' child and deaf child to a day-care centre where sign language was practiced. Comparably, caregivers from rural areas enrolled their children in pre-school community programs that did not always offer sign language at their site.

Susan described the specialized day-care and classroom options available in urban centres:

Officially you have to be two years old to start at Sign Talk, [the] day-care [where] ASL is one of [the] main languages. But you can get special permission to go earlier at 21 months, when he started going part-time, just to get more sign language exposure – from then on through preschool. He went there half days and half days to SMD in the ASL classroom. So it's always been his main language... Kids learn it so easily. [Susan, November 2004].

As an urban resident, Susan was able to organize for a private tutor to come to her home on a weekly and, later, a bi-weekly basis to train her entire family, including interested extended family members. In addition to private sessions, Susan learned about numerous additional programs. She found that the Continuing Education program in her area offered beginner to advanced ASL courses in high school settings, an opportunity for her whole family to learn how to sign. Furthermore, a one-week ASL Immersion Program was available through SMDI during the summer months, and other activities and events were available through contact with the Manitoba School for the Deaf (Susan, November 2004).

Laying a foundation for language and communication

Establishing language: Deciding on a course of action

Caregivers encountered challenges and difficulties in deciding on a communication method between themselves and their deaf child. For example, caregivers often reported that they were pressured by communication specialists to select a mode of communication within the field that he/she represented. At first, all caregivers had looked to hearing aides as a possible option to bridging the deaf hearing gap, but found their children did not want them because they gained nothing from them. Brenda shared her experience as follows:

The first challenge was: Which way should we go with him? We felt we were being pushed that he should only be oral, that we shouldn't sign with him, and that we should just use his ears and oral. (Brenda, November 2004).

Caregivers living in an urban setting had the opportunity to try various communication options:

We started with ASL first and [also] spoke to SMD [Society for Manitobans with Disabilities]...then we had him fitted for hearing aides and they sent a tutor to the house... [We] worked on stuff like recognizing if a sound was on or off – something loud, like the radio. Whatever we did, the drum, he would just get so frustrated because he never knew what [we] wanted out of [him]!! (Susan, November 2004).

After trying different communication methods, Susan found her child responded best to sign language because it had visual characteristics to it:

As soon as we...felt we could do something, we started learning ASL. And...our kid was so ready for language...fourteen months old...The minute we fed him

signs, he learned them. He was just pointy, pointy (pointing with finger) tell me, tell me, tell me! (Susan, November 2004).

Susan had grappled with whether it would be easier for the hearing family to learn sign language or for her child to learn oral English. It had become increasingly clear that it would be easier for hearing members of the family to learn sign language (Susan, November 2004).

Communication supplements

Caregivers reported using ‘communication supplements’ as a means of enhancing the connection and communication between themselves and their deaf child as well as creating a more effective learning experience for all. Caregivers used visual techniques to facilitate greater understanding. This included playing games, role playing, using sign language dictionaries, as well as creating and posting laminated ‘signed’ pictures around the home. Brenda used many of these techniques to ensure that family communication was effective. Caregivers also reported that physically showing or demonstrating what you mean to a deaf child is also very effective. Brenda made the following important point:

Signing is through pictures *and* sign. You can’t just say the word. It is more inventive. It takes a little longer, to get things across. If it’s a new concept he’s learning, you have to invent ways of teaching him new things. So it does take longer. (Brenda, November 2004).

I actually got books...photocop[ied]... the entire book...cut them out...laminated them and posted them all over the house...on the TV...on the sink...I made up little books for going to the zoo...all the signs for different animals and different

outings that you would take. (Glenda, November 2004).

In the case of deaf children, the majority of caregivers indicated they had responded to the early need for communication by labeling pictures as well as “learn[ing] sign from a book”. Brenda shared how she uses ASL dictionaries and demonstrates meanings of words through role play (Brenda, November 2004), while Carole mentioned the importance of visual modeling or demonstration of practical skills such as swimming to facilitate learning (Carole, November 2004).

A communication tool mentioned by Glenda was a TTY, which is designed to hold a telephone receiver and, with its attached key pad, enables the deaf to contact the operator relay services; the operator will then ‘voice’ to the ‘hearing’ and type the responses of the ‘hearing’ back to the deaf person. Glenda stated that for a deaf person, particularly if living in a rural community, it is an issue not to be able to use a telephone in cases of emergency. “[My daughter] requires a TTY. I have one at home. She has one at school... But for her to go to the store and phone me she can’t do that. If there was an emergency she can’t do it” (Glenda, November 2004).

Communication rules and protocol

Caregivers reported additional ways of facilitating greater understanding between themselves and their children. Most stated that more effective communication between themselves and their children required the development of an agreement, much in the same way that unwritten rules are established. For example:

You...can ask him to wait...for awhile...But you can’t just push him away or just tell him to stop. You can’t do that unless it’s very vitally important, where you’re taking care of a cut on a hand, eh? You have to know when [it] is a good time for

certain conversations. And he has to understand that. He will just come and tap you on the hand and go like this, eh? Then you'll know he wants to talk to you. (Rosemary, November 2004).

Just because he doesn't come back for the second time to remind you doesn't mean you can ignore [him]. You have to know that...because if you expect him to listen to you then he will expect you to listen to him...That's the thing (slight chuckle) it's tough but paying attention to him, it's very important. Being here, just looking at him, acknowledging him when he is talking to me, is more important. (Rosemary, November 2004).

Caregivers established communication protocols based on how they observed their children to be sensing, responding to, and engaging with their environment. Rosemary commented on the importance of tuning into one's child: "You know, he can feel you, he can sense your emotions, 'cause that child can read you. Their perceptions [are] very sharp" (Rosemary, November 2004).

For the deaf-blind child, communication depended upon his ability to feel objects with different texture and shapes. He would touch items that symbolized or let him know what event would occur next. For example: "He goes to his little calendar, grabs his coat, or a little miniature something...when he goes to school, he has this texture thing, so he knows he is going to school in the morning" (Alice, November 2004).

Alice also developed a very safe and structured home environment as well as consistent routines that helped her son to feel secure and to have some level of agency. This involved not only the way the home was physically set up in terms of furniture, but also the smells associated with certain daily routines. These were all cues that

communicated to her son where he was. Alice found it very challenging. “You just kind of find other ways to communicate and play with him...It’s really important about the routine...[if] you don’t know what’s happening next, it must be very scary and confusing.” She further indicated that, since he knows his home “down pat”, it was very difficult to take him out of his environment. For example, she was unable to go to a restaurant or to other people’s homes “because he touches everything; that is how he communicates” (Alice, November 2004).

Alice was convinced that her son can communicate with others, but stressed that it is important for ‘hearing’ people to follow the specific communication rules and protocols that he had become accustomed to:

...he doesn’t use sign language and he doesn’t use words. But there are many ways to communicate. I can tell he had enough because he will start fussing in a different way again. You know I want out of here. The way he whines, the way he cries. Before he cries, he’ll start doing like this (uses her hands to demonstrate tapping the arm of the chair) on his little chair. So I know he has had enough. (Alice, November 2004).

Alice added that the tapping is also used as a cue that they will be moving from one activity to another.

Alice emphasized the importance of having a consistent educational assistant at the school as a regular contact for her son. Having a substitute replacement created a significant disruption to his routine which took him a long time to adapt to. Alice stated that the educational assistant learned to meet her son’s needs “by knowing the difference in whines and crying and body movements”, a skill that took months to develop.

Family communication reaches a functional level

Functional level of sign language

Once caregivers were able to use sign language consistently, their family life became easier. There were not many communication issues within the family unit once the deaf child and ‘hearing’ family members learned the same language. This was especially the case over the years as communication increasingly improved.

Reciprocated language

After taking a number of sign language classes, viewing sign language videos, or using a sign language dictionary, caregivers declared themselves to be at a functional level of sign language. This meant that they had the capacity to have a conversation with and be understood by their deaf children and were able to understand what their children were conveying to them. Sign language skills ranged from family to family. Sign posts that caregivers have reached competence with sign language include the ability to compare the characteristics of sign language with oral English.

Caregiver families knew they had reached a functional level of sign language when they recognized that their children understood them. Four of the six caregiver families were in this position. Carole put it very simply: “We are now able to communicate...Once he learned to communicate, [he could] tell us [when he] was mad or...was thirsty or he was hungry...before you didn’t know what he wanted” (Carole, November 2004).

However, they also recognized that they were able to communicate with their child, but could not talk to anyone at an advanced level of sign language:

I wouldn’t know how to talk to an adult on his terms...the way I would talk to my daughter. I understand her and... can communicate with her. But don’t ask me to

go and communicate with somebody at school because I would have a really rough time. (Carole, November 2004).

One caregiver, however, was at an advanced level similar to or above her child's sign language level. They could discuss abstract topics:

If he needs to talk about life and death, or some scientific fact...we communicate about it. So I think that's key! (Susan, November 2004).

Although one caregiver stated that she and her child had achieved functional communication, she still questioned if her child really always understood what she meant. In such situations, most caregivers solicited the assistance of the school for the deaf to explain more abstract terms to their deaf child.

Role reversal

Role reversal was a situation that occurred in the family when the deaf child, who attended the school for the deaf, was learning sign language at such a rapid rate that surpassed the functional level proficiency of his or her own family members. As a result, the deaf child was now teaching family members, and anyone that was willing to learn advanced levels of sign language.

In one sense, this role reversal created another communication gap because family members were struggling to keep up with the progressive learning of new words. However, role reversal also contributed to closing the gap by transfer of skills from the deaf to the hearing using language. Three caregivers stated that they learned more advanced sign language from their deaf child: "We're both good at signing, and every week, [our son] brings home fifteen new words. So... [we] have to learn fifteen more words, if [we] don't know them already" (Carole, November 2004).

Bilingualism

Families of deaf children can literally be considered to be bilingual as they are communicating in two distinct languages. However, although language skills were at a functional level, caregivers reported that it was sometimes difficult to maintain bilingualism in the home. This occurred particularly during large family gatherings, as there was a tendency to shift from sign language to oral English, especially when the deaf child was not directly involved in the conversation. Susan expressed her efforts to balance the use of both languages at such times (Susan, November 2004).

Ongoing communication issues

An established language does not mean communication gaps no longer occur. There are situations in which the child will miss information, even within the home that has established shared language that the deaf child can understand, as demonstrated in the preceding example. Whether communication gaps occur within or outside the home, caregivers may need to provide deaf interpretation to repair the communication breakdown. Susan observed the following: “He is not being included in all the conversations and that is an issue. That bothers me. It bothers some of the other family members. They noticed it. I’m not sure if there is an easy answer” (Susan, November 2004). Caregivers reported that, as long as the hearing public does not take sign language training, there will always be a communication gap. However, caregivers also suggested that the ‘hearing’ appear to be uncomfortable signing in front of others, which may hinder them from signing in public (Susan, November 2004).

Functional communication extends to relationships outside the home

As a result of language development, the child and family are able to engage more

effectively. Successful communication at the family level also extends to other social networks. This section describes efforts made between the deaf child and others during this functional stage, although the communication may not be as successful as that within the family.

Integration with the deaf community. The integration process for the deaf child to the deaf world was a natural process. This was the case for those who were able to access the deaf community for support. For ‘hearing’ caregivers, it took some time to develop a relationship with and feel accepted by the deaf community but, once formed, this was regarded as a valuable support to the family (Susan, November 2004). Carole commented: “[At first], they didn’t treat you quite the same, and now there is no problem. Now we’re deaf culture, and we are deaf people as far as they are concerned. But it was difficult at first” (Carole, November 2004).

Integration with the hearing community. Once language skills were at a functional level, caregivers were equipped to transfer their knowledge regarding communication with their deaf child to other hearing people who were either professionally or socially involved in their child’s life or who expressed an interest in communicating with their deaf child. This required active engagement with the parties involved in order to facilitate a mutually beneficial experience that also empowered the child by acknowledging him/her as a capable individual. Integration approaches and strategies used by caregivers and families will be discussed in the following section on acquired caregiver roles and related skills.

Acquired caregiver roles and related skills

As caregivers gathered information, moved through the process of establishing language skills, and reached a functional level of communication with their deaf children

within home and community, they adopted many roles that were critical to effectively meeting their children's needs.

Advocating

Caregivers learned to be strong advocates for their children on many levels of need. Regarding advocating for services, they reported that this was very time consuming and was not something that came naturally. Glenda commented that “you never realize how much time you've spent just getting services for your child. If I didn't ask for it, it wouldn't have happened. So the best thing is asking for things” (Glenda, Nov 2004). Alice described the persistence required to acquire services, in that you spend time discussing your child's needs with one service provider, but then may be referred to another one because “we have to follow protocol” (Alice, November 2004).

Two caregivers reported that not all advocacy efforts were successful. In some cases, requests have been rejected by the local school board. For example, after advocating for the training needs of their child's educational assistant, Glenda was told by the school board that, since this individual was not a teacher, she was not eligible to travel to an urban centre to acquire sign language training. Glenda went on to say: “You might want ten things but [only receive] one thing. It's...good at least you accomplished something... I don't know necessarily if it's an accomplishment for society [as] a whole but it's a little accomplishment for us” (Glenda, November 2004).

Glenda used her growing advocacy skills to negotiate for signs to inform drivers that a deaf child lived in the neighbourhood:

...my daughter had almost got hit by a car...She was about four. So I...approached the city to get...street signs. Mind you, they don't listen to the street signs

anyways. But they're there and they [the public] can't say they didn't know because they are there and posted. (Glenda, November 2004).

Two caregivers reported that they eventually acquired advocacy skills over a period of time:

I expect a lot of help and...a lot of support. I usually don't stop until I get what I need. If the child has a need where I feel I need respite, they should be involved with Children's Special Services. Tell them this is what I need...But not many people are forward...You have to...remember you are not being selfish. You are doing this for your child. They are the providers for him. It's up to them to get what I think he needs within reason. (Alice, November 2004).

That is something I've learned. Just speak up as a parent when something is not right. I've learned from him. You have to push and you have to push hard for what you think is right for your child. I know there [are] a lot of people in the world and... a lot of people [who] have disabilities... But why do we have to push to get things done?!! That frustrated me. I know... other people [may] have more difficulties than he does, and they might be a little bit more of a priority, but I just felt like no one cared, and that hurt me in the beginning. Once I learned that I can push (laughs), I pushed and that helped things. (Brenda, November 2004).

Providing supervision and safety

Caregivers reported there was more intensive supervision during their children's pre-school years as opposed their current ages. Less supervision was required as the children got older and acquired more and more training and experience. Susan stated that, at age 3 or 4, her son would tend to wander, and calling him back was not an option. "I

was always...holding his hand...because I knew I couldn't call him [at] the last minute, Watch out!" As her son has gotten older, "he is very visual, very attentive as to what goes on in his environment." Susan added that, as a parent, you must learn to be less protective at this stage, for example, because "deaf people drive cars and drive them as safely as hearing people...despite the fact that we think we need a horn to notice something" (Susan, November 2004).

Providing emotional care

Another important role was to provide parental support to manage emotions of the deaf child who is unable to vent feelings in the same way a hearing child expresses through words:

...as a deaf child, he shows more emotions than a hearing child would...he shows a lot of emotions. He likes to have cuddles. If you tell him you're upset with him, he'll get really upset...he'll go to his room. He's very upset because he doesn't know what he did wrong. Even though [I] tell him what he's done wrong, he really isn't quite sure. He knows that you're mad at him and that he did this, but he doesn't know if he should be mad...But I think his need for emotional care and comfort is because he's deaf. I've seen it in other children that are deaf. (Carole, November 2004).

Intervening

In two situations, children were bullied by hearing children, one by school classmates and another by neighbourhood children. Glenda describes how, if she had not intervened to explain the situation to the hearing authorities, her daughter would have been further victimized and labeled as having caused the incident:

[Bullies] had humiliated [my daughter]. And what was she supposed to do? Was she supposed to sit there and take...being bullied all the time every day? Or does she go to stand up for herself and say: No, I am not going to take this? So they took away the disciplinary notice. (Glenda, November 2004).

Situational education of the public

Caregivers reported that they encountered many situations in which they educated the public. In some situations, the public were genuinely interested. In other situations, the caregiver intervened because their child was being mistreated. Carole shared how she responds to children who assume that her son cannot communicate at all: “Whenever we see little kids and [they] say: Oh well, he can’t talk, I’ll say: No, but he can talk. He can talk better than you because he has to talk with his hands” (Carole, November 2004).

Teaching

Several caregivers reported that teachings for their children were more effective if they were provided by spending one-on-one time with the deaf child, and learning was also enhanced with the use of repetition. One caregiver who lived in a rural community relied on the use of videos to teach her deaf child, especially when it came to teaching abstract concepts. Teaching occurred in many different forms throughout the child-raising process, including the teaching of language and the use of communication supplements and learning through exposure to different life experiences.

Deaf interpretation/Communication facilitator

Caregivers reported that one of the main roles in parenting a deaf child is their role as an interpreter. This role was assumed once the caregiver had attained enough knowledge of sign language to facilitate communication linkages between their child and

others: “So if she [goes] to swimming lessons, I [have] to go to swimming lessons. I have to be her interpreter. But then I tend to go to her sporting events” (Glenda, November 2004).

Susan mentioned that, in the case of family members who did not have ASL skills, interpretation was a necessary way of facilitating their relationship with her child.

Several caregivers reported that the hearing sibling of the deaf child would often assume an interpreting role:

When he is with [‘hearing’ child], she is the first to [speak]. She does all the talking for [him]. If someone says something directly to him, [‘hearing’ child] will say he is deaf, he doesn’t hear you. Then she may answer the question. I mean she doesn’t always play that role. As I said, she is a kid, she can’t play that role. (Susan, November 2004).

Caregivers at a functional level of sign language also recognized that they were not able to perform as a qualified interpreter could, and preferred to regard themselves more as communication facilitators between the deaf and hearing:

I communicate for [my daughter]. She’ll say: Tell them what I am saying, or, what are they saying? And I do that for her. I am not qualified to be an interpreter. You have to take years and years of schooling to do that, at different levels, and you got to immerse yourself in the culture. And I would never claim to be that, but I am all she’s got. (Glenda, November 2004).

Caregivers described the task of being a communication facilitator to be about clarifying the meaning of what one may be trying to communicate to the other when one or both parties are in doubt. “His friends will usually say: I don’t understand, could you tell me

what he means?” (Brenda, November 2004).

Coordinating role

A significant role assumed by the caregiver of the deaf-blind child was to coordinate the home therapy and communication among various service providers throughout the medical and school systems:

I meet with them at school and they have his EA, the educational assistant, the resource teacher, myself. You meet as a team and go over the goals from the previous month, or the previous visits, those that have been reached already. Then if not... we make some modifications. If we didn't meet it this way, then let's try it this way. The section on communication is followed by the school speech pathologist. (Alice, November 2004).

Alice reported that she needed to coordinate all the medical service providers who were in her child's life. This team included an occupational therapist, who helps with fine motor skills, as well as a physiotherapist who focuses on gross motor skills. She felt that she needed to “keep on top of it” all the time. She planned to raise the issue, at the school, of needing two trained EAs (educational assistants) available for her child, not just one. If neither was available, then she preferred to have her child at home where she knew he would be safe. “I know that the school is reliable, but in the end he is the one who is going to get hurt” (Alice, November 2004).

Training family members to care for the deaf-blind child

Another role played by the caregiver of the deaf-blind child involved training family members so they had the capacity to assist with his physical care needs. It was critical for this child to have consistency and structure in his environment both at home

and at school. His mother described this process as follows:

They [can] even tube feed him and flush him. They know how to change his gauze. They [family and close friends] do everything, they know the routine... They are like part of the family. So, yeah, you had to train them. It's all understood for a long time, since seven years. Normally we try to follow through the same thing with him so that he learns and he catches on. (Alice, November 2004).

Facilitator: Integrating deaf children into the larger community

Caregivers were in a pivotal position to facilitate the integration process. Having acquired many skills as a result of the many supportive roles they played, they increased their competence and were able to create positive linkages between their children and others in the community. Caregivers recognized the importance of their children participating in the deaf world as well as the hearing world and encouraged their children to be connected to both. Specific roles came into play as caregivers set the stage for their children's growth and development in these directions.

Facilitating social relationships within the deaf community. Most of the deaf children living in an urban centre had deaf peers that they had met through the school for the deaf, which became part of their family's social network.

Both Carole and Susan stated that they had acquired a large network of friends over the years (November 2004). Caregivers also made sure their children's network consisted of 'hearing' friends, families, and deaf peers. This was not possible for deaf children in rural communities as they had bad experiences being bullied and experienced social isolation due to the lack of deaf peers to relate to. For these reasons, one family provided

closer supervision of their deaf child, and restricted her social contact to primarily family. *Facilitating integration with the 'hearing' community.* Such integration often started in a family's own neighbourhood. Parents reported that their deaf child and 'hearing' playmates learned to adapt to one another and figured out how to communicate with one another without signing. Parents encouraged such social learning and intervened as appropriate as a 'communication facilitator' in order to clear up any misunderstandings that may arise.

Caregivers reported they encouraged their deaf children to participate, not only in programs or field trips offered by the school for the deaf but, also, in extracurricular activities offered by the 'hearing' community. This may include activities such as baseball or other team sports, which offered further opportunity for deaf children to develop relational and assertiveness skills in a 'hearing' world:

Things in the 'hearing' community: he plays baseball, soccer, swimming lessons, speed skating...there is no one that signs usually. He plays baseball on a team with a deaf friend at the Manitoba School for the Deaf and that works out really nicely because there are two of them. And then there are four of us parents and everyone signs. So we sort of take turns and, yes, we play the interpreter role.

(Susan, November 2004).

Susan reported that her son feels the 'hearing' should make more effort to connect with him" – that some people sign with him and others do not. Susan expressed her belief that her son "should try a little harder, too...to take the time to sign to them slowly so that they will learn...get better and get motivated, but sometimes he can't be bothered"

(Susan, November 2004).

In rural areas, caregivers had few options for their deaf children, and thus facilitated linkages of their child to various social systems in the community, even though these programs were not optimal:

[My son] was basically the first deaf kid in the school system up in [name of community]. So they [public school] were learning from it. They were good in some respects. Teachers, and stuff like that, they were very willing to adapt their school or their classroom for him. (Brenda, November 2004).

Thus, in the process of facilitating linkages for her son in the larger community, Brenda's role also became one of educating the public school with regard to her son's special needs. Although no one at the school had sign language training, communication between home and school was maintained through the use of a communication book that kept everyone on the same page.

In the case of two rural caregivers, efforts to facilitate a linkage between their deaf children and the larger community within the context of the public school system were not bearing positive results on the level of learning as well as social relations, because of the lack of a common language. The decision was, therefore, made to seek more positive social and learning networks in an urban setting where supportive resources from the Manitoba School for the Deaf would be much more accessible [Glenda, November 2004].

Caregivers described the Manitoba School for the Deaf as a valuable support in several ways. Not only do they offer basic language, learning, and communications skills and promote vibrant social networks, but they offer teachings related to safety and independent living skills that parents are able to reinforce in the home. Supports of this nature were regarded as important for the natural integration process of the deaf child into

a 'hearing' world.

In recognizing that their deaf children needed more independence, caregivers often set up situations in which the deaf child had to address the 'hearing' public, such as going for a hair cut, or ordering food at a restaurant:

We try to get him more independent, so we'll...drop him off and tell him to go in and...tell her that he wants a haircut [while we park the car]. And usually by the time we go in, he's sitting down waiting for her to cut his hair...no problem. He's given her the money after and...[a] tip...he's able to communicate. (Carole, November 2004).

Susan encouraged her son to order his own food at a restaurant or food court. "He is old enough. We give him the money and he...gets it. He brings paper and pen...and he is independent...that is what he'll do later in life" (Susan, November 2004).

Some caregivers described that their children's language skills became quite advanced, such that they were capable of teaching 'hearing' people to sign. Parents strongly encouraged this development in their children and validated their ability to thrive and grow with the tools of their own culture (Glenda, November 2004).

The following is another example of a deaf child teaching 'hearing' people:

... ['hearing' sibling's female friend] ...is around a lot and...trying very hard to sign ... for him...he'll watch her and know that she's trying to learn. He does teach some people sign... ['hearing' sibling's friend] is...one that he teaches. And over at the babysitter's, he'll teach their kids to sign, too. (Carole, November 2004).

Adjustment to Deafness in the Family

Caregivers, over a period of time, acquired specialized skills and knowledge on

deafness which included the following: learning sign language, navigating the health system to access deaf resources, and gaining a specialized knowledge of deafness. At the adaptation or adjustment stage, caregivers learned to overcome obstacles related to their child's deafness.

Aspects of Adjustment

Glenda indicated that her method of coping was to regard a problem situation as a matter of personal choice:

If you were to let it sit there and simmer, it would be not a good thing. I think it would make you sick inside. You have to kind of let it go and: "Let's go on to the next thing." (Glenda, November 2004).

Having accessible information about deafness was critical in order for families to move through the adjustment process more effectively. As one caregiver reported:

We are used to doing research. We intuitively knew some stuff like the library and internet, but some [other] places were [also] really helpful. Our first reaction was: "What is there here in the city?" and we were referred to SMDI [Society for Manitobans with Disabilities] I remember meeting a social worker [there], and she was very helpful, and right away realized our bets were already ASL. Gave us some literature, gave us a really good book to read. We...contacted Manitoba School for the Deaf, knowing that...he didn't need that for years. But I wanted to see deaf kids in action...and there we met people... [who] told us about...newer ideas of bilingual bicultural education and the theory behind it. We...bought every [book] we could get our hands [on] about parenting deaf kids... a family friend...their brother is a psychologist who works...in Vancouver with deaf

individuals...He knows ASL and ...provides whatever support they need...we were on the phone like three hours long distance and he just gave me a ton of...general information, a lot of reassurances. (Susan, November 2004).

Two caregivers reported that setting up a “system” of day-to-day routines in the home contributed greatly to the adjustment process and benefited the whole family. For Alice, this involved encouraging her family and friends to acquire training so that they could help support and maintain set routines, linkage of supports, and consistent communication among the helpers (Alice, November 2004). One caregiver scheduled a Saturday to do special activities, such as shopping, yard work, or even a supper out. It required dedicated time, however, to ensure that the “system” within the home was maintained. This involved consistent communication, ongoing training, and focus on the needs of the family as motivators to keep a good system working for the family. Most caregivers indicated that the positive support of a spouse contributed to the adjustment process:

We had to do some convincing of our parents maybe. But not of each other. We both read the same stuff. Felt the same way. Interpreted the same way. We were lucky in that sense and saw the priority the same way. So it didn't take long. (Susan, November 2004).

Caregivers shared that, once the needs of their child and their family were looked after, they looked after themselves. Glenda stated that she goes to the gym to work out: “So it's necessary – you feel so much better after you punched a bag” (Glenda, November 2004).

According to caregivers, some aspects of their adjustment involved problem-

solving how to negotiate various public situations. The following example reflects the process a family undertook to adjust to restaurant outings over time:

We used to find it really, really hard to take him any place. To take him to a restaurant or any place, it was big a pretty big thing. We just didn't bother to go out because it was too hard for everybody. Everybody would get upset. But now...he loves to go out to eat. We'll do games or stuff that will keep him busy and occupied. We often play 'I spy' in the restaurant, so then this keeps him busy and he is waiting. He knows what he wants to eat. I think that over the years he's gotten better and we've gotten better. (Carole, November 2004).

Formal supports for urban and rural families

Part of the adjustment process involved facilitating the establishment of linkages between the deaf and the hearing, providing supports to the child, the caregiver, and overall family. Such supports were received in several ways.

Rural caregivers eventually received printed material from professionals. As well, the caregivers in this study had their child assessed by the school for the deaf, which also provided them with a report of their child's strengths and weaknesses. One caregiver reported:

They [mobile therapy] gave me sign language books and different types of things and I started taking sign language courses in [name of city]...They [school for the deaf] would do assessments and referrals back to the school, and what areas they should be focusing on. So the school [for the deaf] in Winnipeg is really good (Susan, November 2004)

Although caregivers pursued their own information, some information or options

did not benefit the family and were dropped, as mentioned below:

The Spencer-Tracey clinic, it's a correspondence thing, and they send letters back and forth to you and give you exercises to work with your child. You send them a report every week and you get to know one person who monitors your experiences. We did that for awhile but...eventually we felt that was pointless and we gave up (Susan, November 2004).

Caregivers commented that the city had only recently started to provide deaf interpretation services along with their recreational programs. This was highly valuable to the caregiver families:

The next year the city of Winnipeg got funding for interpreters for any city of Winnipeg programs, parks and rec kind of program. So now we get a professional interpreter each time for swimming lessons and it was way better (with emphasis). (Susan, November 2004).

As families felt more and more adjusted to their situation, they knew they had supports and where to locate them if needed. Alice stated: "If I had any issues, I could phone the social worker, but I didn't need anything (Alice, November 2004). She went on to say:

I have never been in a situation where I was so overwhelmed that I didn't know what to do or who to call. There is always somebody to call and there is always somebody to tell me what I should be doing, and what I shouldn't, or just change your whole frame of thinking for the moment. I just tell myself, you know, one day at a time. (Alice, November 2004).

Programs and services employing staff with sign language skills were more

available in the city as opposed to rural areas. These included a day care; children's summer camps that served both deaf and hearing children; sign language classes; private tutors; child care providers; and many other organizations and professionals who work with children with hearing loss.

Adapting to a new language

Caregivers reported that they have adapted to a new language and are able to maintain a bilingual language system within their home, in which 'the hearing' are particularly considerate and include the deaf child in as much of the social interaction as possible. One caregiver stated the following:

It's totally part of our life. It actually added a really neat dimension to our life, you know, social community – a group of deaf people that are friends. Part of our social agenda includes the deaf community. My [hearing] daughter likes them too. Those events are part of her life as they are part of ours. I miss people if I don't see them. (Susan, November 2004).

Alice encouraged family and friends to acquire training in sign language so that they could participate in integrating the deaf child into the wider community (Alice, November 2004).

Developing social networks

Caregivers developed their own social networks. They indicated that it was much easier for families who lived in an urban environment to meet with other families also raising a deaf child:

Here [name of community] I got a long network of people...families, other kids that go down to MSD (Manitoba School for the Deaf) ...it's really good...a close

knit group. Not everybody, but certainly with a whole bunch of families. That's really nice support and, for the kids, you have them over for dinner and they go out and play and there is no communication issue... (Susan, November 2004).

Lessons learned

Caregivers shared that they have learned tremendously from their parenting experiences. For many this has meant a life-long learning experience. Experiences were seen as "learning how to parent" and in some situations "you take two steps back and then you just start again". All caregivers, including the male caregivers in this study, indicated that they did not focus on their own needs, but placed the focus on the needs of their child, which helped them endure many of the difficult situations they encountered. Robert put it very simply: "My kids are grown up already. When I was young, I didn't realize these things. Now as I go along I learn more and more (Robert, November 2004).

Alice has this to say about her experience:

It's a lot of work. But, you know, nothing gets done without a lot of work. At the end of the day it's worth every moment that I spent fighting and arguing and just dealing with day to day life. It's a lot of work, you know. But, you know, there is also reasons that it is worth every minute of it, right. (Alice, November 2004).

Taking into consideration the many different ways of coping with deafness, caregivers described coping as a natural process in which "over the years we've both grown, all of us have grown". Sometimes caregivers recognized just how much they had changed when they reconnected with old friends with whom they had had no contact for a long period of time. Susan explained as follows:

That was a fairly intense period [talking to her friend]. Then, it was like, "Can we

just get on with normal things now?!” Then you have friends... [that] you haven’t seen in awhile and a year later, for them, it’s all novel. They want to delve in[to] this. So you sort of educate [them]: “But it’s not an issue anymore”. And they think it should still be. “Why aren’t you still worried about this?!” No, not really you know (chuckles). Why are we rehashing this out so? (Susan, November 2004).

Recommendations made by Caregivers

Caregivers made numerous recommendations based on their personal experiences caring for a deaf child and navigating through the system. Their recommendations fell into four basic categories:

- (1) caregiver need for information about child’s handicap and available community resources, advocacy, and support regarding decision-making about child’s care;
- (2) caregiver need to be able to access the resources that *are* available;
- (3) need for a more balanced distribution of resources provincially so that rural communities are not so resource depleted; and
- (4) need to address issues of social stigma and isolation.

1. Caregiver need for information about child’s handicap and available community resources, advocacy, and support regarding decision-making about child’s care

Caregivers stressed that, in the early stages when a child needs to be diagnosed, information needs to be readily available for parents. The recommendation was made that an information package be prepared by, for example, the Society for Manitobans with Disabilities (SMD). This information package could include a wide range of information including a list of subsidized resources available to families and what costs may be

claimed on your income tax.

Caregivers participating in the study identified the need for new caregivers to be prepared to encounter and deal with the medical community. New caregivers are advised not to allow the medical system to pressure them to act quickly; rather, they are encouraged to take the time to get all the information they can in order to make informed decisions that they will be able to live with. It is strongly recommended that new caregivers “listen to their own inner voice...nobody knows your child better than you do” (Glenda, November 2004). It is further stressed that approaches to the communication, care, and education of their children need to be tailored to some extent to suit the child’s particular needs, and not be standardized.

Caregivers interviewed in this study stated that more education is required for new caregivers. “How is she going to ask for something if she’s not aware it’s out there?!” It was stressed that if new caregivers are more educated, they will be better able to advocate for their children. Caregivers recommend that new caregivers also get guidance from those who have already been through the process and can tell them in hindsight what worked well and what they would have liked to do differently; this saves cutting through the ‘red tape’ (Alice, November 2004).

One caregiver recommended that there ought to be northern workshops or conferences organized annually or bi-annually which, among other things, could offer information from a range of professionals to parents and families (as well as the larger community) about the needs of deaf children, steps to take in planning a child’s education and care, and the options and resources available. Speech pathology, audiology, social work, and pediatric medicine were identified as a sample of professions that ought to be

represented at such events (Alice, November 2004).

It was strongly emphasized that new caregivers need to be connected to formal resources, specific to deafness, so families may pursue language development with their children as soon as possible, and be provided with the knowledge, tools, and training to lay that foundation (Glenda, November 2004). Part of this education includes raising parents' awareness not only about their children's disability, but also their strengths and capacity – what they can expect from their child.

2. Caregivers need to be able to access the resources that are available

The caregivers interviewed in this study identified numerous systemic barriers that need to be dealt with in order to improve access to necessary resources. Given the limited special resources in rural and northern areas, families needed to access information as well as urban resources in a more timely way in order to better meet the needs of their deaf children and not prolong the absence or shortage of critical health care as well as developmental learning experiences. Many of their recommendations for increased resources in rural and northern communities are highlighted in the next two recommendations that underline the need for more balanced resource distribution province-wide. In lieu of adequate services in rural and northern areas, one caregiver suggested greater use of telephone or video conferencing with specialists in the south (Brenda, November 2004).

3. Need for a more balanced distribution of resources provincially so that rural communities are not so resource depleted

The majority of caregivers emphasized the need for more resources in rural and northern communities to facilitate critical access. They stressed that a deaf child has a

right to an education in his/her home environment, and that families should not feel pressured to relocate in order to access resources for their child.

Caregivers identified several resources that would be helpful in rural environments. Firstly, they stressed the importance of more services brought to the north by the deaf community in the south. This included more signing classes, and more information, resources, and activities to enhance both family support and awareness of the deaf culture in the larger community. These recommendations are detailed further in the final recommendation which follows, and which is framed around the need to address the issue of social stigma and isolation in rural and northern communications.

4. Need to address issue of social stigma and isolation

Caregivers highlighted the issue of isolation in rural and northern communities that entailed both the inadequacy of necessary resources and the absence or scarcity of peers and meaningful social support for the deaf child and family. One caregiver emphasized the need to link families who are raising a special needs child with one another – the importance of connecting with other families going through similar issues and concerns (Brenda, November 2004). Some caregivers recommended the establishment of monthly support groups wherever possible, to provide parents with the opportunity to share their experiences and debrief with one another about their process. It was suggested that this may require the assistance of an agency to become aware of other families with similar needs.

Caregivers also felt a strong need to raise the awareness of ‘hearing people’ about the deaf culture. They would like to see more ‘hearing people’ learn sign language (Carole, November 2004), and recommend sign language classes for siblings and other

extended family members – something that has not been promoted much as yet (Susan, November 2004) . Some families are not feeling the support of their extended family members, who have not taken an active interest in learning how to sign, and wish to see a greater awareness emerge in the larger community (Carole, November 2004).

Many recommendations were made regarding the need for public education in order to facilitate greater community awareness. The educational workshops/conferences mentioned under the first recommendation targeted families, but caregivers felt that these workshops/conferences could also target the larger community and local professionals, including the school system (Alice, November 2004).

With regard to the ordinary public, caregivers identified the need to raise awareness that deaf people are literate and are no different than others with the exception of their inability to hear – that they are first and foremost a person and that their deafness does not define who they are. They felt that ‘hearing people’ need to increase their comfort level with regard to engaging with people who are deaf. They expressed the desire to close the gap between the ‘deaf’ and the ‘hearing’, and recommended that ‘deaf awareness sessions’ and sign language classes ought to be promoted for the general public. Some simple suggestions made by caregivers to facilitate engagement with a deaf person included using eye contact; emotional language; and paper and pencil!

Caregivers strongly recommended increased professional development in the school system to facilitate greater awareness of deaf students and their educational needs. One caregiver stated that more trained educational assistants and interpreters are needed to work with deaf children in the school system and that this cost should be covered by the school system (Brenda, November 2004). It was further recommended that a new

caregiver be sure to inform the school in a timely manner of the fact that their child will be attending so that the school is fully aware of the child's special needs and recognizes the need for a resource teacher (Alice, November 2004). A final recommendation was that public schools offer sign language training, and empower the deaf student by including him/her in the teaching team.

CHAPTER FIVE - DISCUSSION CHAPTER

This study focuses on caregiver families who learn of deafness in the family and who are seeking to overcome challenges associated with deafness and deaf-blindness. The study is exploratory and used open-ended inquiry to invite caregivers to share their experiences of raising their child. Five families were raising a deaf child, while one was raising a deaf-blind child. A qualitative, semi-structured interview allowed caregivers to share parenting experiences within their own context.

The caregivers provided a retrospective view of their personal accounts of raising their child from birth up to school age. One objective of the study was to identify the types of concerns or experiences each encountered. The second objective was to identify what caregivers did to respond to the needs of the child in each of these experiences. The third objective was to explore what the caregivers recognized as helpful supports, including what they tried, what they would have done differently, and what they would recommend to new caregivers and people in the hearing society (such as helping professionals and the public).

There are four main findings in this study. The first is that a strong, reciprocated communication is possible between the family caregiver and the deaf or deaf-blind child. As the caregiver attends to and adjusts to a child's communication needs, the child, in turn, also adjusts and reciprocates communication. This exchange facilitates an understanding between one another and leads to the formation of deep intra-family relationships. The second findings is that the caregiver's approach to integrate the deaf child with the hearing succeeded through the establishment of shared language within the home as well as the caregiver's use of acquired roles to create linkages between the deaf

child and the social institutions that could be of assistance to them. Third, the availability of deaf specific resources, information, and formal supports (deaf specific services and professionals) as well as social supports were needed to help the caregiver family in their adjustment process. Fourth, this study reports that the integration processes described in this study helped both the child and the caregiver family adjust to deafness. These four main findings will be presented following the format of the research questions that were presented in Chapter One.

The parents provided in-depth stories of their particular situations. The result was a rich base of information from six family caregivers: two in-depth case studies of caregiver families who relocated from a rural community and who are in the difficult adjustment process of living in an urban area; two in-depth case studies of families who reside in an city that offers a number of resources for the deaf; and two in-depth case studies in which caregiver families still live in smaller urban cities that lack the required deaf resources for their child.

Participants self-declared their level of ASL proficiency. Four caregivers claim to be in the “middle,” which means a functional level where the caregiver is able to maintain a conversation and understand the deaf child. The caregiver for the deaf-blind child had not yet received ASL instruction, and the sixth caregiver was at an advanced level of signing which met the qualifications of a formal interpreter for the deaf.

Research question # 1: “What were some of the major experiences in raising a deaf child up to this point?”

Caregivers indicated that many life experiences led to parental stress, including

issues and barriers related to deafness and new learning. The reaction to confirmed deafness varied among the six participants, ranging from a minimal reaction of “it’s only deafness” to anxiety. Some perceived the diagnosis of deafness as less significant because a life threatening situation already existed in the family, so a confirmed diagnosis of deafness seemed minimal. Meinen-Derr et al. (2008) found that parental stressors change over time in accordance with unique family contexts and developmental needs of deaf children, thus requiring appropriate support services to families to meet changing needs.

This study shows that caregiver families are unique. Every family had its own encounters and experiences with stressors such as financial challenges, multiple moves from apartment to apartment, and lack of family support. Common stressors related to encountering barriers when it came to diagnosis, searching for the most appropriate resources for their child, learning a new language, and searching for information and resources for their child and overall family. Unfortunately, appropriate services were not always available to the families in this study in a timely way or may not have been available at all if they lived in a rural community.

Deaf-Hearing communication

Caregivers confirmed that it is possible to reach reciprocated communication between themselves and their child over a period of time. Families were able to establish a shared language within the home. Initially the hearing family perceived deafness or deaf-blindness as a highly complex matter. However, once deafness was approached as a language issue, the family reported that life was much easier. Bailes et al. (2009)

emphasize that, whereas deaf children were historically considered language delayed because of their lack of spoken and written English, there is a growing perspective today that language delay is not the cause of a lack of achievement. Rather, it is the result of language deprivation. Vervloed et al (2006) and Holte et al (2006) stated that it is possible for a deaf child to communicate non-verbally to hearing caregiver families and is essential that they have a space that they know intricately.

The families in the present study realized that they needed to establish a common language (ASL) that could capitalize on their children's sensibilities as well as maximize their children's ongoing development and spoken English did not meet these needs.

Parental stress and barriers

A common concern voiced by caregivers had to do with the late diagnosis of deafness. This was especially true for those living in rural areas who encountered problems accessing the proper testing facilities. One caregiver describes her experience as "having to push" or insist that her child be tested at an urban centre where there was more promise of equipment to assess her child's hearing. There is much in the literature to support the importance of early diagnosis which, in turn, facilitates earlier onset of language development, and thus provides a foundation for appropriate developmental sequences of learning (e.g. Lyon & Lyon, 1982; Johnson et al., 2011)

Caregivers in this study varied in the waiting time for services as well as in the nature of the services that they received. Some caregivers received services within a year but the services were provided to the caregiver family, not to the child. For example, one rural caregiver received respite as her first service rather than the communication services

that her child desperately needed. Alice described Joey as medically complex and did receive a number of services, compared to others who had deafness as their primary health condition.

All of the caregivers had to search for information on their own, and they report that this information was not centralized or readily accessible. Initially, caregivers deemed themselves powerless, not knowing how they could assist their child. No guidance was provided to the parents, which added to the stress of the diagnosis. Once knowledge was gained and a plan formulated, the caregivers gained confidence and took on an active role. One caregiver says, “Once we knew we could do something,” the family felt better knowing what to do and took action through learning language and seeking information. A Canadian study identified that caregivers are overwhelmed because there is much to be learned about deafness as well as adjusting to their new role as a parent to a deaf child (McKellin, 1995).

This study also found that families are diverse in their circumstances, which influences how well they adjust to deafness and how long the adjustment period takes. Furthermore, this depends on the level and quality of resources accessible to them. Allen and Allen (1979) indicate that it is difficult to make generalizations about families because of this heterogeneity. It follows that professionals including health care, social work, and school personnel need to have an understanding of the deaf and work toward gaining specialized knowledge, skills, and abilities to serve this diverse population as well as to respond to their changing needs (Meinzen-Derr et al., 2008; Pray & Jordan, 2010; Wilson, 2006). This resonates with my findings as families in both studies were affected by the level of supports available to them. No matter what the circumstances in

their lives, all families agreed that deafness affected them and changed their course in life. It is common for a diagnosis of deafness to abruptly change the life of a family which must accommodate itself to deafness (Bailes et al., 2009; Erting, 1985).

Unequal distribution of services/resources in urban and rural areas. Rural participants reported encountering barriers when attempting to access formal supports such as communication services for their child, accessible ASL opportunities, deaf specific intervention programs, and accessible deaf interpretation supports. McKellin (1995) and Williams and Darbyshire (1982) say that caregivers have encountered many of the barriers that my study uncovered. These studies identify barriers such as the difficulty of obtaining a diagnosis and eventually being forced to relocate because of the lack of access to the resources and inequality of service distribution. The issue of a lack of resources was significant for caregivers in this study because limited resources affected how much longer it would take for the family to learn language and experience less stress and frustration due to not establishing a shared language in the home.

McKellin (1995) also mentions that deaf children from rural communities are often enrolled in programming that is generic for children with all types of disabilities, and not specific to deafness. Bowen and Ferrell (2003) report similar issues for deaf, hard of hearing, blind, and visually impaired students in rural districts of the United States. For example, they point out the lack of knowledgeable, trained, and skilled professionals as well as the poor availability of personnel for rural areas.

Rural caregivers had more difficulty adjusting to deafness because they did not have the deaf specific information and resources required to help both their child and

overall family to address the issue of language in the home. For rural families it meant a struggle to overcome a number of barriers related to finances, time, and travel to access ASL training at an urban centre. Caregivers, especially those who lived in a rural community, and who have now relocated, are able to see the comparative difference in resources in urban and rural areas. Two families who relocated describe the hardship of encountering one problem after another. They experienced situations that involved very tough decisions as well as dealing with the abruptness and emotional grief associated with relocation. Caregivers described relocation in phases: contemplation to move, the actual decision to move, planning the move, actual move, and, finally, post-move adjustment. The literature is limited on the subject of caregiver families who have had to make decisions about relocating so that their child may access the resources available at an urban centre.

Caregivers strongly emphasize the need for increased deaf-specific resources in rural communities, particularly in the areas of public education, training of public school staff, provision of deaf and social resources for both the child and overall family, and support or mentor training for caregivers who are new to the experience of raising a child who has special communication needs. Wilson (2006) raises similar resource issues and solutions for rural areas in the United States.

Multiple roles

Caregivers, especially those who live in a rural community, state they acquired an expanded family role and needed to “be all that they can be to their deaf child.” In acquiring a knowledge base, caregivers were also taking on roles with the intention of

helping to facilitate the connections between their child and others who are hearing. The nature of the work done by caregivers in the early years of their child focused mostly on language development and once language was at a functional level, caregivers dedicated more time and work to creating linkages between their child and family to extended family, neighbors, professionals, school, and attending events in the hearing community. Caregivers reported doing a lot of work but required the resources to help them perform their roles, but also assist their child with language and the technical aides required to live and participate in a hearing world. Rural caregivers state that the type of resources that they require includes communication services for their child, opportunities to learn ASL, a need for deaf specific intervention programs, and access to deaf interpretation supports and technological aides used by the deaf. One family was angry when speaking about the difference of service and resource between rural –urban forcing their family to move so that her child may access the resources at the city.

Many of the roles that were assumed by caregivers were more intense in some situations. Caregivers describe that a large proportion of their time is dedicated to their attempts to close the deaf-hearing communication gap between themselves and their child. Caregivers learned ASL but also searched for resources that the child needed, including opportunities for their child to participate in educational and recreational programs in the community. Caregivers continually found themselves in social situations needing to clarify and educate the hearing public about deafness. Once caregivers were competent in ASL, they were also able to provide deaf interpretation that would benefit both the deaf and the hearing. These key roles resulted in creating linkages between their deaf child and people in the hearing community.

Overall, caregiver roles were mainly geared to meeting the needs of the child, the family, and the community in general. However, once the work was completed in one role, it led to work in another role. For example, once information was collected, caregivers received information on another aspect of deafness to understand and assess its applicability to their child. The literature has recently shifted attention to families as a means of meeting the needs of a special needs child. Jackson, Traub & Turnbull (2008) and others recommend the importance of placing attention on the provision of family focused services. My findings from this study concur with these authors.

Public school

Caregivers who had their child attend a school for the deaf reported no concerns. However, most families whose child attended a public school had negative experiences. Most public schools were described as not making an effort to close the communication gap between themselves and the deaf child who was attending their school. This resulted in making a decision to enroll their child in a school for the deaf which was perceived to be in a better position to meet the communication needs of the deaf child. Caregivers described a communication gap between their child and public school staff that led to their child's poor grades and their struggle with academics delivered to them using oral language. Caregivers also identified a communication gap between their child and school staff which limited their assigned educational assistant to assist their child with academic learning in a public school setting. Koesaroff & McLean, (2006) found in their study the necessity for a deaf child to access information from their social surroundings if they are to participate and gain anything from it. This finding was similar to my findings, three children who attended a public school and got little academically but thrived when they

received educational material in a language that they understood at the school for the deaf.

It was difficult to integrate Joey, who is deaf blind, to a hearing community due to his physical limitations. Despite these limitations, Alice expressed her wish for Joey to connect with hearing school peers and ‘have real friends’ but this is not always possible considering his limitations to a structure environment both at home and at school.

Family

Caregivers in this study emphasized the importance of family. This was expressed in their descriptions of how family members assist the child at home or offer a supportive interpreting role for the child when they are out in the community and receive inquiries from hearing people. Caregivers describes that addressing deafness is most effective when all family members are involved. Caregivers also shared that family members not only help with the tasks of the child but also are a valuable support to the caregiver. There is very little literature on the extensive work that caregiver families perform, however Keilty and Galvin (2006) write about the active role that caregivers in their study have done to assist their child’s progressive learning. My finding of caregiver work is similar in that the caregivers showed a progressive movement from knowing nothing about deafness to increased abilities.

Research question # 2: “How have the caregiver families responded to these significant events and experiences and how did they turn out?”

Caregivers in this study reported two ways of approaching deafness: using language to ensure that family members understood each other; and caregiver families

using themselves in their roles, as they link with various social institutions in the community.

Caregiver work to integrate the deaf – hearing

Caregivers reported that deafness is a language issue and that families need to establish this position internally as well as inform others who are outside the home of their plans to use language to address deafness in the family. Once a shared language was established in the home, relationships were formed within the home as well as outside the home. With the help of their caregivers, deaf children had access to a wide network of friends, family, and school contacts. One caregiver credited ASL as saving their family. My findings show that established language leads to reciprocated communication forming strong family relationships and access to family life and life in a hearing world. My findings are consistent with those of Bodner-Johnson (1991), who states that a deaf child needs to be a part of family life through a shared language.

Language development. The rate of language development depended on how frequently ASL training opportunities were available to caregiver families and their ability to access to such opportunities. Caregivers from rural areas were at a disadvantage because ASL classes were only available sporadically or they had to travel a full day to access such training that is often associated with high costs in attending such training. Urban caregivers from urban settings reported that they participated in the services and resources available in the city, which resulted in rapid and progressive language development. The rate of language development of rural caregivers was slower than that of urban families. My finding is that access to ASL opportunities influences how

progressive and the rate of learning language can be for caregiver families.

As part of the process of language development, caregivers emphasized that communication is a two-way process, and while it is important for the hearing to remember that it is common practice is for the hearing to assess the deaf, it is also important to know that the deaf child has an important part in communication. Caregivers saw the importance of engaging their deaf child by setting mutually agreed upon communication rules and processes. Rosemary states: “If you expect him to listen to you, you need to listen to him, too.” She emphasizes the importance of paying attention to the deaf child and watching the child’s non-verbal messages and emotions. She also supplements her child’s subtle non-verbal messages with the use of visuals, physically demonstrates what she means, and uses communication aids which further encourages cooperation from the deaf child. In addition, caregivers also continue to read their child’s behavior as an effective means of ensuring that they understand the child. This was a key finding. Caregivers implemented these early communication processes along with learning ASL. The literature speaks about the importance of effective communication, such as the need to ensure that conversation partners are synchronizing their messages in turn and that they are both actively involved in the conversation. My finding agrees with this finding but also adds the caregiver’s perspective of acknowledging the child’s input in their communication process.

Caregivers also reported that they have witnessed their child teaching others sign language and very often accommodating and adapting to the communication needs of the hearing by finding ways to connect. An example of this is when the deaf child assesses the communication abilities of the hearing and then, in most cases, adjusts to the

communication abilities of the hearing. Caregivers observed and commented that their child would often make every attempt to find a way to connect with the hearing (who do not understand ASL) so that the hearing will understand them. Caregivers describe a situation referred to as role reversal which helped to bridge the gap between the deaf and hearing. Their deaf child was acquiring knowledge and skills in ASL at such a rapid rate that they were beginning to teach their family members and any others who were interested in learning sign language. This teaching situation helped integrate the deaf and the hearing with one another, sharing the same visual language that the deaf use. My finding supports that deaf children initiate communication with others who are hearing demonstrating a capacity to first of all, know sign language and oral English well enough, and then in turn teach others sign language.

Empathic Parenting and Problem Solving. Participants' empathic parenting led them to develop parenting practices that took into consideration what their child has experienced in life. For example, Alice described that her family members will close their eyes and ears to develop sensitivity about deaf-blindness and understand Joey's situation. The same holds with the deaf child. A family, in observing the deaf or deaf-child child, understands the child's reliance on their visual and/or feeling senses to gain information about the world around them.

Caregivers also found themselves relying on their child's responses to shape their own parenting practices and, in some situations, their decision-making regarding the child. Their child's response was the best guide to know whether their parenting practices were effective. As caregivers learned the visual ways to communicate with their child, they became accustomed to parenting their child using visual communication, providing

the same teachings as they did to their hearing child.

Caregivers continually demonstrated problem-solving abilities and responded intuitively. Koester and Lahti-Harper (2010) support that caregivers have a natural ability to communicate with their child without much thought. Desjardin (2006) points out that hearing caregivers of deaf children intuitively adapt their language techniques according to their children's language level. This is consistent with my finding that caregivers in this study who responded intuitively as their child responded to activities that drew attention of their visual and emotional senses.

Research question # 3: “What was useful when others offered help and what was not so useful?”

Adjustment

Caregivers reported that language and creating linkages between their home and social systems (including deaf resources) helped caregiver families adapt to deafness.

Caregivers reported a feeling of success when they were able to effectively communicate with their child and they no longer had to “guess” what their child was trying to say.

Family members also described validating that they had understood the deaf child with occasional points of clarification. Caregivers who were bilingual in the home experienced less stress. However, they described that bilingualism is difficult to maintain. This is because there is a tendency for the hearing to switch from one language to another and not use ASL consistently. Also, when a household includes a deaf child with his or her language needs along with other family members who have an oral language, it is difficult to prioritize which language to use. Having a language in the home that both the

hearing and deaf understand resulted in improved family relationships, but not perfectly. The difference is that the child now has a chance of being understood as well as understanding family events. Thus, it was very helpful to the adjustment process when extended family members were 'onside' with regard to learning ASL.

Caregiver competence

Recommended practices for children who are deaf emphasize the importance of parental involvement as well as parental competence, such that parents perceive themselves as capable of supporting their children's growth and development. Parental self-efficacy beliefs are defined as the sense of knowledge and abilities to accomplish daily parenting tasks and roles (Desjardin, 2006). Caregivers increased their capacity over the years, moving on to roles that required specialized knowledge and skill sets as they handled issues on deafness. Some roles such as navigating the health care system to access resources and providing deaf interpretation are examples of this specialized knowledge. Wilkins (2005) and Keilty and Galvin (2006) demonstrated in their studies that caregiver competence in parenting roles and skills can occur in progressive stages. My findings concur with the studies that show that caregiver families can move from knowing nothing to a progressively competent state.

Caregiver roles evolved and changed throughout the helping process as they were geared to help integrate their deaf child and hearing family with one another. As a result of experiential knowledge, caregivers gained skill sets in the area of addressing deafness and learned a new language so they may pivot between the two language sets, deaf and hearing. Caregivers reported that building knowledge about deafness is a continual

process because learning the full implications about deafness extends across their life time.

Pivotal role of the caregiver facilitating the deaf-hearing integration. This study shows that caregivers are pivotal in bridging the two cultures: deaf and hearing. Caregivers acquired roles to close the deaf-hearing gap they often witness during social encounters between their child and those who are hearing. The numerous roles taken on by caregivers demonstrate the many ways in which they mediate between the hearing and the deaf and how difficult this integration process would be without their dedicated efforts. There is a strong sense from the data that caregivers feel these efforts have often been one-sided, with inadequate support from the hearing community.

Caregivers have adjusted. Caregivers self-declared that they have adjusted to deafness. They comment they have reached a level of stability, using phrases such as: “We have overcome most of the obstacles now” and “There are no communication issues” or “We have grown together as a family” and “I know to access help if I need it.” Adjusted families in this study are characterized by effective communication, positive family relationships, and being connected to the social systems outside of the home. Researchers are becoming increasingly alert to the need to understand the issues and experiences that caregiver families encounter as they are raising a child with special communication needs (Munroz-Baell & Ruiz, 2000; Jackson & Turnbull, 2004). I agree with McKellin (1995) who indicates that there is not enough research documenting parental experiences.

Valued supports

Caregivers identified supports that were most helpful to them and indicated that

the best supports were people who allowed the caregiver to vent and did not voice an opinion about anything. Friends and extended family who were considered supportive were those who supported decisions made by the family, particularly those who made the effort to learn ASL and/or participate in family life. Deaf adults and other families who have encountered similar experiences were also considered a valuable resource, as they had the capacity to be role models, mentors, or even surrogate family. As well, some caregivers had the opportunity to access the deaf community and school for the deaf, which connected them to an abundance of social and academic services and resources, and a sense of belonging within this very unique cultural group.

Research question # 4: “What recommendations do caregiver families offer for others who may be interested in assisting them, such helping professions, the public, extended family, a neighbour?”

Recommendations made by caregivers

Caregivers in this study have a common message in all their recommendations, which is that the hearing society must be more responsive to the needs of the deaf. This includes advocating for ASL training and deaf awareness to be accessible to the hearing community. Resources need to be accessible to all deaf people regardless of where they live to assist them in becoming participating and contributing members of society.

Caregivers in this study expressed loudly that resources need to be made accessible to the deaf child as well as to the family. Unnecessary hardships were felt by caregivers when they know that services, such as deaf interpretation services, should be provided in rural communities. Caregivers encountered many situations that conveyed a

communication breakdown between the deaf and hearing and caregivers often acquired a responsibility to repair, clarify or educate both of them. Public education and awareness were capitalized on, including deaf awareness, increased sign language training opportunities, and deaf culture. Caregivers reported a need to learn, persist and negotiate with the health system from a leadership position in which caregivers play an important contributor role when meeting with health or agency professionals. Most of these recommendations are specific in nature. The recommendations that are discussed in the literature speak to recommended change at program levels.

Research question # 5: “What implications does this study’s finding have for services and care for children who are deaf or deaf-blind?”

This study has demonstrated that caregiver families can provide valuable information for medical teams on a child’s strengths and capabilities they may not otherwise have opportunity to see. Observational information over the years has provided caregivers with a knowledge base that includes awareness of common deaf situations but, also, of situations that are family specific and an opportunity to celebrate their success and outcomes of from their own problem solving. Hearing caregivers, who have become immersed in the world of the deaf, are in a pivotal position to facilitate connections between the deaf and hearing and could be a valuable resource to those who are interested in the deaf. Professionals who influence how services are designed and delivered could look to parents to help design services specifically for the deaf, helping to meet the unique needs of the deaf.

CONCLUSION

Caregivers described their journey over a span of time from receiving confirmation of deafness with their child to having attained a knowledge base and acquired skills sets from the extensive work that they do establish a shared reciprocated language within the home as well as creating linkages to social systems within their communities and outside of their communities. The social systems they connected to informed the family as well as provided them with deaf specific supports that were formal and informal. Although all families connected with social systems, these systems better served some families than others and depended on the geographical location in which they lived.

The literature illustrates that families are diverse and that it is difficult to predict their adaptation to deafness. Due to the diversity of families, it is difficult to provide assistance to families using a “one size fits all” approach. Some researchers (Benedict & Sass-Lehrer, 2007) point to the need for greater partnerships between the caregiver family and professionals to address issues related to deafness. Morgan-Redshaw et al. (1989) recommend that professionals need to involve parents as partners to obtain a better understanding of deafness and to work more effectively with families. Other researchers recommend a collaborative model where parents are part of the intervention process with social workers in designing programs and resources (Zimmerman & Dabelko, 2007), and social workers provide unbiased information, promote self-determination, and empower families of deaf children as they navigate through existing options and resources (Pray & Jordon, 2010). Keilty and Galvin (2006) recommend that professionals must be sensitive to the fact that caregivers play a lead role in their child’s

care, as they and their families move towards an adaptive state. For this reason it is essential that professionals, including social workers, work with caregivers as equal partners and contributors when planning and setting goals for the child's development.

This study can be helpful to social workers who are new to the field and who want to gain a family perspective on deafness. The literature underlines the diverse characteristics of caregiver families, and this study provides a detailed view of deaf specific situations that caregiver families encounter. For the generalist social worker, this study may offer valuable information regarding how families are affected by deafness and how they have attempted to raise and communicate with their deaf children and they may assist families with the gaps in 'goodness of fit' are where social workers may play a helping role to assist caregiver families adapt to deafness. Research recommends that professionals take into consideration the diversity of families and apply an ecological view in their practice. Using an ecological perspective in practice means a holistic assessment and deeper understanding of the family situation. The role of the social worker is to assist caregiver families to resolve and adjust to their life situation. In most helping situations, caregiver families experience and live a challenging and stressful journey that involves difficult decision-making. A social work practitioner can be an important resource to the family. Munoz-Baell (2000) states it is important for helping professionals to learn the uniqueness of the deaf, as they may encounter individuals who require their assistance. It is best that social workers know what type of obstacles they encounter, the implications of deafness in a hearing world, and how to counsel and advocate for them (p.42).

Most policy planners and programmers depend upon documents such as

community health needs assessments and statistics to inform them about family needs. The work of caregivers has not yet been recognized at the research level however, this study has offered a parental perception of adjustment to deafness by the six families who participated in this study. They have much to offer.

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APPROVAL CERTIFICATE

August 25, 2004

TO: Sandra Gendreau
Principal Investigator
sor – T. Heinonen)

FROM: Wayne Taylor, Chair
Joint-Faculty Research Ethics Board (JFREB)

Re: Protocol #J2004:129
"Perceptions of Caregivers in Problem Solving of Communication Issues
Encountered in Social Settings with their Deaf Child"

Please be advised that your above-referenced protocol has received human ethics approval by the **Joint-Faculty 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) in order to be in compliance with Tri-Council Guidelines.

Bringing Research to Life

APPENDICES

Appendix A: Sample Letter of Consent

Research Project: A Family Perspective on Barriers with Deafness

Researcher: Sandi Gendreau (Masters of Social Work, University of Manitoba)

Dear Parent;

I am a student with the University of Manitoba, Masters level in the faculty of Social Work. You are invited to participate in research around deafness discussing the types of social situation around deafness and how you and your family have attempted to problem solve in dealing with various situations encountered in your home environment and in your local community.

I will not make reference to you personally in my thesis or subsequent publications using data generated by families whom I interview. Any information obtained by the study where you can be identified will be held in the strictest confidence and will only be disclosed with your permission. Please note that although I work with an agency Society of Manitobans with Disabilities, this research will be conducted by myself independently, strictly for purposes of completing the MSW program at the University of Manitoba.

Although you may decide to participate in this interview, please understand that you are free to withdraw your consent and stop participation at any time. In such a case there is no explanation required nor penalty imposed.

If you have any questions you can contact me through email XXXXXX or at my work number during business hours XXXX. Please direct research questions to my Faculty Advisor Tuula Heinonen, at the University of Manitoba at 474-9543.

Your signature on this document indicates that you have decided to participate in the study.

Thank you for your cooperation.

Signature of Investigator

Signature of Participant

Appendix B: Sample letter to the Audiologist -

Research Project: Family perspectives on barriers with deafness

Researcher: Sandi Gendreau (Master of Social Work, University of Manitoba)

Dear Audiologist;

I am a student with the University of Manitoba, in the Masters of Social Work. I am proposing to do research on how caregivers problem solve communicative experiences between a school-age deaf child and others in various social situations in their home, school and in the community. This information will be helpful for other families in similar circumstances and may help professionals who may not have enough information about caregiver views on deafness.

The criteria include a family who are raising a school-age child who has medical confirmation of a severe to profound deafness. The child must be attending a school and be from five to fourteen years old. Six caregivers required for the Northern sample. Caregivers are the legal guardians of the child and may include biological parent(s), foster parent(s), grandparent(s), or others whom the child lives with.

Please feel free to inform potential participants that you, and your employer, is not connected with this research. Your role is to help recruit potential research participants and you are not obligated in any way to speak to, answer questions, or promote the research.

If potential participants agree to participate you may disclose contact information about them to the researcher. The researcher will clarify any questions and review the purpose of the research with you. The research is monitored through my faculty advisor Tuula Heinonen or graduate ethics review board or send an email to...

If participants agree to participate, it is only at that time, the audiologist may disclose personal information about potential participants to the researcher. The researcher will make contact and further answer any questions and review the research schedule and process. If participants agree then they will sign consent forms to proceed with the research process. The research process is monitored by an University Advisor and must continually meet university standards and ethics at all times.

If you have any questions you can contact me through email XXXX or at my work number during business hours XXXX

Your signature on this document indicates that you are willing to assist with recruitment of potential study participants.

Signature

Appendix C: Sample letter to the Manitoba School for the Deaf

Research Project: A family perspective on barriers with deafness

Researcher: Sandi Gendreau (Masters of Social Work, University of Manitoba)

Dear XXXX, School for the Deaf;

I am a student with the University of Manitoba, in the Masters of Social Work program. I am proposing to do research on school - age child deafness in Manitoba. This research project will look at the means of communication that families have with a deaf child, the types of social encounters experienced in various communicative settings such as their home, school and in the community. This will include discussion on how families have attempted to problem solve social situations, their outcomes and what they would recommend to be helpful for other families raising a deaf school age child.

The criteria for study participants include medical verification of severe to profound congenital deafness. The child must be attending a school and at an age range from 5 years to 14 years old. Caregiver families are required to be two parented and living in Winnipeg, Manitoba. There are three families required in the Winnipeg sample. Participants can be assured that any information will be held in the strictest confidence and will only be disclosed with their permission. The research is completely voluntary meaning participants are free to withdraw your consent and stop participation at any time. And in such a case, they are under no obligation to provide an explanation nor will there be any penalty imposed.

If participants agree to participate, it is only at that time, that you may disclose personal information about potential participants to the researcher. The researcher will make contact and further answer any questions and review the research schedule and

process. If participants agree then they will sign consent forms to proceed with the research process. The research process is monitored by an University Advisor and must continually meet university standards and ethics at all times.

Please note, the Manitoba School for the Deaf is only recruiting potential participants. The Manitoba School for the Deaf is in no way affiliated with the research. Therefore it is not expected they speak to, nor answer questions, regarding the research project. The Manitoba School for the Deaf will only initiate contact and it is up to families to decide if they would like to set up a preliminary meeting with the researcher. If you have any questions you can contact me through email XXXX or at my work number during business hours XXXX

Your signature on this document indicates that you are willing to assist with recruitment of potential study participants.

Signature

Appendix D: Consent to Audiotape the Research Interview

Research Project: A Family Perspective on barriers with Deafness

I _____ grant permission to audiotape the research interview that will be conducted by primary researcher Sandi Gendreau

I understand that the information given in the interview will be held in the strictest confidence, that is obligatory in the ethics of conducting research. Further, the researcher will ensure that I will not be identified personally when the research is published.

I consent that I may stop the interview process, and have the audiotape be stopped immediately, when I am in anyway uncomfortable with the interview process.

Your signature on this document indicates that you consent to audiotaping the interview sessions.

Signature of Investigator

Signature of Participant

Date

Date

Appendix E: Interview Schedule

Part 1: Proposed introductions to all interviewees

You have agreed to doing this interview and this session will be audiotaped.

Please understand that you can stop the interview at any time and withdraw your consent to partake in this project. The interview will take approximately 2 hours depending if you need less time or more time to complete the interview.

Your questions are open-ended so feel free to provide as much or as little information as you want.

After the interview I will transcribe the audiotapes and categorize the information that you share into a summarized version of the interview. At that point, I can meet with you a second time and we can go through the information you presented and if there are any questions we can discuss them. Your input in this research is very important and is valuable not for others who work with families, but as well other families who are in a similar situation as you.

You should know that the transcriptions will stay true to the intent of your comments. Any repetitions, false starts, and hesitations will be removed to provide a more appropriate text rendition of what you said.

Part 2: My introduction

At this point I will begin by re-introducing myself and my interest in the research. Then I will share some of my background and end with the type of questions I have attached.

Part 3: Preliminary Interview Questions:

Not all these questions will be needed to get the dialogue moving along, however I will be prepared to establish rapport and get some data at the same time and use those

questions if I need to.

Some of the questions refer specifically to demographic information and I hope to get this information from the participants' perspectives as well as from the referring audiologist.

Preliminary interview questions for caregivers:

1. When your child was diagnosed deaf what was that like for you? how old is your child? what school does your child attend? how many in your family?
2. What thoughts, feelings, and questions went through your mind when you learned about your child's deafness?
3. How did the rest of your family members respond to learning about the deafness?

Indepth Interview Questions for the caregiver families being interviewed:

5. Can you share what your experiences were as you were raising your child?
6. Can you describe how you problem solved through some of these barrier situations and how did it turn out?
7. In your opinion have you and your family adapted to deafness? what does that look like ?
8. What would be your advice for others who are in a similar situation, and what would you like others to know about families who are raising a deaf child?